HOMELESSNESS, HEALTH, AND LITERACY:
AN INSTITUTIONAL ETHNOGRAPHIC STUDY OF THE SOCIAL
ORGANIZATION OF HEALTH CARE IN ONTARIO, CANADA

by

Naomi Hughes

A thesis submitted in conformity with the requirements
for the degree of Doctor of Philosophy
Graduate Department of Curriculum, Teaching and Learning
Ontario Institute for Studies in Education
University of Toronto

© Copyright by Naomi Hughes 2013
HOMELESSNESS, HEALTH, AND LITERACY:  
AN INSTITUTIONAL ETHNOGRAPHIC STUDY OF THE SOCIAL  
ORGANIZATION OF HEALTH CARE IN ONTARIO, CANADA  
Doctor of Philosophy 2013  
Naomi Hughes  
Graduate Department of Curriculum, Teaching and Learning  
University of Toronto  

Abstract  
This thesis presents findings from an institutional ethnographic study that examined the experiences of 27 individuals who frequented an Open Access homeless shelter in Greater Toronto, Ontario. Many participants interviewed in the study either lacked an Ontario Health Insurance Card, or they expressed little interest in acquiring one. Individuals who had chosen not to seek reissuance of their health cards either implicitly or explicitly self-excluded themselves from participation in programs and services that, although useful to them, might be seen to regulate, control, and thereby subordinate their interests to those of the dominant institution. This study sought to map, locate, and make visible the local, everyday experiences of individuals at an Open Access shelter, and to situate that map within the translocal and often invisible realm of broader neoliberal ideologies and their related bureaucratic health care policies and directives. Neoliberal doctrines have also been evidenced in recent health care reforms, including the reduction in welfare spending and social subsidies, the centralization of federal power and authority over provincial mandates, and the implementation of high-tech computerized monitoring and management systems designed to reduce fraudulent access to health care. This study not only explicated the different forms of literacy (organizational, technological and health literacies) that are both employed and reproduced in institutional settings, but it also examined the role of literacy within larger social, political, and economic contexts. Using an institutional ethnographic method of inquiry, this study examined the ways in which literacy (or the lack of
literacy) shapes and mitigates the experiences of homeless individuals attempting to gain access to health care. This study asked: How are institutional health policies evidenced in the everyday, material lives of real people? Are such policies potentially exclusionary?
Acknowledgements

I wish to express my gratitude to my supervisor, Dr. Roxana Ng, who offered invaluable inspiration, support, and guidance throughout the course of this study. I am deeply grateful to Roxana. She not only encouraged me to explore my own research interests, but she also ensured that I remained focused during my exploration. Roxana passed away on January 12, 2013 after a short and courageous battle with cancer. Roxana left an indelible mark not only on this thesis, but also on the students with whom she worked. Roxana was more than my mentor: she was also my friend.

I wish also to extend gratitude to members of my supervisory committee, Dr. Karyn Cooper and Dr. Catherine Chalin, who provided thoughtful and detailed feedback at various junctures during this study. When Roxana became ill, Karyn graciously stepped forward and supported me through the final stages of the thesis. I am also indebted to the participants of this study, many of whom sat with me late into the night at the Open Access shelter. I recognize that this research would not have been possible without both the financial assistance of Ontario Graduate Scholarships and OISE, University of Toronto (Graduate and Research Assistantships). I wish to express my gratitude to these organizations.

My family has always been a source of unwavering support. I wish to thank my husband and best friend, Rob McGee, for his constant love and reinforcement. Despite geographical distances, my family has always been close. My father, Neil Hughes, has always provided me with help, feedback, and advice. Lastly, and most importantly, I wish to thank my mother, Denny Hughes. My mother has, and will always be, the compass of my life. To her I dedicate this thesis.
Table of Contents

Acknowledgements ........................................................................................................ iv
List of Tables .................................................................................................................... vii
List of Figures .................................................................................................................. viii
List of Appendices .......................................................................................................... ix
Chapter 1: Introduction .................................................................................................. 1
  Background ....................................................................................................................... 1
  The Philosophical Background of the Study ................................................................. 5
Methodology ..................................................................................................................... 7
Research Questions ......................................................................................................... 9
Organization of the Thesis .............................................................................................. 10
Definition of Terms ......................................................................................................... 10
Chapter 2: Open Access: ............................................................................................... 15
A Research Setting .......................................................................................................... 15
Chapter 3: The Social Inequalities of Health ................................................................. 27
  The Social Inequalities of Health .................................................................................. 30
  The Rise and Fall of the Social Welfare State .............................................................. 33
  Language, Literacy, and Inequality .............................................................................. 46
  Homelessness Discourse: Language, Culture, and the Power of the Media .............. 62
  Situating the Health of Homeless Individuals in Ontario, Canada ............................ 68
Chapter 4: Methods ....................................................................................................... 77
  Introduction .................................................................................................................... 77
  Conceptual Framework: Marx’s Method of Analysis .................................................... 78
Institutional Ethnography ............................................................................................... 78
Research Design ............................................................................................................. 83
Research Setting ............................................................................................................. 83
Research Population ...................................................................................................... 85
Data Collection ............................................................................................................... 86
Data Analysis .................................................................................................................. 88
Summary ......................................................................................................................... 91
Chapter 5: Results and Participant Summaries ............................................................... 94
  Participant Summaries ................................................................................................. 100
Conclusion ...................................................................................................................... 112
Chapter 6: Politics, Power, and Praxis: A Study of Organizational Literacy in the Provision of Health Care Delivery in Ontario, Canada ................................................................. 114
Chapter 7: Mapping Neoliberal Ideology: The Translocal and Invisible Realm of Bureaucratic Health Care Delivery and the Everyday Lives of People .................................................. 131
Chapter 8: So What? You Got No Life Anyway: The Complex Nature of Mutually Established Exclusion ........................................................................................................... 149
Chapter 9: Conclusion ................................................................................................................................. 165
  Summary of Research ................................................................................................................................. 165
  Study Limitations ........................................................................................................................................ 167
  Study Strengths ........................................................................................................................................... 168
  Significant Findings ................................................................................................................................. 169
  Recommendations ...................................................................................................................................... 173
  Individuals' Personal Accounts: Problems, Observations, and Recommendations ...................... 175
  Suggestions for Future Research ............................................................................................................. 177
  Implications for Future Practice ............................................................................................................... 179
  References ............................................................................................................................................... 182
List of Tables

Table 1: Introducing the Participants................................................................. 99
Table 2: Mapping the Coordination of Text-Based Documents ......................... 113
List of Figures

Figure 1. OHIP Coverage Services for Homeless Persons ................................................................. 41
Figure 2: Ontario Ministry of Community and Social Services Newsroom Press Release .......... 44
Figure 3: 2004 Special Diet Allowance Form (page 1 of 3) .......................................................... 56
Figure 3: 2004 Special Diet Allowance Form (page 2 of 3) .......................................................... 57
Figure 3: 2004 Special Diet Allowance Form (page 3 of 3) .......................................................... 58
Figure 4: 2011 Special Diet Allowance Form (page 1 of 2) .......................................................... 59
Figure 4: 2011 Special Diet Allowance Form (page 2 of 2) .......................................................... 60
Figure 5: 2010 - 2011 Open Access Site Schedule ..................................................................... 117
Figure 6: Lifework Map ..................................................................................................................... 118
Figure 7: Ontario Works Dental Coverage ....................................................................................... 122
Figure 8: Ontario Health Insurance Plan (OHIP) .......................................................................... 138
Figure 9: British Columbia Medical Services Plan (MSP) ............................................................... 139
Figure 10: Private and Executive Health Care ................................................................................ 152
Figure 11: Free Health Care Services Available on The Rotary Health Bus ............................... 153
List of Appendices

<table>
<thead>
<tr>
<th>Appendix</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appendix A</td>
<td>Narrative Exhibits</td>
<td>192</td>
</tr>
<tr>
<td>Appendix B</td>
<td>Letter to Participants</td>
<td>230</td>
</tr>
<tr>
<td>Appendix C</td>
<td>Interview Questions</td>
<td>231</td>
</tr>
</tbody>
</table>
Chapter 1
Introduction

I don’t really want one. When everything else gets settled, I will think about it. But day-to-day, when you are on the street, you can’t really think about that. Like a health card, what am I gonna do with that?

Tanya, Interviewee

Background

This institutional ethnographic study sought to examine the structures of health care organizations that may serve to institutionalize or limit homeless individuals’ access to health care services. While there have been a number of informative studies in Canada regarding the problems and challenges encountered by homeless individuals in their attempts to access health care, little has been studied regarding individuals’ sense of perceived personal agency in directing their everyday health care. This study aimed to explicate the broader lineages of administrative and governmental entities that not only mediate and control homeless individuals’ everyday experiences, but that also mediate their access to health care services.

Participants in this study were drawn from an Open Access shelter located in Greater Toronto, Ontario. Individuals’ first-hand, personal accounts highlight the complex nature of social exclusion: many individuals perceived themselves as “pushed out” or excluded by the structures of health care services that purport to support and service them. However, individuals interviewed in this study were also perceived as active agents in a complex, mutual form of exclusion (referred to as “mutually established exclusion” throughout this thesis), in which marginalized individuals chose to “drop out” or remove themselves from institutional and
bureaucratic mainstream services. In this study, mutually established exclusion was evidenced in the ways in which interviewees chose to withdraw either partially or fully from multilayered, bureaucratic governance and mainstream health care services.

The transient and unstable nature of living without a fixed address presents significant challenges for homeless individuals. The everyday work of basic survival (referred to as “lifework”\(^1\) in this thesis) consumed a significant portion of homeless individuals’ everyday activities. Lifework for homeless individuals may include obtaining emergency health or dental care, locating showering facilities, doing laundry, using the telephone or Internet, retrieving belongings from storage facilities, and relocating lost or stolen identification or paperwork. Such work often involves repeated interactions with institutional organizations, such as governmental agencies, homeless shelters, drop-in centres, or hospital emergency rooms. Through an in-depth examination of individuals’ first-hand experiences accessing health care services in Ontario, this study aimed to explicate the institutional practices or rules of governance that not only mediate relations between homeless individuals and institutional organizations, but that also perhaps serve to discourage homeless individuals from seeking access to institutionally mediated services. Of particular interest in this study are the complex social interactions and interrelationships that exist between people who operate in institutionally mediated bureaucracies. This study examined the ways in which specific texts (legislation, regulations, policy directives, and standard paperwork) shape, control, and standardize homeless individuals’ experiences within bureaucratic institutional systems. This study explicated the nature of power

\(^1\) Lifework was a term originally coined by G. Smith, Mykhalovskiy, and Weatherbee (2006), when describing the everyday survival activities assumed by PLWA’s (people living with HIV/AIDS) as they attempt to maintain basic health and wellbeing. In this thesis, lifework refers to everyday survival activities undertaken by homeless individuals.
and authority inherent to the processes of administration and governance, and the role of institutional texts in both standardizing and coordinating individuals’ interactions with health care services.

Literacy, or the lack of literacy, was an essential focus of this study. Organizational literacy\(^2\) is employed, reproduced, and promoted in institutional settings. Individuals who are able to navigate institutional and textually mediated processes are able to “hook up” effectively to mainstream health care services, while those without such essential knowledge are subsequently rendered “illiterate” and thereby perhaps excluded from participation in mainstream services. Literacy has historically been viewed as an effective means of social control through which the ideological interests of the dominant class are preserved (Lévi-Strauss, 1973). In particular, literacy may be employed both to legitimize and perpetuate unequal sociopolitical power relations, both by promoting mainstream, dominant forms of knowledge and by excluding or sidelining those who are not privy to such knowledge. Giroux (1987) argues that illiteracy may often be understood in terms of resistance to domination and subordination, rather than as ignorance or lack of knowledge: “That is, members of the working class and other groups may consciously or unconsciously refuse to learn the specific cultural codes and competencies authorized by the dominant culture’s view of literacy” (p. 13). In this study, resistance to mainstream ideologies and practices was evident in participants’ unwillingness to engage in institutional processes, especially where such processes wield governmental or regulatory powers.

In an effort to circumvent or avoid bureaucratic regulations that mediate and control

\(\text{\textsuperscript{2}}\) Organizational literacy (Darville, 1995) is defined as the ability to navigate, decipher, and interpret organizational texts and textual sequences.
access to mainstream health care services, many interviewees in this study instead sought care from informal health care providers located in church drop-in centres or non-profit traveling buses. Approximately 50% of participants interviewed in this study (14 out of 27 individuals) did not possess a health card. These individuals either experienced difficulties obtaining replacement cards, or they expressed little interest in acquiring health cards. For many interviewees, informal health services not only offered non-invasive, inclusive, and patient-friendly care, but they eliminated the need for the completion of lengthy paperwork or the rendering of proof of valid health insurance.

In 2007, a report by Street Health (Cowan, Hwang, Khandor, & Mason) found that 28% of homeless individuals were refused care because they did not possess a health card, compared to a similar study conducted in 1992, in which only 7% of homeless individuals were refused care (Ambrosio, Baker, Crowe, & Hardill). In 2010, researchers found that 31% of homeless individuals in Toronto did not have a health card in their possession (Hwang et al., 2010). Tightened or increased regulatory practices and additional paperwork (designed to reduce fraud and counterfeiting) have resulted in discouraging many homeless individuals from completing the extensive documentation that is a prerequisite to obtaining mainstream health care insurance. These stricter regulatory policies may potentially have had a profound effect on the health and welfare of homeless individuals in Ontario. The literature review (Chapter 3: The Social Inequalities of Health) reveals that homeless individuals are not only more likely to deal with illness, disability, and mental-health issues, but that they are also more vulnerable to physical and sexual abuse than the general population. Despite these health care needs, homeless individuals often experience difficulties when attempting to access mainstream health care services.
Quantitative research studies have comprised a significant and useful contribution to the literature that pertains to the health of underserved populations. However, critical ethnographic research brings another dimension to the existing body of scholarly knowledge, as participants maintain an active and authoritative voice throughout the course of the qualitative research endeavour by initiating, guiding, and directing the avenues of exploration. This study recognizes that all human beings come from authoritative positions of “seeing” and “knowing” that are grounded in their own unique backgrounds, experiences, and education. Throughout this qualitative study, individuals’ first-hand accounts formed the basis for a systematic, embodied, and reflective examination of personal experience. The employment of first-hand, personal accounts provided a means to contextualize individuals’ experiences within the broader sociopolitical and socioeconomic parameters in which public health care institutions operate. Excerpts from individuals’ first-hand accounts are found in Appendix A.

The Philosophical Background of the Study

The philosophical basis of this study is grounded in critical pedagogy (Freire, 1970; Giroux, 1987), which draws philosophical insights from the Marxist understanding of class formation and class conflict (Marx & Engels, 1932/1970). Freire (1970) argued that socially and politically marginalized individuals possess first-hand, ground-up knowledge of unequal power structures in human society: “Who are better than the oppressed to understand the terrible significance of an oppressed society?” (p. 45). Giroux (1987) writes that the “pedagogy of empowerment” challenges ideologies that “subjugate the poor, minority groups, women, or people of color” (Giroux, 1989, p. 12). For Giroux, the central issue in the study of adult literacy surrounds agency: those with agency are equipped with the dominant “social grammar” to
function successfully in the world, while those without agency are illiterate and consequently excluded from the literate world of authority and power (p. 14). Giroux views both literacy and illiteracy as ideological constructs that serve the hegemonic interests of the ruling class. Literacy (or the lack of literacy) may serve as “cultural markers” for referencing or differentiating unequal relationships in society (p. 3). Members of oppressed groups may either “consciously or unconsciously” refuse to embrace the cultural values of the dominant group (Giroux, 1987, p. 13). Thus, the term “illiterate” may signal a group’s lack of political, intellectual, or technological expertise, or it may equally signal a group’s resistance to governance and cultural hegemony (p. 12).

Freire (1970) theorizes that disenfranchised individuals gain empowerment through critical literacy education, and that such education prepares individuals to participate in society as active and informed citizens. Darville (1995) asserts that literacy education should go beyond teaching individuals how to read and write: rather, literacy education should also teach learners how to uncover the coordinative and often invisible practices that exist in institutional regimes. Examining institutions in critical and analytical ways encourages learners not only to engage analytically with dominant forms of institutional literature, but it also encourages learners to draw upon their own experiential knowledge in efforts to assess and resist institutional domination and subjugation (Darville, 1995, p. 259). Giroux (1989) promotes a form of critical awareness that “moves beyond moral outrage” and instead promotes a critical understanding of the broader dimensions of power that have a direct impact upon people’s everyday, immediate lives (p. 39). Education, thus, can serve two purposes: it can either create docile citizenry, or it can instil a form of critical awakening in individuals (Giroux, 1989, p. 28). In this study, education and acquired literacy are viewed as most effective only where they serve the latter of
these two purposes.

**Methodology**

This study employed an institutional ethnographic method of inquiry. Institutional ethnography provides a means to explicate the complex and often invisible relations that exist between people, places, and things (D. Smith, 2006). Institutional ethnography draws insights from both the ethnomethodological study of social order and routines (Garfinkel, 1976) and historical materialism (Marx & Engels, 1932/1970). The world is an inherently social place, in which human beings interact with each other in organized and coherent ways. This thesis examined the ways in which individuals are interconnected and intertwined as human beings, while it also examined the power structures that emerge as a result of such relationships. Institutional ethnographers often seek understanding from commonplace or everyday experiences, such as reserving a book at the public library, negotiating car insurance, or visiting a doctor. In many of these social interactions, wider bureaucratic activities are at play. Institutional ethnographers, like social theorists, are interested not only in everyday life experiences, but also in the translocal social relations that mediate such everyday experiences. In this study, interviewees were not perceived as passive agents: they were instead viewed as active agents who negotiated and perpetuated their “nested” roles within the broader, hierarchical, ruling apparatus (Ng & Mirchandani, 2008, p. 39). This study sought to map, locate, and make visible the local, everyday experiences of 27 individuals at an Open Access shelter, and to situate those

---

3 Historical materialism is the scientific study of social life and holds that the social world is interdependent and interconnected.

4 Marx and Engels’ first major joint work, the German Ideology, initially failed to find a publisher. Although it was written during the years of 1845–1846, it was first published through the Marx-Engels Institute in Moscow in 1932.
experiences within the translocal and often invisible realm of both bureaucratic health care delivery and broader neoliberal ideologies. Collins Dictionary defines neoliberalism as “a modern politico-economic theory favouring free trade, privatization, minimal government intervention in business, and reduced public expenditure on social services” (Collins Dictionary, n.d.). Proponents of neoliberalism support reduced taxation for wealthy individuals and corporations, privatization of public entities to further the interests of private entities, and the reduction of welfare expenditures to reduce governmental costs, deficits, and taxation. Neoliberal ideology purports that capital or surplus wealth accrued by wealthy individuals will eventually “trickle down” to poorer individuals. In this study, neoliberal policies are characterized as including cost-effective restructuring of public health care and education systems, privatization of public entities, and the reduction of welfare spending, all of which contribute in significant and potentially negative ways to creating the social determinants of health.5

This study aims to conceptualize and make visible the everyday, commonplace experiences of one group of individuals (drawn from an Open Access shelter in Toronto) seeking access to mainstream health services. In this study, the first-hand, personal accounts of individuals living without a permanent home guided the ethnographic direction of the research. This inquiry emerged from individuals’ first-hand, personal accounts, and then moved outside individuals’ immediate experiences, in order to examine the wider, translocal relationships in which these experiences are embedded (D. Smith, 2005). It should be noted that this study did not aim to present the Ontario health care system in a negative light. Rather, this study sought to examine the complex and multifaceted nature of institutional health care delivery.

5 The social determinants of health refer to factors such as poverty, economic disparity, social status, and social exclusion that predetermine the extent to which certain societal groups are predisposed to illness (Wilkinson & Marmot, 2003).
A concise summary of the institutional ethnographic method is as follows (G. Smith, 2006, p. 44):

1. Start from the lives of real people.
2. Be situated in the practices of people.
3. Use social relations as an analytic.
4. Employ officials’ input to gather ethnographic data.
5. Analyze texts to describe how ruling relations work.
6. Provide an authentic account, which draws from people’s everyday lived experiences.

Research Questions

The overarching research question is as follows: How are health care services socially organized with regard to homeless individuals’ access to mainstream health insurance?

The subset of research questions is as follows:

1. What problems, if any, emerge for homeless individuals when seeking care without a valid health card?
2. How does organizational literacy, or the lack of such literacy, facilitate or mediate access to health care?
3. How do current governmental policies and directives impact homeless individuals’ access to health care?
4. How does technological literacy, or the lack of such literacy, facilitate or mediate access to health care?
Organization of the Thesis

This thesis consists of nine chapters. Chapter 1 (the Introduction) provides the reader with a summary of the research background, philosophical framework, methods, questions, and definition of terms. Chapter 2 (Open Access: A Research Setting) situates and orientates readers in the setting in which this study took place. Chapter 3 (The Social Inequalities of Health) reviews the main body of existing literature that examines homelessness, health care, and literacy. Chapter 4 (Methods) describes and justifies the methods and conceptual framework employed in this study: institutional ethnography. In Chapter 5 (Results), the results are presented, along with summaries of participants’ first-hand experiences. Chapter 6, 7, and 8 present the thesis discussion, in which the implications of the findings are discussed. Chapter 9 (the Conclusion) includes a summary of research results, review of study limitations, and implications for future research and practice.

Definition of Terms

Homelessness. The Oxford dictionary states that a homeless individual “is a person without a home, and therefore typically living on the streets” (Oxford Dictionaries, n.d.). Rossi (1989) notes that the term homeless can refer to precarious or unstable housing as equally as it can to no housing at all. A number of interviewees drawn from the Open Access shelter identified themselves as homeless, although they had access to marginal housing, such as low-cost hotels or rooming houses. These individuals often chose to remain with the Open Access shelter rather than return home to their low cost hotels or rooming houses. Individuals cited many reasons for abandoning these establishments, including fear of social isolation, prevalence of rats, bedbugs, and cockroaches, and prolific drug use among hotel or rooming house co-
inhabitants. A number of individuals discussed their preference for the food and sleeping conditions available at Open Access. For these individuals, “homelessness” did not specifically refer to living without a fixed address. Instead, it often referenced individuals’ preferences for sleeping at a shelter, as opposed to returning to their low cost hotels or rooming houses.

**Informal health services.** Informal health services refer to health care services that exist outside mainstream services and that are designed to support economically disadvantaged individuals. Many of these services are non-profit and community funded. For example, a number of non-profit, privately funded, charitable organizations in Toronto offer mobile, on-the-spot nursing care. These services do not require individuals to show identification or to produce a health card.

**Lifework.** Throughout this study, the everyday survival activities assumed by individuals as they attempt to maintain basic health and wellbeing is referred to as “lifework” (G. Smith, Mykhalovskiy, & Weatherbee, 2006). “Healthwork” is a form of lifework that refers to health-related work undertaken by individuals (Bresalier et al., 2002). For an individual without permanent shelter, the onerous nature of daily lifework is often exacerbated by the need to manage both life-threatening health needs and preventive healthcare. For homeless individuals, the daily work of meeting basic health needs involves expending significant time and energy. In this study, a close examination of homeless individuals’ lifework revealed the everyday challenges experienced by such individuals.

**Mainstream health services.** Mainstream health services refer to general-population,
standardized health care services available to Canadian residents who possess provincially mandated health cards.

Neoliberalism. Martinez and Garcia (1997) describe neoliberalism as “a set of economic policies” employed by conservative governments to reframe conservative, “right-wing” ideologies as progressive (p 1). The main tenets of neoliberalism include supporting free enterprise, cutting social services, deregulating any policy that threatens to infringe upon profits, privatizing of state enterprises, and reducing welfare benefits in favour of “individual responsibility” (p. 1). More specifically, neoliberal policies include cost-effective restructuring of public health care and education systems, privatization of public entities to further the interests of private entities, and the reduction of welfare spending to reduce governmental costs and taxation. Each of these policies ultimately contributes in significant ways to creating both economic hardships for marginalized groups and the associated social determinants of health for these groups.

Organizational disjuncture. Organizational disjuncture is a text-based, systematic phenomenon indicative of many bureaucratic systems. Organizational disjuncture is a problem or disconnect between an individual’s expectation of an institutional process or procedure and the actual substantive experiences encountered by that individual within an institutional hierarchical system. Organizational disjuncture creates a sense of disquiet or unrest in individuals (G. Smith, 2006, p. 167). Such disjunctures often reveal incoherence or separation between the artificial regulations and expectations promoted by institutional organizations, and people’s first-hand experiences of bureaucratic processes. An example of organizational disjunctures that emerged
for participants in this study include the prolonged institutional waiting period governing health card registration, their inability to secure housing located in the downtown core, and their difficulty obtaining ongoing health or dental care.

**Organizational literacy.** Organizational literacy is the ability to navigate, negotiate, and interpret organizational texts and textual sequences. Organizational literacy is both facilitated and reproduced in institutional organizations. Organizationally literate individuals are able to interpret dominant forms of literacy (e.g., regulations, contracts, policies, licenses, procedures, and text-based dialogues) in ways that often elude individuals who are not privy to such organizational knowledge (D. Smith, 2005, p. 183). Unsophisticated readers (or those who lack organizational literacy) are unable to read texts critically, whereas more sophisticated readers are able to strip texts of their implicit references to institutional power processes, thereby “seeing” texts as potential pretexts for coordination and control (p. 116).

**Social organization.** The term social organization in this thesis refers specifically to the patterns of social interaction that constitute people’s interrelated experiences within institutional or bureaucratic settings. Institutional ethnography provides researchers with a means to investigate the organization of the social world through the use of mapping techniques, which trace or connect the complex set of human relations embedded within social organizations. Translocal social relations exist outside of individuals’ local, everyday experience. Administrative, governmental, and managerial entities operate in translocal or extra-local settings, and they have the capacity to mediate, shape, and control people’s local experiences. In this institutional ethnographic study, translocal (macro) processes are linked to local (micro)
Technological literacy. Technological literacy is defined as the ability to use technology in order to employ technological tools, navigate websites, understand technologically mediated information, and access online service. Technologically mediated literacy relies heavily upon the use of computers, laptops, smartphones, and cell phones, many of which are employed to access the Internet from web browsers. While terms such as technologically “literate” or “illiterate” reveal an individual’s level of competence in the use of technology, such terms also often reveal an individual’s relative class or position within the social hierarchy, as technological tools are costly and thus largely unavailable to economically disadvantaged individuals (Statistics Canada, 2009). Technological literacy denotes an individual’s social status or position of power in society: those who can afford to buy and maintain computer technology demonstrate that they possess the economic means by which to purchase and maintain such technology. Health literacy (which draws heavily upon technological literacy) is defined as the ability to locate and access information related to health, which in turn relies not only upon the ability to read and write, but also upon the ability to access online learning tools (Rootman & Ronson, 2005, p. 3).
Chapter 2

Open Access:

A Research Setting

You go to that place, and then to that place, and then back to Open Access. It’s like a circle. Same circle everyday.

Antonio, Interviewee

This chapter seeks to shed light upon the research setting in which this study was conducted. Open Access is one of 19 community-based, emergency homeless shelters located in churches and synagogues in Toronto. It is not a conventional shelter. Unlike other shelters that provide daily shelter, each Open Access shelter remains open only one night per week. Guests do have the option to spend the remaining six nights of the week at other Open Access shelters, all of which are located in churches and synagogues dotted around the Greater Toronto area. There are approximately 19 faith-based Open Access organizations that provide emergency overnight shelter for homeless individuals. Although the word “emergency” is employed to describe the ad-hoc, impermanent nature of the Open Access shelter, for many homeless individuals, the Open Access program is a place to call home for the winter season. In the warmer spring and summer months, Open Access closes its doors and reopens again in the winter season. Many individuals sleep outside in warmer weather, and spots such as the Green Mile, a stretch of land bordering Rosedale Valley Road, constitute popular campgrounds. Very few individuals indicated that once Open Access closed its doors, they planned to seek out other shelters. While Open Access provides only transient shelter, it nevertheless provides guests with a sense of
continuity and community throughout the winter months. The dinner tables are collapsible, the cutlery is plastic (and rewashed many times throughout the night), and fold-up gym mats serve as mattresses. There are no shower facilities, and few guests, if any, brush their teeth before bed. Still, a sense of the comforts of home is present, if only for short periods: each night, dessert is available after the late-night movie has ended, and early each morning, hot coffee is served in ceramic mugs.

Open Access is supported by donations from both church congregations and surrounding communities. Paul, the coordinator of this particular Open Access site, informed me that rigorous funding campaigns undertaken by host sites provide the majority of funding for the program. The City of Toronto provides limited funding for the provision of security services at each shelter. Currently the Dixon Hall Agency provides security for Open Access. Security includes limiting access to disruptive individuals, breaking up occasional fights, and removing guests who consume alcohol or drugs on shelter premises. Paul did not view funding as a problem in any way. Donations from the community and congregation are generous, and church leaders of this specific site accept donations only until the program is fully funded for the season. Once this Open Access site has met its financial goals, no further donations are solicited.7

Paul sat down with me one night after dinner preparations were well underway. I had asked him if the shelter had any pressing issues. Paul informed me that organizers were currently grappling with problems related to the distribution of hygiene products. Paul explained that each night, guests line up in front of the broom closet to receive such products. (Mouthwash is

6 Pseudonyms are employed not only in this chapter, but also throughout the entirety of this thesis.

7 Each Open Access site is responsible for its own fundraising campaign. At the Open Access shelter in which this study was situated, community donations were not distributed or shared with other Open Access sites. Rather, donations were no longer solicited from patrons or donors.
prohibited, due to its alcohol content.) Many guests request a new toothbrush each week, although few, if any, appear to brush their teeth at night. Paul wondered if other Open Access sites dispensed similar quantities of toothbrushes. “How many toothbrushes do you need each week?” Paul asked. He was planning to raise this problem, along with a few other minor issues, at the next church committee meeting.

Volunteering at the shelter required little training, and during my visits to the shelter, longtime volunteers explained the basic rules and procedures to which I should adhere. (For example, two servings of meat are considered more than ample, a paper ticket must be presented to receive dinner, and dessert may only be served after the late-night movie has ended.) A night of volunteering might entail serving food to guests, filling the punch bowl with orange drink, operating the commercial dishwasher, and collecting dirty dishes from collapsible tables set up by volunteers. One day each week, approximately 200 guests stay for dinner and approximately 100 guests sleep overnight. Although the majority of meals are cooked onsite at this particular Open Access, volunteers who have access to professional kitchen facilities may choose to prepare meals off-site.

Snowball sampling presented itself as the most effective way to locate informants within the shelter. This technique involves asking initial participants to recruit future potential participants from their network of acquaintances. I interviewed both male and female participants, the aged and the young, the long-term and the newly homeless, all of whom were drawn from a diversity of ethnic and sociocultural backgrounds. At the conclusion of my four-month period with Open Access, I had accrued over 27 interviews situated across a diversity of demographic groups.

Allan was my first interviewee. He asked me for my astrological sign as I was clearing
his dishes, and he was pleased to hear that I was a Capricorn, believing our astrological signs made us compatible. However, Allan appeared to enjoy few, if any, compatible associations within the shelter. “I like isolation, because when you’re isolated you can concentrate on yourself. When you’re in places like this, you have to keep watch. You’re on the lookout. You don’t have time to relax, study - have time for yourself. You have to keep your eyes open. I have people who respect me or hate me.” I led Allan through my first few questions, in which I attempted to elicit his experiences when seeking health care in Ontario. Allan told me that he occasionally visits the Rotary Club of Toronto Health Bus, which offers mobile, on-the-spot nursing care. He has avoided visiting conventional doctors located in clinic settings. Allan's views regarding the Ontario health system were clear. He sees the Ontario system as two-tiered and unfair, consisting of one system that services professional working people, and a second, somewhat inferior, system that services those on social assistance programs: “Under OHIP, you’re working under the fact that you’ve been working for years. So you’re getting the benefit from the CPP, all the taxes that you’re paying. So that gives you OHIP. We’re not on OHIP. We’re on disability.”

Allan expressed feelings of social exclusion and isolation. He attributed his perceived exclusion to judgmental societal responses to his mental illness and his reliance on social-assistance: “Yeah, but when you’re on ODSP, you become a so-called mental issue. It’s hard for you to get back into society. Margo Kidder and Britney Spears made a statement about it. When you go crazy, everybody tends to know, and then you end up wacko.” Allan believed that mainstream individuals in mainstream society dislike and mistrust him: “The blue-collar people in society hate you. Don’t go to Hamilton. Don’t ever go to little cities in Ontario if you’re on disability or anything. Because they have this little belief that they work their entire lives to
support your dirty ass.”

A variety of societal, organizational, and personal factors contributed to individuals not only becoming homeless, but also remaining homeless. For Allan, a fire in his home had contributed to his current homeless situation. Other individuals discussed mitigating factors such as loss of employment, lack of affordable downtown housing, breakdown in a marital or familial relationships, periods in jail, and alcohol or substance abuse. Each of my participants had been without a home for a number of months, and in many cases, for a number of years. However, many informants in no way represented the quintessential stereotype of homelessness. Antonio wore clean, white Nike running shoes, and he smelled of designer cologne. “I’ve been homeless a long time. Even before I was in jail I was doing Open Access. Yeah, before I was in jail I was doing Open Access, too.” During the day, Antonio visited different facilities located in downtown Toronto that offered free shower and laundry facilities. “I’m not one of these guys who drink and do drugs and do this and that,” Antonio informed me. “I’m trying to get my shit together. I don’t want to do this. I used to be a bad druggie. I’m not a druggie anymore. The only thing I do is smoke weed. It’s better than doing the crack and the heroin. That’s why I got my shit together. I gotta dress good and smell good. I come from a good family.” Antonio had spent the past 20 months in jail. He was estranged from his family and was finding it difficult to secure employment.

Many participants expressed the need for secure, affordable housing located in a central downtown area, as opposed to housing located in suburban, non-centralized areas. A number of participants had chosen to leave their subsidized homes and to seek associations and assistance located in the downtown area. Feelings of social isolation contributed to these decisions. Lynn, for example, said that loneliness was the primary factor that prompted her to abandon her
suburban, subsidized home for a life in the downtown streets of Toronto. “Yeah, I’ve had housing, but I gave it up. I can’t stand it. They put you in some area that you’re not familiar with, and it’s not good. Not in the city – like Wilson or something. I used to go there to pick up my cheque once in a blue moon, but you know, it’s so far. No friends – I don’t know where my resources are. Like downtown, I know where to eat. I know how to survive downtown. But I know in some of these other places their food bank system is different. But to get to the doctor, my doctor is downtown. The AIDS services are downtown. Everything I need is downtown.”

Without a secure place to store their personal belongings (Open Access offers no storage facilities), individuals often lose their identification. Many participants at the shelter did not possess an OHIP health card: 50% of participants (13 out of 27 participants) reported that their OHIP health card had been either lost or stolen. Lynn has lost her identification on a number of occasions, and she now stores her few possessions (along with her current identification) in the trunk of a friend’s car. Lynn has lived on the streets “off-again, on-again” since she was twelve. Now in her late forties, she faces a complex set of health issues, including both HIV and hepatitis C. “I’m probably going to be forced through that process again [obtaining a health card]. It’s just bullshit, more time. It’s frustrating. That’s why I give up. I have nodules in my right lung. I don’t even care. I don’t care.” A number of individuals in the shelter sought health services from either the emergency department of a downtown hospital or a mobile clinic such as the Rotary Club of Toronto Health Bus, as neither of these two services requires an OHIP health card.

The business of taking care of everyday needs (or “lifework”) is often an arduous task for homeless individuals. Once guests leave the Open Access shelter, they must find a variety of places to eat, shower, wash clothes, check email, and sleep for the night. They must also perform these activities at little or no cost. Eric explained the nature of his lifework: “My day – do you
want to know how it is? I wake up at 7, and I go for coffee. I have coffee and breakfast here, and then I go to Timmie’s [Tim Horton’s] for another coffee. Then I walk to the next place that I have to go – to another Open Access. I may not eat lunch. Sometimes I’ll go to another drop-in to eat lunch. Like today there is a place on Church where you can have a shower. Showers are big, like finding a place to have a shower. Streets to Homes is good. You just walk in there. You can shave in there and do your laundry. Then I make my way to the next Open Access and eat around 5:00.\(^8\) It takes up your day.” Individuals often walk long distances to the various drop-in centres that help to support their lifework needs. At this particular Open Access shelter, guests are supplied with one TTC token after breakfast, and any subsequent travel must be conducted on foot.

Attending to daily lifework entails adhering to a strict, daily schedule. At Open Access, individuals receive dinner at 6:30 p.m. and they are awoken at 6:30 a.m. each morning. I asked Antonio during our interview what his day looked like. He saw his day as circular, one that both began and ended at any one of the 19 Open Access sites. “There are different locations [that] you have to go to throughout the day that are open. They give you one bus token when you leave in the morning. I’m doing all this running around. I’m busy during the day. You gotta eat lunch, then go take a shower. The morning place we go to after here will give you breakfast and lunch, and then we go to another place to relax and freshen up, and then we go to wherever we’re going that night. You go to that place, and then to that place, and then back to Open Access. It’s like a circle. Same circle everyday.”

For many individuals, little time remains available for addressing basic health or hygiene

---

\(^8\) At this particular Open Access shelter, doors open at 5:00 p.m., at which time guests are offered soup and bread. The main meal is served at 6:30.
needs, such as showering, dental care, changing sanitary pads, or using nail clippers. Peter explained that although looking after his health included visiting a doctor or obtaining a new health card, it also involved addressing routine care issues, such as cutting his fingernails. Lifework consumed the majority of his time: “Sometimes you spend most of your day trying to get a bed. You’re always chasing after your health. For example, I have a nail clipper, but I’m probably the only one in this room who has one. Everyone knows I’m the one with the nail clipper. Do you know how many people have used this clipper? Hygiene is an issue.” Peter was once a general contractor, and he at one time employed a staff of seventeen. This year marks Peter’s twelfth year without either employment or a stable home. He showed me two sharp metal pegs in his mouth, vestiges of dental care performed a number of years ago. Peter’s interview was lengthier than most. During our discussion, he had recited poetry and sang a song, none of which he permitted me to capture on my digital recorder.

Dental care is an essential component of good health. Dental cavities, gum disease, and abscesses were common ailments among participants. Many individuals experienced pain specifically related to poor dental health and were forced to wait lengthy periods in order to receive dental care. Eric, a young, unemployed roofer new to Out of the Old, complained of severe tooth pain during our interview. Eric explained that he must be able to render both a physical Ontario Works payment stub, along with a physical health card, in order to have his tooth pulled. “I have to wait until the end of the month to get my pay stub, so I can go see a dentist, free for people on OW [Ontario Works] and Social Assistance. For people on Street Allowance, same thing: they basically will pull it. But you need your OW statement and your health card. There’s a big list of dentists, but I’m still gonna have to wait a week and a half.” Although there is no public dental insurance in Ontario, minimum dental coverage is available to
those on social assistance. Complete removal of the tooth is the only option available for individuals with no means of paying for dental cleanings, fillings, root canals, or crowns. Eric is a young man in his late twenties, and despite having many years ahead of him, he is facing the prospect of having a permanent gap in his gum line. Removing the tooth will no doubt relieve Eric’s toothache, which is already threatening to abscess. “I gotta tooth ache.” He told me. “But it’s not inflamed yet.”

Open Access provides guests with more than dinner and overnight shelter: it also provides opportunities for guests to interact in an informal social setting. Social interactions and friendships between my participants became increasingly apparent throughout my time at the shelter. Past interviewees were often eager to reestablish contact with me, and many stopped to say hello while I was in the process of conducting other interviews. During my interview with Lynn, for example, Dennis interrupted to ask if we thought he had too many girlfriends. Dennis was an avid computer user, and he had spoken to me at length about his involvement on several online dating sites. “Yeah, you do [have too many girlfriends],” Lynn told him. We all laughed, and Dennis moved on, clearly pleased with the roguish reputation he had apparently secured among women at the shelter.

Women experience homelessness differently from men. Women are more susceptible to sexual violence, and they also have uniquely female sexual and reproductive issues. Homeless women are often more vulnerable than their male counterparts when either sleeping on the streets or sharing communal accommodation in shelter settings. A few years ago, Lynn was raped in a downtown Toronto stairwell. Although Lynn feels more secure sleeping at the Open Access shelter, she nevertheless finds herself deflecting unwanted sexual advances from men: “It happens on a daily basis that guys are hitting on you. Trying to pick you up. Asking if you want
to do dates. ’Cause you’re a lowly homeless person they think you’re a hooker. And they offer you money for sexual favours – for like $10 bucks, $20 bucks, $40 bucks, whatever. Dirt cheap kinda crap. Don’t want to use condoms.”

Professionals working in institutional settings (e.g., health care workers, social workers, case workers) exerted significant power and control over the lives of many of the participants interviewed in this study. Institutional plans of action, put into motion by professionals, had direct and significant consequences for individuals in the study. One female participant, Stacey, recounted the birth of her child, a boy, who was apprehended by Children’s Aid Society immediately after birth. At the time of our interview, Children’s Aid Society had mounted a case for complete removal of Stacey’s maternal rights, which would allow no future contact with her newborn child. Stacey did not discuss the specifics of her infant’s apprehension, although she did discuss her disappointment when informed that she would not be permitted to provide breast milk for her premature infant. Children’s Aid did not allow her to pump milk for her infant, and neither hospital staff nor Children’s Aid explained to her why she was prevented from doing so. Stacey was not consulted regarding a number of institutional decisions regarding the birth process and the subsequent apprehension of her child: “The doctor looked at me and says, ‘You either give birth to this baby right now, or we’re putting you out.’ So I said, ‘Whatever’s best for the baby.’ I wasn’t thinking about me or anything. I woke up, and there’s my baby. I was scared.” Stacey remained hopeful that she would one day regain custody of her infant boy, and towards that end she was seeking a two-bedroom rental apartment. Her latest rental application had been rejected.

Open Access has no prerequisites to access. Anyone can use the shelter, and no personal identification is required of guests. At least one of my participants chose to use a pseudonym for
legal reasons. Dennis explained that he avoided conventional shelter programs (such as the Salvation Army), as these institutions usually requested personal information from guests. Dennis explained: “They [the Salvation Army] are all about numbers in that organization. But like here [Open Access] they say, ‘What’s your name? Dennis? Here’s your ticket for the meal.’ If you go to the Sally Anne [Salvation Army] to get a place to stay, you have to give a health card number, and you have to sign a release of information. Now they want to know the last time you had a poop, and everything else, and I’m not telling them that. If you’re a nurse or a doctor, then I have to give you permission to go and check it. So when you want to get a bed, you have to go through murder. They’re all about numbers.” The non-bureaucratic nature of Open Access shelter is what initially attracted Dennis to the shelter. Indeed, the lack of permanency has perhaps resulted in the shelter being less bureaucratic and therefore more accessible to individuals seeking short-term shelter.

Open Access, although non-bureaucratic and readily accessible, offers only limited support, however. This Open Access site offers no storage facilities. Many participants expressed problems both locating and retaining secure storage in the city. Many therefore were forced to carry small bags, suitcases, backpacks, or duffle bags around with them from one location to another. On the last night before the Open Access closed its doors for the winter season, Allan asked me if I would look after his suitcase. I agreed, as I knew he had no friends at the shelter. Allan carried around an old CD carrying case, although he described it as a suitcase. “I’m carrying this from morning ‘til now.” Allan had told me weeks earlier, referring to his suitcase. “I have a bad leg because – lift it up with your whole hand [indicating that I should lift the suitcase]. I’ve been doing that for a whole day. I go everywhere. I just look like a man with a suitcase. They are probably thinking why is he limping all day with this suitcase? Why don’t he
just throw it away?” Having kept Allan’s suitcase with me until late that night, I was concerned
when he did not return to retrieve it. I eventually decided to leave it with Dixon Hall security
staff members. But the Dixon staff informed me that they did not know Allan personally and
would have problems identifying him. I struggled briefly with providing an appropriate
description of Allan. I eventually mentioned that he might easily be identified by his strong odor
of Vick’s VapoRub, although I felt somewhat disloyal in doing so. Although Dixon Hall staff
members were reluctant to assume responsibility for Allan’s personal belongings, they agreed to
store Allan’s suitcase under their front reception table.

Security and enforcement at the shelter is rigidly enforced. The Dixon Hall security
employees are instantly recognizable at the Open Access shelter, as they wear high-visibility,
neon-orange reflective vests. The aim of security is to diffuse or manage arguments between
belligerent or confrontational guests. Although Open Access has few access restrictions, the
program enforces a strict “bottle check” at all times. Any guest caught drinking on the property
is swiftly removed from the church. During one cold night late in April, Dixon Hall staff
removed a full table of guests who had been sharing a bottle of Listerine. I had interviewed one
member of the group earlier that season, and I knew he was struggling with both heroin and
alcohol addiction. Although it was April, it was below freezing that night. As I left the church
later, I saw the group huddled in a dark alley behind the church. As most of the Open Access
shelters were operating at full capacity that night, it is likely they slept outside that night.
Chapter 3

The Social Inequalities of Health

I’m really homeless. Not like 70% of people here. They like the food and they like the breakfast. My throat is sore. I sleep outside.

Lyle, Interviewee

Institutional ethnographic research is grounded in the work of Marx, as it aims not only to understand inequities in society, but it also aims to challenge and resolve such inequities. Marx’s theories provide a means for researchers to shed light upon the “spatial dimensions” of given social inequities, specifically through standing with and alongside marginalized individuals (Carroll, 2006, p. 235). In Marx’s view, understanding the role of the oppressed is as essential as understanding the role of the oppressor when attempting to uncover the true nature of capitalistic subjugation. “The proletariat was not only a source of transformative agency, it functioned as a standpoint, internal to capitalism, from which to uncover capital’s secrets” (Carroll, 2006, p. 235). D. Smith (2005) argues that assuming the “standpoint” or perspective of another individual enables the researcher to gain a more complete and comprehensive picture of human experience through entering the everyday, “local actualities of people’s lives” (p. 25). In this thesis study, individuals drawn from one Open Access shelter in Toronto, Ontario were seen as operating from a distinctive, “ground up” position. Standing with and alongside these individuals led to deeper understandings of the social inequities inherent to institutional health care provision in Ontario.

Marx and Engels (1932/1970) were early critics of capitalistic social relationships, which
they viewed as complex, contradictory, and unequal. They define two basic class divisions: the ruling capitalists (or bourgeoisie) and the working-class labourers (or proletariat). Throughout history, the relationship between capitalists and labourers has been marked by conflict, competition, and class struggle. Inherent to this conflict is a hierarchy of power and status between the haves and have-nots, the rich and the poor, and the state and the people. Marx and Engels argued that class differences in society denote not only the social circumstances into which individuals are born, but they also denote individuals’ capacity to purchase property and employ a means of production. In capitalistic societies, the ruling classes have access to and control over the means of production, which subsequently enables the ruling classes to subjugate others as workers in the machinery of production, and thus to exercise control over others in society. The bourgeoisie not only generates income through owning the means of production (e.g., land, factories, and machinery), but this class also purchases the labour power of the proletariat to expand this income. Social class may be perceived as an antagonistic relationship between individuals, whereby those who own income-generating, productive land and property inevitably wield power over those without such acquisitions.

In *Das Kapital*, Marx (1867/1996) argued that the root causes of economic and social inequalities in society are a direct consequence of capitalism. At the root of capitalism is the pursuit of money, status, and power. The ruling classes perpetuate class social inequalities through exploiting and controlling society’s poorest individuals, in efforts to maintain ready access to slave labour. Marx argued: “The Roman slave was held by fetters: the wage labourer is bound to his owner by invisible threads” (p. 292). Capital accumulation is the essential aim of capitalism. Capital is defined as wealth that is accumulated and reinvested in order to produce ever greater, exponential wealth. Capital accumulation grows over time, and this growth is fueled
by people’s often insatiable desire for increased status and wealth. The working classes function as machines in the production of surplus wealth for their employers. Over time, the working classes become locked in a symbiotic, hierarchical relationship with their oppressors, which is at once beneficial and destructive: the working classes rely upon fixed wages to sustain their basic sustenance, and capitalists rely upon cheap, working-class labour in order to generate surplus wealth.

Capitalism uses and abuses individuals, and it also readily discards individuals no longer deemed useful (Marx & Engels, 1848/1964). In *The Communist Manifesto*, Marx and Engels (1848/1964) defined individuals who are discarded in this way as the Lumpenproletariat. Derived from the German noun “Lumpen” (meaning rags and tatters), the Lumpenproletariat references those without a foothold in organized forms of labour, and as such, marginalized and excluded from mainstream society. A parallel version of the Lumpenproletariat today includes individuals living without a fixed address. The Lumpenproletariat constituted a pivotal position within the Marxist understanding of class formation and class conflict. Marx and Engels (1848/1964) viewed the Lumpenproletariat as a malleable, marginalized non-class, which is potentially receptive to revolutionary causes: “that passively rotting mass thrown off by the lowest layers of old society, may, here and there, be swept into the movement by a proletarian revolution” (pp. 75-76). Frantz Fanon, a revolutionary theorist and Marxist scholar, developed the notion of the Lumpenproletariat further. Fanon (1961) argued that the Lumpenproletariat of today is positioned to assume a leading revolutionary force in society, as this group operates outside capitalistic modes of production: “The Lumpenproletariat, this cohort of starving men, divorced from tribe and clan, constitutes one of the most spontaneously and radically revolutionary forces of a colonized people” (p. 81). Fanon argued that as the Lumpenproletariat
is sufficiently divorced from the ruling classes, it is thus enabled to mount an effective resistance against colonization and domination in society. In recent years, a wave of activist groups has launched successful social campaigns that have brought about significant social, political, and economic change on behalf of low or no-income groups. In Toronto, the Ontario Coalition Against Poverty (OCAP) has employed effective labour-organizing tactics and publicity-generating, anti-poverty strategies to promote and advance the interests of poor and disenfranchised individuals. Rather than tapping into the potential of marginalized groups, OCAP stands alongside individuals in the fight against unfair conditions and unequal opportunities in society. Other successful grassroots, anti-poverty campaigns include New York’s Movement for Justice in El Barrio (Movement for Justice in El Barrio, 2006), Take Back the Land in Miami (Take Back the Land, 2012), and the Brazilian Homeless Workers’ Movement (Kjeld, 2011).

The Social Inequalities of Health

A review of the literature suggests that a healthy life is not only a state of physical and mental wellbeing, but that it is also often a measure of socioeconomic status. Social and economic inequities between the advantaged and the disadvantaged in society are often manifested in the form of health differences. A review of the literature reveals a high correlation between economic standing and health. In the United Kingdom, the groundbreaking Whitehall I and Whitehall II longitudinal studies of over 28,000 British civil servants found that poorer individuals experience more illness and have a lower life expectancy than richer individuals (Marmot, Rose, Shipley, & Hamilton, 1978; Marmot et al., 1991), and subsequent research in the United Kingdom replicated these findings (Townsend, Davidson, & Whitehead, 1992). Studies
across North America have revealed similar findings. In the United States, Hajat, Kaufman, Rose, Siddiqi, and Thomas (2010), Kitagawa and Hauser (1973), and Menchik (1993) established a strong correlation between wealth and increased longevity. In Canada, Frohlich and Mustard (1996), and McLeod, Lavis, Mustard, and Stoddart (2003) also found a strong correlation between socioeconomic status and health.

**The psychosocial approach.** Theorists who examine the social inequalities of health are often informed by two distinct, although closely aligned, theoretical approaches: the psychosocial approach and the materialist approach. Psychosocial theorists argue that individuals’ relative class position strongly influences the determinants of health, while materialist\(^9\) theorists specifically seek to explore the broader societal factors that are the determinants of health. For psychosocial theorists, factors such as poverty, unemployment, and class position affect psychosocial wellbeing, thus predetermining the extent to which certain societal groups are predisposed to illness (Wilkinson & Marmot, 2003). Baer, Singer, and Susser (1986) define good health as the “material and nonmaterial resources that sustain and promote life at a high level of satisfaction” (p. 95). Resources that are utilized by individuals in higher socioeconomic brackets might include gym memberships, vitamin supplements, elective physiotherapy, and spa or relaxation treatments. Good health is often dictated and governed by class position, whereby the wealthier classes have the financial resources to pursue not only costly health therapies, but also the specific consumption choices that reinforce a well-trained and youthful appearance: “These choices… are constrained by the individual’s social class

\(^9\) Materialist theorists explicate the societal factors that impact and determine health outcomes (poverty, economic disparity, social status, and social exclusion), while they also seek to explicate broader national policies and practices (neoliberalism, globalization, privatization) that equally impact health incomes.
position” (Lupton, 2003, p. 44). Bourdieu (1984) posits that members of each social class inhabit a “habitus”, or an embodied, unconscious form of class condition that distinguishes them from other classes. Bourdieu writes that the ways in which we administer our bodies reveals a great deal about the classificatory schemes indicative of our class and position in society: “the body is the most indisputable materialization of class tastes” (p. 190). Thus, the way we treat, care for, and maintain our bodies reveals the deepest disposition of our social standing.

Mainstream health caters to the dominant classes. A healthy life may perhaps be more aptly framed as a wealthy life, and a wealthy life, in turn, may perhaps be more aptly framed as one that confers power and status within the complex and hierarchical structure of capitalist societies. Wealthy people often have distinct personal tastes for healthy living, which implicitly suggests that they have the resources to live a healthy lifestyle. Power and ideology are central to issues surrounding health and wellness. In particular, wealthier, dominant groups assert the cultural parameters of what it means to lead a healthy life, and by doing so, they promote within their social class distinct cultural advantages. Thus, a healthy life may be perceived as a predominant social value that is promoted by members of culturally “rich” mainstream society. Dominant institutional health care systems cater to dominant social classes, thus further facilitating and reproducing relationships of social inequality.

The materialist approach. Materialists argue that the psychosocial approach places too much emphasis upon the individual, thereby ignoring broader sociopolitical disadvantages experienced by poorer individuals. Muntaner and Lynch (1999) maintain that the psychosocial approach fails to examine the relationship between low income and unequal socioeconomic status and opportunity. Conversely, materialists highlight the relationship between the broader
sociopolitical causes of poor health (poverty and unemployment) and the health status of poor individuals. In short, materialists study how social detriments or inequalities come to be (Eckersley, Dixon, & Douglas, 2001, p. 94). Materialists delve into the broader distribution of money, power, and resources located at all levels of governance, including global, national and local levels of governance (Raphael, 2004, p. 1). The materialist approach is also concerned with the political ideologies that drive policy decisions and public health discourse at broad, far-reaching, and influential levels of government. Materialists examine the ways in which governmental entities implement, administer, and regulate multi-level social welfare systems. This approach explicates the extent to which governments use their power, control, and influence to manage the lives of their citizens (Navarro, 2004).

The Rise and Fall of the Social Welfare State

The Great Depression (1929–1939) served as a catalyst for the expansion of state-run social welfare programs. Berton (2001) posits that in the very early years of the Great Depression, the Canadian government failed to respond decisively to the mounting economic crisis in Canada. During these early years, church-run soup kitchens, food pantries, and breadlines offered non-governmental food relief to economically disadvantaged, unemployed, and often hungry individuals.¹⁰ Indeed, during periods where governmental assistance has lagged or stalled, faith-based support programs have not only nourished and sustained poor and disenfranchised individuals, but they have also provided hygiene and nursing care, as well as information and referral services to other social support systems.

Granatstein, Abella, Bercuson, Brown, and Neatby (1986) argue that Canadian politicians

¹⁰ For example, during the Great Depression, the Salvation Army provided food and lodgings for poor individuals.
eventually mounted a unified, non-partisan response to the Great Depression, which significantly contributed to postwar economic security and social equality in Canada. In 1934, the Bank of Canada was established to regulate monetary policy and mitigate Canadians citizens’ exposure to severe and prolonged economic stagnation. In 1935, the Canadian Wheat Board was created to market and establish a minimum price for wheat, a move that strongly supported the interests of labour unions. In 1940, the federal government introduced the Unemployment Insurance Act (a national unemployment insurance scheme), which assumed responsibility for unemployed individuals. In 1946, Saskatchewan was the first Canadian province to introduce universal health care coverage, which guaranteed free hospital care for Saskatchewan citizens. In 1966, the federal Liberal government of Lester B. Pearson extended this coverage to each province under the Medical Care Act. Granatstein et al. argue that the federal government played a pivotal role in promoting socialist nationalist movements during the decades after the Great Depression: “Because of the strength of [Tommy] Douglas’s consensus, opposition to medicare was forced out of party politics” (p. 181). The essential tenets underpinning Canada’s universal health system largely remained intact throughout the latter half of the 20th century. In both 1984 and 1999, provincial leaders reaffirmed the earlier 1957 Canada Health Act: leaders underscored the necessity of a universal, comprehensive, portable, and universally accessible health insurance program.

In more recent years, the Canadian social welfare state has undergone a series of philosophical shifts, however. Health institutions have increasingly framed health care in terms

11 The 1962 Saskatchewan College of Physicians and Surgeons strike was a significant test for universal health care in Canada. Although many doctors objected to working under a compulsory, government-directed health scheme, the public voted strongly in favour of extending universal health care coverage.
of personal responsibility (rather than state or governmental responsibility), and by doing so, they have been able to shift unwanted attention away from public debate of inequalities in the health care system, and more into the realm of individual responsibility and personal choice (Lupton, 2003). The beginnings of this shift can be traced as far back as the mid-1970s, when Marc Lalonde, the Canadian Minister of National Health and Welfare under Pierre Trudeau, proposed a “new” approach to health care in the 1974 Lalonde Report: rather than focusing upon improving the medical system, Canadians were urged to consider their individual lifestyle choices. The Lalonde notion of a healthy life emphasized individual action over collective action. The report, formally entitled, A new perspective on the health of Canadians, informed Canadians that good health promotes happiness: “A nation of healthy people can do those things that make life worthwhile, and as the level of health increases, so does the potential for happiness” (p. 5). Lalonde drew a connection between good health and increased economic opportunities, reasoning that greater health results in a more productive and illness-free workforce (p. 5). A healthy life promises “not only to add years to our life, but life to our years” (p. 6). This behavioural approach suggests that if we experience poor health, it is our responsibility to make changes to our lifestyle (Townsend et al., 1992). Thus, we should aim to prevent disease through exercising more often, consuming less fattening food, and eliminating the harmful effects of drugs and alcohol. Lalonde referenced “ominous counter-forces” (all largely the choice of irresponsible individuals), such as “environmental pollution, city living, habits of indolence, the abuse of alcohol, tobacco and drugs, and eating patterns which put the

12 The Lalonde report did, however, explicitly raise the issue of health inequalities and the social determinants of health, as well as raise the issue of personal responsibility. Although the Trudeau government embraced Lalonde’s emphasis upon personal responsibility in an attempt to curb government-funded health care costs, the report nevertheless laid the foundation for current perspectives regarding health prevention and promotion.
pleasing of the senses above the needs of the human body” as the root causes of ill health (p. 5).

For Marc Lalonde, a “healthy life” held the promise of personal empowerment and economic reward. The notion of maintaining a healthy life is thus seen as a ritualistic, habitual practice for individuals, by which good health is achieved through individual self-restraint, self-denial, and willpower: “Talking about health becomes a means by which we participate in a secular ritual. We affirm ourselves and each other, as well as allocate responsibility for our failure and misfortune, through these shared images of wellbeing” (Lupton, 2003, p. 43).

A healthy life is commonly viewed as a universal right, such as the right to adequate housing, sustenance, and education. However, although viewed as a universal right, a healthy life is nevertheless also largely viewed as an issue of personal responsibility. Universal rights are traditionally based upon the Kantian concept of liberty and equality for all members of society (Sahakian & Sahakian, 1993). Immanuel Kant stressed duty and obedience, and he believed that it was the individual’s responsibility to maintain a healthy lifestyle and thus a healthy mind and body (Edelman & Mandle, 2005). Kant’s moral philosophy has provided the conceptual framework for many of the policies and directives found in present-day health care discourse and practice. For Kant, a moral society is one that functions rationally, in which individuals strive to promote not only the happiness and wellbeing of others, but also their own (Kant & Gregor, 1992, p. xxii). Kant reminds us to look within ourselves and to “live righteously, commit no injustice, and, by being moderate in pleasures, and patient in illnesses, rely primarily on the self-help of nature” (p. 49).
The notion of a healthy life may be seen as both a social and ideological construct, which is largely shaped by public health discourse. Public health discourse is widespread and influential, and its message often captivates and informs individuals who are unaware that the discourse has a disciplining influence upon their lives (Lupton, 2003, p. 35). Health discourse may thus be viewed as a form of pedagogy, designed to legitimize ideologically-inspired behaviors, such as what people should eat, how often they should exercise, and how frequently or in which manner they should express their sexuality (p. 35). Although the term “healthy life” appears to have universal applicability, this construct represents both an unrealistic and utopian ideal for poor or marginalized individuals.

In recent years, neoliberal ideologies (e.g., belief in fostering economic growth by promoting corporate wealth, increasing economic competition by privatizing state services, supporting monopolies as a means to monopolize corporate growth, and reducing governmental spending by decreasing or eliminating welfare subsidies) have promoted detriments to health for poor or marginalized individuals. McGregor (2001) notes that neoliberal discourse has increasingly found its way into health care policy reform around the world: “This trend is especially evident in the United Kingdom, Canada, United States, Australia and New Zealand, where neoliberal philosophy resonates with policy makers and members of the private sector” (p. 82). McGregor references neoliberal rhetoric as including phrases such as:

- Spending cuts, dismantling, de-indexing, deficit cutting, haves and have-nots,
- competitiveness, downsizing, declining welfare state, inefficiencies, inevitability,
- closures, chopping services, de-insured, user-pay fees, two-tier health care, for-profit

---

13 Althusser (2001) argues that ideological constructs (ideas and beliefs) are products of social practices, rituals, and discourses. Ideologies may be seen as fictional representations of individuals' relationships to the social world: “Ideology represents the imaginary relationship of individuals to their real conditions of existence” (p. 109).
health care, escalating costs, free markets, erosion of health care, being forced to make
difficult policy choices, unfortunate necessities and justifiable sacrifices. (p. 83)

Health care discourse has undergone dramatic change in recent decades throughout the
United Kingdom, Canada, United States, Australia and New Zealand. Neoliberal policies,
practices, and directives have effectively shifted attention away from notions of public good,
social justice, and universal care, and instead have focused public attention on the urgent need to
promote accountability, cut governmental debt, and limit welfare spending.


This review of the literature is broadly situated in the study of the development and
implementation of institutional policies, directives, and practices, through which the government
or ruling apparatus is able to exert power and control over others. In this study, texts (and in
particular texts employed and disseminated by governmental entities of ruling organizations) are
examined as informative and influential printed forms of language. D. Smith proposes that texts,
due to their communicative quality, invite us to read, watch, and listen to them in ways
analogous to spoken communication (D. Smith, 2005, p. 101). Texts, although often perceived as
static entities, play an active and influential role in mediating people’s lived experiences.
Language is viewed as a communal act that is arbitrated by people’s symbolic interactions with
one another (Blumer, 1986; Mead, 1967). Of particular interest in this study are the specifics of
textually mediated, institutionalized processes that shift emphasis from people-focused
interactions to textualized and administrative interactions within health care settings.

Language constitutes a social proposition between individuals. In particular, words
indicate people’s intentions and their subsequent actions within social settings (D. Smith, 2005, p. 80). In this thesis, language is not perceived as a static entity: rather it is perceived as a dynamic, social activity. The insights of both Mead (1967) and Blumer (1986) regarding the interrelated nature of human behavior, social interaction, and the constituents of human reality contribute to our complex understandings of social interaction and community-based practices.

Individuals’ concept of health is largely dependent upon their unique situations, and more specifically, the financial, organizational, and social barriers that mitigate their relations with others within broader, bureaucratic health systems. Accessing health care is a social process, which is comprised of many individuals communicating with one another in routine ways. In order to understand the challenges health-seeking individuals experience in their daily lives, we must first explicate the “social act” of seeking, accessing, and engaging in health-related activities as they occur in health care settings.

While it is true that texts are written, rather than spoken, individuals nevertheless respond in active and demonstrable ways to the printed material with which they engage. Texts are employed as the essential interface or mediator governing people’s interactions with institutional entities. Health-seeking individuals must respond to, and thereby activate, numerous texts in their daily lives, such as application forms, health cards, informative brochures, printed regulations, and agency directives or correspondence. By responding to a text, an individual “takes up” the text, thereby activating it outside his or her own local setting (D. Smith, 2005, p. 105). D. Smith further explicates this process: by activating a text, an individual interacts and engages with its language, thereby becoming an agent of the text (p. 104). Text-reader conversations thus occur as individuals both interact with texts and subsequently activate ensuing text-initiated events outside their immediate or local setting. Such conversations also enable us to
see how individuals (employees and bureaucratic officials) play a significant role in organizing a specific sequence of standardized action (D. Smith, 2005, p. 108). In this study, texts not only comprise the essential, interlocking connection between health-seeking individuals and service providers, but they also direct and mediate the events that ensue following such interactions.

Institutions employ texts in order to transmit a one-sided flow of information through time and location. Institutions also categorize (or identify and label) the individuals or groups whom they are either targeting or servicing in this one-sided flow of information. In the institutionalized or bureaucratic standardization process, the health-seeking individual is removed from the situation, and he or she is instead replaced by a categorization or representation of a person (D. Smith, 2005, p. 120). Typical examples of such representations include “single mothers,” “welfare recipients,” or “the homeless.” People disappear from the frames of reference or discursive language employed by the ruling institution, and only selectively chosen fragments or descriptive categories remain as a representation of either the individual or groups of people discussed. Such fragments are known as the categorization of individuals. D. Smith clarifies: “Institutional discourses shift from the perspectives of individuals to a view from nowhere” (p. 20). The categorization of “homeless” activates a specific course of action regarding how best to mitigate the needs of this particular group (see Figure 1).
3.6 OHIP Coverage/CCAC Services for Homeless Persons

Homeless persons do not always have Ontario Health Insurance Plan (OHIP) coverage or the supporting documentation required to obtain coverage. With the person's consent, a Community Care Access Centre (CCAC) must contact the local district OHIP office to confirm whether the individual has valid OHIP coverage using the Health Number Release form process (outlined in subsection #3.2).

A homeless person who does not have OHIP coverage nor the documents required to obtain coverage, can apply for coverage with the support of an agency (as approved under the Long-Term Care Act, 1994 (LTCA)) that works with the homeless. The local OHIP office can advise how to assist the person. The process is as follows:

- To eliminate barriers to health care access, the Ministry of Health and Long-Term Care (MOHLTC) policy permits an "approved agency" dedicated to serving the homeless to issue a special "agency letter" that confirms the person's identity and supports the person's application for OHIP coverage. In the letter, the agency commits to assisting the person in obtaining necessary documents to meet eligibility requirements for health coverage and to provide the agency's residential/mailing address for the person.
- The homeless person visits a local MOHLTC office or an outreach registration site (usually a community health centre) and provides the "agency letter" plus whatever documents the person has to register for health coverage.
- The MOHLTC will usually provide the person with one-year interim health coverage to allow the agency to assist the person in obtaining necessary documentation to meet eligibility requirements for health coverage.
- Persons who use the "agency letter" process to obtain health coverage must meet the photo and signature requirements of the photo health card. There are no exemptions.

Note. Individuals do not receive agency letters directly from an OHIP branch (incorrectly stated above), but rather from an OHIP approved agency. For many individuals, the registration process includes locating an OHIP-approved agency, receiving an agency letter, submitting the agency letter in person to an OHIP office, fulfilling the digital photograph renewal requirement at the OHIP office, arranging for the health card to be mailed to a proxy address, and periodically visiting this proxy address in order to check if the reissued health card has arrived.
Texts can be written in either subtle or overt ways to assert power and authority over individuals to whom the texts pertain, by the use of syntactical or semantic devices. Linguists understand the use and application of syntactical devices that are designed either to influence or to distract readers, and they are therefore able to “unpack” or dissect texts in ways that often elude people without such skills. One example is the nominalization device, by which verbs are reframed as nouns (Eggins, 2004). Nominalization is an effective semantic device that occurs frequently in institutional literature. For example: “He decided to change the system for individuals” employs the verb “decided” and references the perpetrator “he.” In nominalized format, the verb “decided” is reframed as a noun: “A decision was made yesterday to change the system for individuals.” Nominalization removes human actors or “doers” from the intent of the text, thereby enabling institutions to remove active perpetrators or potentially culpable individuals from any perceived responsibility for institutional policies or outcomes proposed in the text. D. Smith (2005) explains that while tasks and duties appear to be both planned and accomplished, the agent (or person responsible) has been purposefully deleted (p. 111).

Changes to the Special Diet Allowance,¹⁴ a press release published on the Ontario Ministry of Community and Social Services Newsroom website, is accredited to a large, amorphous, and faceless entity (Ontario): “Ontario is revising the Special Diet Allowance to make it more accountable to taxpayers” (Ontario Ministry of Community and Social Services, n.d.). The second sentence of the press release: “The Special Diet Allowance will be one of a broad range of special purpose benefits considered in the context of Ontario's comprehensive

---

¹⁴ In an attempt to improve accountability, the Ontario government announced in 2011 that the Special Diet Allowance would be eliminated and replaced with a Nutritional Supplement Program, administered through the Ministry of Health, rather than through the Ministry of Community and Social Services. The Ministry of Health not only plans to remove medical conditions deemed incommensurate with the subsidy, but it also plans to implement a tracking system that will identify any “questionable” trends in the number of referrals submitted by physicians (Ontario Ministry of Community and Social Services Newsroom, n.d.).
social assistance review” is fully nominalized, in which the noun “review” is selected in favour of the verb “review” (which would elicit an agent or perpetrator). Nominalized text is depersonalized and obtuse. Conversely, unpacked non-nominalized text is presented in straightforward and accessible language, which resembles direct, spoken-word format. Eggins (2004) suggests that an institution is able to position itself as a “distant, objective specialist” through textual discourses that are nominalized, depersonalized, and inaccessible (p. 99). Nominalized text also subtly elevates the status of the institution through contributing to the perception that the institution is prestigious and inaccessible (Eggins, 2004). Individuals who possess the ability to unpack and dissect textually based, semantic mechanisms employed by agents or policy writers of governmental directives, forms, and regulations are less likely to be manipulated, misdirected, or confounded by such texts. Conversely, those without such abilities inevitably experience considerable difficulties when attempting to navigate or decipher institutional texts. Figure 2 shows the use of nominalization in the Special Diet press release (Ontario Ministry of Community and Social Services, n.d.).
Changes to the Special Diet Allowance

November 30, 2010 2:45 AM

Ontario is revising the Special Diet Allowance to make it more accountable to taxpayers and compliant with the recent Order of the Human Rights Tribunal of Ontario.

By revising the allowance, the province will help social assistance recipients who have eligible medical conditions receive the special diets they need to help manage their conditions.

The Special Diet Allowance will be one of a broad range of special purpose benefits considered in the context of Ontario’s comprehensive social assistance review, which begins January 2011.

Changes to the Program

Ontario is revising the Special Diet schedule - the list of conditions eligible to receive a Special Diet Allowance - to be compliant with the Human Rights Tribunal of Ontario decision and improve accountability measures in the program. The revised schedule is informed by the recommendations of the Special Diets Expert Review Committee. Changes include:

- removing conditions that the Special Diets Expert Review Committee found to not require a special diet allowance
- requiring that recipients consent to the release of relevant medical information to support their application, and
- putting much stronger tracking methods in place, so that questionable trends can be identified earlier, and appropriate action can be taken.

With these changes, some Special Diet Allowance recipients will no longer be eligible for the program. There will still be a $250 per month maximum cap for people with multiple medical conditions who qualify for more than one allowance.
In “What is An Author?” Foucault (1979) asks us to consider how the “author” functions in textual discourses. Foucault writes that the author-function has changed historically: over the last fifteen hundred years writers have sought credibility either through authorship or through an affiliation to a field of study. For example, scientific discourse from the 5th through to the 15th centuries required an author-function, and was largely situated in religious teachings and subjective references to spiritual insights (p. 149). In the 1700’s, scientific and technical texts steadily gained acceptance as objective and factual, and therefore no longer required either the author-function or religious affiliation in order for content to be accepted and verified. Indeed, scientific texts were more often appraised for the merit of their subject area, rather than the merit or the esteem attributable to the author (p. 143). The notion of ownership is at the centre of the author-function paradigm. Foucault notes that authors are susceptible to societal “punishment” or criticism where their discussion challenges current sociocultural ideologies (p. 148). Texts that are penned by anonymous entities not only receive less scrutiny, but they also benefit from a perceived sense of objectivity. Conversely, authored texts are often perceived as literary, subjective, and refutable (p. 143). This perhaps explains why institutional texts (including institutional websites) may choose to avoid the author-function in their textual discourses. Foucault reminds us that political power structures often direct or mediate textual discourses in the public setting. Authorship manifests a particular “discursive construct” or “mode of being” that underlines the status or position of a text within society (p. 147). In an analysis of a specific text, Foucault asks the following: “What are the modes of existence of this discourse? Where does it come from; how is it circulated; who controls it?” (p. 148).
Textual discourses\(^{15}\) convey not only information, but they also often convey wider political agendas, sociocultural ideologies, and intended outcomes. D. Smith (2005) argues that “Institutional discourse is designed, and the processes of design are essentially political” (p. 120). More specifically, texts are employed by bureaucratic entities to coordinate, manage, and control the activities of individuals. Texts are an essential component of modern-day technologies of ruling practice, and often serve as important vehicles in hierarchical or oppressive relationships of ruling. Within an institutional setting, the employment of texts as a means of communication and dissemination of information provides bureaucratic entities with effective ways to exert and maintain hierarchical power over the individuals whom they purport to serve. The Ontario Health Insurance Plan (OHIP) is one such entity that uses texts (application forms, letters, and documents) to regulate health card issuance and subsequent access to health care services. One example of a text-based document is the OHIP health card. The text (or card) holds the power and represents right of access. It is the ruling instrument that coordinates people’s access to fully insured health care.

**Language, Literacy, and Inequality**

There is a strong connection between literacy and overall health and wellbeing. In both educational and public health fields in the United States, the connection between low literacy levels and poor health has been well documented (Pamuk, Makuc, Heck, Reuben, & Lochner, 1998; Rudd, Colton, & Schacht, 2000; Snow, 1991; Weiss, Hart, McGee, & D’Estelle, 1992). Health literature in Canada has further highlighted the connection between literacy and health

---

\(^{15}\) In this study, textual discourse is defined as discussion, thought, and ideology that is presented in printed text. Meaning is derived from textual discourse through the reader interacting with the text, rather than merely reading the text (D. Smith, 2005, p. 71).
outcomes, and has been documented both in the Ontario Public Health Association Report (Perrin, 1989), the Canadian Public Health Association Report (Rudd, 2001), and the Health Literacy Report (Canadian Council on Learning, 2007).

Literacy skills are inextricably tied to socioeconomic status. In this study, socioeconomic status refers to an individual’s relative position within hierarchical social structures and can be assessed by that individual’s access to wealth, status, and power in society (Mueller & Parcel, 1981; Willms & Shields, 1996). In the 2000 International Adult Literacy Survey, Canadian adults from lower socioeconomic backgrounds scored poorly in all functional literacy\textsuperscript{16} domains, including reading, writing, numeracy, and document literacy (Statistics Canada, 2000). However, literacy skills include more than working knowledge of text-based or computer-based documents. For many people, cell phones, computers, and Internet access comprise the necessities of modern life. Informational and accessibility obstacles, such as those encountered in technologically mediated environments, often hinder or stymie individuals who are attempting to negotiate websites or automated telephone systems. Examples of such obstacles may include complex or lengthy automated voice systems, or the inclusion of numerous hyperlinks in the navigation of online documentation. People’s ability to function in the world today hinges not only on their ability to read and write, but also on their ability to adapt to a world in which technology plays an increasingly pervasive role (Haste, 2008).

Technological literacy\textsuperscript{17} comprises the use of technology to support learning, productivity, and performance (United States Department of Education, 1996). The acquisition

\begin{flushleft}
\textsuperscript{16} Functional literacy refers to a broad set of skills that are necessary for an individual to function effectively in society, which include the ability to read and write simple text and to decipher numeric data and graphs.

\textsuperscript{17} Technological literacy is defined as the ability to use technological tools, navigate websites, and understand technologically mediated information.
\end{flushleft}
of technological literacy enables individuals to use the Internet for empowerment and learning, and it facilitates and promotes interactive access to information. This collaborative process creates “well-informed, publicly active citizens” (Carvin, 2000, p. 39). Technological literacy also correlates with socioeconomic status. A 2009 Canadian Internet Use Survey conducted by Statistics Canada found that Internet usage across the country correlates with household income. In Canada, 97% of individuals in households with an annual income of $87,000 used the Internet, compared to 54% of individuals in households with a combined income of less than $30,000 (Statistics Canada Canadian Internet Use Survey, 2009). Individuals in a higher income bracket are able to utilize the advantages of the Internet, such as engaging in online commerce, reading informative print, and conducting searches related to health, while those in low income brackets are unable to benefit from such searches. Technologically disseminated information has increased dramatically over recent years: both government agencies and businesses are increasingly offering online, informative content, access to services, and interactive tools and communication. For those who can afford to carry the monthly service fees, broadband Internet offers continuous connectivity, access to instant globalized information, and the ability to download large data files.

Health literacy (which draws heavily upon technological literacy) is defined as the ability to locate and access information related to health, which in turn relies not only upon the ability to read and write, but also upon the ability to access online learning tools (Rootman & Ronson, 2005, p. 3). Technologically mediated health literacy relies heavily upon Internet usage. Health

---

18 Technological literacy not only correlates with socioeconomic status, but it also correlates with age and education. Statistics Canada (2009) found that among those aged 16 to 24, 98% used the Internet. Among those aged 45 or older, 66% used the Internet. Among those with some form of post-secondary education, 89% used the Internet. Among those without a post-secondary education, 66% used the Internet. Low-income groups accounted for the widest divide: among those drawn from low-income households, only 54% used the Internet.
queries comprised the most popular Internet search for housed Canadians in 2009: 70% of those with Internet access at home routinely sought health information online (Statistics Canada Canadian Internet Use Survey, 2009). In the United States, the Pew Research Center listed similar findings in 2011, which indicated that 80% of users sought health information online on a regular basis. However, less than half of individuals in a lower income group ($30,000 or less) used the Internet to access health information (Fox, 2011).

**Critical literacy and relations of power.** Those with the power and authority to exert political control have historically employed textual practices and devices to maintain their positions of dominance. While reading and writing is now viewed as commonplace, historically the ability to read and write was restricted to those who held elite power and control in society (Graff, 1991, p. 19). Centuries ago, people (primarily men) in administrative positions used written symbols to track and manage both their subordinates and material possessions. Critical literacy theorists view literacy as an inherently hegemonic tool, by which individuals can overcome domination through challenging social inequities. Critical literacy, unlike functional literacy, is inherently political (Street, 1984). Functional literacy refers to a skill or ability over which individuals may gain competence or mastery. Critical literacy theorists see literacy as a dominant discursive social practice, which governmental or ruling entities often employ to exert power and control over others (Street, 1984, p. 105). While terms such as “literate” or “illiterate” may be seen to reflect an individual's level of acquired education or competence, critical literacy theorists argue that such terms instead more accurately reflect an individual’s relative class or position within the social hierarchy. Street (1984) argues that literacy is not a set of personal, “autonomous” skills, but instead it is a product of social construction. Within this context,
literacy reflects social status or positions of power in society: those who hold positions of power are able to use literacy to exercise influence over others (Street, 1984, p. 99). Darville (1995) posits that all types of literacy are powerful tools that may dominate as equally as they may liberate: “Any literacy is like a currency. It buys into the social organization” (p. 254).

Critical literacy theorists seek to convey an emancipatory and liberating concept of literacy. Critical literacy draws upon paradoxical understandings of literacy praxis: literacy may be used as a tool to subjugate, control, and disempower the masses, as equally as it may be employed to empower, liberate, and improve the material lives of individuals. Paulo Freire brought a critical, activist viewpoint to literacy theory, which in turn, brought a sense of political conscience and social responsibility to literacy theory. The Freirean notion of adult literacy is inherently tied to cultural processes and to the concept that knowledge and power are interconnected. Freire’s view of critical pedagogy holds that the dynamic interplay between the knower and the world is an active, conscious, evolving process (Freire, 1998, p. 82). Thus, human beings “come to see the world not as static reality, but as reality in process, in transformation” (Freire, 1970, p. 71). The notion of empowerment is also an essential component of Freire’s concept of critical literacy and education. Freire’s approach to literacy acquisition is in sharp contrast to the traditional “banking” approach to education, whereby individuals are encouraged to accumulate knowledge, rather than to question critically the unfolding and changing reality in which they live. Freirean critical pedagogy asserts that individuals’ past experiences are compelling and motivational, as these experiences may be “problematic” or framed as significant problems that require solutions. In his work with rural farm workers in Angicos, Rio Grande de Norte, Freire found that literacy instruction was most authentic and inspirational when instruction was loaded with significant, emotive vocabulary, and when controversial social topics were used as themes for discussion.
Thus, words such as government, wages, or poverty provided compelling topics for discussion. Freire’s “Pedagogy of the Oppressed,” although primarily centred upon larger themes grounded in history, politics, and empowerment, argues that the acquisition of critical, analytical literacy is essential both to the struggle for survival and finding the strength to defeat the oppressor.

Freire viewed education as an inherently political act. He believed that individuals are able to overcome hegemonic control structures that exist within mainstream society when they are equipped with knowledge and understandings related to their worlds. Giroux (2010) further explicates the teachings of Freire by asserting that critical pedagogy offers a means for individuals “to develop and assert a sense of their rights and responsibilities,” thereby resisting domination in society (p. 1). Giroux argues that Freire’s work is as relevant today as it was decades ago, particularly in light of the growing commercialism of education. Giroux notes that public institutions have become increasingly corporatized and commoditized in recent years, which perhaps reflects the larger sociopolitical and socioeconomic environment in which public institutions operate. Public education plays an important role in both advancing social justice issues and sustaining democratic belief systems in society. However, Giroux argues that this essential function is currently undermined by a private model that is “slavishly wedded” to corporate demand (Giroux, 2010, p. 2). Education provides the conditions for individual autonomy, emancipation, and liberation from the suppressor. Giroux encourages us to remain vigilant, and to remain attentive to Freire’s message of self-empowerment, resistance, and subversion wherever repressive sociopolitical governances seek to control us.

Organizational literacy is a form of critical literacy. Organizational literacy is the ability to understand, navigate, and decipher organizational texts and textual sequences. Individuals who possess expert organizational literacy skills have learned how to engage effectively with
organizational texts and textual sequences. These individuals are able to interpret dominant forms of literacy (e.g., regulations, contracts, policies, licenses, procedures, and text-based dialogues) in ways that often elude individuals who are not privy to the knowledge, intent, or assumptions behind such texts (D. Smith, 2005, p. 183). D. Smith describes unsophisticated readers as those who are not able to read texts critically, and more sophisticated readers as those who are able to strip texts of their references to institutional power processes, thereby “seeing” texts as potential pretexts for coordination and control (p. 116). Darville (1995) argues that people can successfully negotiate dominant forms of literacy, and subsequently use these texts to their own advantage, if they are equipped with organizational literacy skills. Darville argues: “the difficulty is not in reading skills in a rudimentary sense, but practical knowledge about how certain information is organizationally relevant, [and] how it will be used” (p. 257).

Organizational literacy is concerned with how individuals locate their place within wider institutional systems. Rather than developing the personal skills and interests of the adult learner, organizational literacy enables the learner to explore the context of his or her relationship to external, organizational systems. Organizational literacy references the individual’s ability to read into and understand organizational courses of action (Darville, 1995, p. 256). Darville argues that organizational literacy is a dominant form of literacy that is “part of the power of those who have power,” and that such power furthers the interests of those with the background knowledge of the inner workings of systems designed to perpetuate and replicate power (p. 250). Individuals who do not possess this knowledge are thereby rendered illiterate, or not privy to the policies, objectives, or ideologies described and promoted in the texts disseminated by organizational entities (p. 256). Indeed, anyone in society may be rendered illiterate if faced with an unfamiliar text or oblique, institutionally mediated course of action.
Campbell and Gregor (2002) discussed the uses and applications of organizational literacy in a research study conducted in New Brunswick, Canada. They present the story of Jan, a health care assessor, who is employed to evaluate the level of assistance appropriate for elderly patients in her care. Jan grapples with the anomalies of her position within the organizational health care system: she acts both to subvert and support the “social relation of dominance and subordination” in which she is engaged (p. 22). Jan is organizationally literate and therefore able to grasp the intent and inner workings of the broader health care system. She is able to manipulate or “dress up” her elderly charges’ needs-based assessments. For example, Jan routinely ensures a “Level 2” assessment is elevated to a “Level 3” assessment (which secures additional in-home care services for her elderly charges) by completing regulatory paperwork in carefully modulated and scripted ways. Jan grasps her complicity in supporting the organizational system that employs her, while she also works at times to subvert it (p. 23).

Campbell and Gregor focus on further complexities inherent to Jan’s employment. They note that a highly efficient system may seek to make financial or logistical cuts, and that wherever Jan’s work appears to be accomplished too quickly or too easily, system managers may perceive her role as redundant. Jan must therefore ensure that she is not only perceived as efficient and competent, but that she is also perceived as an indispensable and critical member of an organization handling an unresolved workload. Campbell and Gregor (2002) argue that people come from positions of “seeing” and “knowing” that are grounded in their upbringings, experiences, and education. Organizational literacy enables individuals (such as Jan) to move beyond the use of literacy in basic or functional ways, and instead to utilize their knowledge and skills in order to resist domination and control by people and practices “standing over and against them” (Darville, 1995, p. 259). Organizational literacy is more than an acquired skill. It is
the ability to decipher, analyze, and understand the implicit power structures inherent to institutional operations and systems.

Individuals who possess expert organizational literacy skills are often able to manipulate or influence the operational outcomes of institutionally mediated, health care systems. One example is physicians’ application of the Special Diet allowance. The Special Diet (a subsidy outlined by the 1997 Ontario Works Act) was designed to ensure that low-income individuals living with a medical condition were able to support special dietary requirements through the provision of increased welfare benefits (Ontario Ministry of Community and Social Services, n.d.). Wong (2012) outlined recent changes to the Special Diet allowance. Initially, special dietary requests were listed on an open-ended form, which allowed medical practitioners to design special diets based on their patients’ unique health needs. In 2005, the Special Diet subsidy was dramatically scaled back, whereby only 43 medical conditions were then deemed valid prerequisites, and in 2011 it was further scaled back, allowing only 29 medical conditions as valid prerequisites. (For example, although liver failure was no longer deemed a valid prerequisite, a person might qualify for a subsidy covering cirrhosis of the liver, provided he or she could prove weight loss or body wasting.) Low-income individuals still receiving the Special Diet subsidy have either been fortunate enough to have their condition subsumed in the allowable list of remaining 29 eligible medical prerequisites, or they have the organizational literacy skills necessary to ensure their condition is “worked up” or “dressed up” enough by their physicians in order to satisfy bureaucratic regulations (see Figure 4: 2011 Special Diet Allowance Form). Dr. Roland Wong, a medical doctor working in Toronto, is facing disciplinary charges regarding claims that he over-

---

19 In an attempt to improve accountability, the Ontario government announced that the Special Diet Allowance would be eliminated in 2011 and replaced with a Nutritional Supplement Program, administered through the Ministry of Health, rather than through the Ministry of Community and Social Services.
prescribed Special Diet allowances for his most impoverished patients (Wong, 2012). If found guilty of violating professional ethics, Dr. Wong faces loss of his medical license:

I had to stop filling in forms for the masses or risk not working as a physician, because the College of Physician and Surgeon says so. You would think that the Ministry of Social Services would leave me alone. I continued to fill in Special Diet forms for my regular patients but did not bill or charge for my services. I knew they were tracking me according to my billing submission. I felt that they had no right in knowing my treatment of my patients. I was wrong. The Ministry of Social Services set up a system where all the forms were sent to a central office. They isolated my forms and checked off what I had filled in for each of the forms…the OPP [Ontario Provincial Police] closed their case one year ago, and Social Services continues to hunt me down.

The Ministry of Health not only plans to remove medical conditions deemed incommensurate with the subsidy, but it also plans to implement a tracking system that will identify any “questionable” trends in the number of referrals submitted by physicians (Ontario Ministry of Community and Social Services, n.d.). Wong’s public battle with both Social Services and the Board of Physicians highlights the obscure and often subversive use of literacy in managing, controlling, and directing the outcomes of people’s lives. For example, in order to obtain the Special Diet subsidy, applicants need to know which ailments to “work up” in their interactions with practitioners (see Figure 3). Medical practitioners, in turn, need to “work up” these ailments in cleverly modulated written terms that appear commensurate with the subsidy requirements. Further, medical practitioners need to be aware that governmental agencies closely examine the forms, applications, and texts submitted within the health care hierarchy.
The 2004 Special Diet Allowance provided substantive equity for economically disadvantaged individuals. In particular, it supported the provision of therapeutic foods, which are often costly.

Individuals were able to access:

- Egg free or wheat free foods.
- Bottled water and cranberry juice.
- Foods aimed at supporting milk production in breastfeeding women.
Individuals were also able to access:

- Low-fat foods, aimed at preventing or treating diabetes.
- Low-cholesterol foods.
- Gluten-free foods.
- Infant formula.
- Iron-rich foods.
- Lactose-reduced foods.
- Organic foods.
- Healthy foods aimed at supporting prenatal health.
- Probiotics.
- Prunes and pureed foods.

### Figure 3: 2004 Special Diet Allowance Form (page 2 of 3)

<table>
<thead>
<tr>
<th>Diet Prescribed</th>
<th>Length of Time Diet is Required</th>
<th>Special Diets Application Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>D</td>
<td>No Review</td>
<td>- Low-fat foods, aimed at preventing or treating diabetes.</td>
</tr>
<tr>
<td>E</td>
<td>N/A</td>
<td>- Low-cholesterol foods.</td>
</tr>
<tr>
<td>F</td>
<td>1 Year 2 Years Permanent</td>
<td>- Gluten-free foods.</td>
</tr>
<tr>
<td>G</td>
<td>1 Year 2 Years Permanent</td>
<td>- Infant formula.</td>
</tr>
<tr>
<td>H</td>
<td>1 Year 2 Years Permanent</td>
<td>- Iron-rich foods.</td>
</tr>
<tr>
<td>I</td>
<td>1 Year 2 Years Permanent</td>
<td>- Lactose-reduced foods.</td>
</tr>
<tr>
<td>J</td>
<td>1 Year 2 Years Permanent</td>
<td>- Organic foods.</td>
</tr>
<tr>
<td>K</td>
<td>1 Year 2 Years Permanent</td>
<td>- Healthy foods aimed at supporting prenatal health.</td>
</tr>
<tr>
<td>L</td>
<td>N/A</td>
<td>- Probiotics.</td>
</tr>
<tr>
<td>M</td>
<td>N/A</td>
<td>- Prunes and pureed foods.</td>
</tr>
<tr>
<td>N</td>
<td></td>
<td></td>
</tr>
<tr>
<td>O</td>
<td>1 Year 2 Years Permanent</td>
<td></td>
</tr>
<tr>
<td>P</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q</td>
<td></td>
<td></td>
</tr>
<tr>
<td>R</td>
<td></td>
<td></td>
</tr>
<tr>
<td>S</td>
<td></td>
<td></td>
</tr>
<tr>
<td>T</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Ontario**

Ministry of Community and Social Services

Ontario Disability Support Program

**Diet Prescribed**

- Diabetic Diet (includes low fat, high fibre and unsweetened products)
- Gestational Diabetic Diet
- Enteral/Tube - Refer Person to the Ontario Feeding Drug Benefit Program
- Fat/Cholesterol and/or High Fibre Diet
- Low-fat foods, aimed at preventing or treating diabetes.
- Low-cholesterol foods.
- Gluten-free foods.
- Infant formula.
- Iron-rich foods.
- Lactose-reduced foods.
- Organic foods.
- Healthy foods aimed at supporting prenatal health.
- Probiotics.
- Prunes and pureed foods.
Figure 3: 2004 Special Diet Allowance Form (page 3 of 3).

Individuals were also able to access:

- Low-sodium foods.
- Thickening products.
- Vitamins and herbals supplements.
- Sugar-free or unsweetened products.
Conversely, the 2011 Special Diet Allowance included foods deemed commensurate with a list of close-ended medical conditions:

- Allergies to wheat.
- Celiac disease.
- Diabetes.
- Extreme Obesity.
- Gestational diabetes.
- Hypercholesterolemia (high cholesterol).
- Lactose intolerance.
- Insufficient lactation to sustain breastfeeding.
- Osteoporosis.
- Renal failure.
- Chronic wounds.
- Unintentional weight loss (see following page).

### Section III - Special Diet Allowance

<table>
<thead>
<tr>
<th>MEDICAL CONDITION</th>
<th>Length of Time Special Diet is Required for the MEDICAL CONDITION</th>
<th>Confirmation of Medical Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allergy to Wheat</td>
<td>☐ 6 m ☐ 12 m ☐ Indefinite</td>
<td>Health Professional's Initials</td>
</tr>
<tr>
<td>Celiac Disease</td>
<td>☐ 6 m ☐ 12 m ☐ Indefinite</td>
<td>Health Professional's Initials</td>
</tr>
<tr>
<td>Diabetes</td>
<td>☐ 6 m ☐ 12 m ☐ Indefinite</td>
<td>Health Professional's Initials</td>
</tr>
<tr>
<td>Extreme Obesity: Class III BMI&gt;40</td>
<td>☐ 6 m ☐ 12 m ☐ Indefinite</td>
<td>Health Professional's Initials</td>
</tr>
<tr>
<td>Gestational Diabetes (Note: Allowance will be provided during pregnancy and for 3 months post partum)</td>
<td>☐ 6 m ☐ 12 m ☐ Indefinite</td>
<td>Health Professional's Initials</td>
</tr>
<tr>
<td>Hypercholesterolemia/Hyperlipidemia</td>
<td>☐ 6 m ☐ 12 m ☐ Indefinite</td>
<td>Health Professional's Initials</td>
</tr>
<tr>
<td>Hypertension</td>
<td>☐ 6 m ☐ 12 m ☐ Indefinite</td>
<td>Health Professional's Initials</td>
</tr>
<tr>
<td>Allergy to Milk/Milk Products</td>
<td>☐ 6 m ☐ 12 m ☐ Indefinite</td>
<td>Health Professional's Initials</td>
</tr>
<tr>
<td>Lactose Intolerance</td>
<td>☐ 6 m ☐ 12 m ☐ Indefinite</td>
<td>Health Professional's Initials</td>
</tr>
<tr>
<td>Insufficient Lactation to Sustain Breast-feeding or Breast-feeding is Contraindicated</td>
<td>☐ 6 m ☐ 12 m ☐ Indefinite</td>
<td>Health Professional's Initials</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>☐ 6 m ☐ 12 m ☐ Indefinite</td>
<td>Health Professional's Initials</td>
</tr>
<tr>
<td>Renal Failure - Pre-Dialysis (GFR&lt;30)</td>
<td>☐ 6 m ☐ 12 m ☐ Indefinite</td>
<td>Health Professional's Initials</td>
</tr>
<tr>
<td>Renal Failure - Peritoneal/Hemodialysis</td>
<td>☐ 6 m ☐ 12 m ☐ Indefinite</td>
<td>Health Professional's Initials</td>
</tr>
</tbody>
</table>
Although liver failure was no longer deemed a valid prerequisite, a person might qualify for a subsidy covering cirrhosis of the liver, provided he or she could prove weight loss or body wasting.

<table>
<thead>
<tr>
<th>MEDICAL CONDITION that requires a Special Diet</th>
<th>Length of time the Special Diet is required for the MEDICAL CONDITION</th>
<th>Confirmation of Medical Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1 &amp; 2 chronic wounds or burns 1-10% body surface area</td>
<td>□ 6 m □ 12 m □ Indefinite</td>
<td>Health Professional's Initials</td>
</tr>
<tr>
<td>Stage 3 &amp; 4 chronic wounds or burns &gt;10% body surface area</td>
<td>□ 6 m □ 12 m □ Indefinite</td>
<td>Health Professional's Initials</td>
</tr>
<tr>
<td>Note: Applicants with both conditions indicated will qualify under Stage 3 &amp; 4 only</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Unintended Weight Loss Due to one or more of the following conditions (please check the degree of weight loss):</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Amyotrophic Lateral Sclerosis</td>
<td>Lupus</td>
<td></td>
</tr>
<tr>
<td>Anorexia Nervosa</td>
<td>Malignancy</td>
<td></td>
</tr>
<tr>
<td>Cirrhosis (Stage 3 and 4)</td>
<td>Multiple Sclerosis</td>
<td></td>
</tr>
<tr>
<td>Congestive Heart Failure</td>
<td>Ostomies</td>
<td></td>
</tr>
<tr>
<td>Crohn's Disease</td>
<td>Pancreatic Insufficiency</td>
<td></td>
</tr>
<tr>
<td>Cystic Fibrosis</td>
<td>Short Bowel Syndrome</td>
<td></td>
</tr>
<tr>
<td>HIV/AIDS</td>
<td>Ulcerative Colitis</td>
<td></td>
</tr>
<tr>
<td>□ &gt;5% and ≤ 10% weight loss</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ &gt;10% weight loss</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Section IV - Applicant Declaration & Consent for Release of Information

The person applying for the Special Diet Allowance, or someone lawfully authorized to sign on behalf of the child, must sign this declaration and consent for release of information. If the Special Diet Allowance is for a child under 18, then this declaration and consent for release by the social assistance applicant/recipent or other individual who is lawfully authorized to sign on behalf of the child.

[Important: the application will not be approved if the declaration and consent to release of Information not signed]

I declare to the best of my knowledge that the information on this form is true, correct and complete and I consent to the release, by the Ministry of Community and Social Services designated under the Ontario Works Act, 1997 ("delivery agent"), of any information in my health record on this application form. I understand that the ministry and/or delivery agent will use this information to determine my eligibility or ongoing eligibility for the Special Diet Allowance.

I have read and signed this consent freely and voluntarily. I understand that I can refuse to sign and the consent will not be provided if the consent is not signed. I understand that I can revoke or change the consent at any time but that this may affect my eligibility for the Special Diet Allowance.

[Signature of Applicant or Other Lawfully Authorized Individual] [Date]


Notice with Respect to the Collection of Personal Information

The information on this application form is collected under the legal authority of the Ontario Disability Support Program Act, 1997, Sections 6, 11, 46 or the Ontario Works Act, 1997, sections 7, 8, 57 & 56 for the purpose of determining recipient eligibility for the Special Diet Allowance ("Allowance") and monitoring that the Allowance is properly issued in accordance with the eligibility requirements and purpose of the Allowance by compiling trends and/or data with respect to: Allowance usage, the medical conditions for which recipients qualify under the Allowance, and the completion of the Allowance form.

For more information contact ( ) in your local Ontario Works or ODSP office.
**Literacy and lifework.** The notion of “lifework” specifically pertains to the everyday activities individuals must undertake in order to manage their basic survival needs. G. Smith, Mykhalovskyi, and Weatherbee (2006) employ the term lifework to describe the everyday survival activities assumed by PLWA’s (people living with HIV/AIDS) as they attempt to maintain basic health and wellbeing. For individuals living without a fixed address, lifework includes securing emergency health or dental care, obtaining food, showering, doing laundry, using the telephone or Internet, retrieving belongings from storage facilities, and relocating lost or stolen identification. Daily lifework often involves not only the search for adequate food and shelter, but it also involves managing essential health-related needs (e.g., mental health counselling, prescription drug treatments, and emergency treatment for assault). It also involves obtaining preventive health care (e.g., Papanicolaou smears, mammograms, immunizations, and tuberculosis tests), as well as completing health-related paperwork (Special Diet Allowance). Bresalier et al. (2002) further extended the notion of lifework to include “healthwork” in their study of individuals living with HIV/AIDS. Healthwork referred to the health-related work undertaken by individuals with HIV/AIDS and included the ways in such work is subsumed within the broader organization of health care provision in Canada (p. 58). Healthwork in this study is employed in a broader context, and includes obtaining health care insurance, accessing pharmaceuticals, and managing illness and addiction. For women, healthwork may also include obtaining sexual or reproductive care. Literacy played an essential role in accomplishing the everyday lifework of individuals in the Bresalier et al. study. Participants in the study described their difficulties understanding “treatment information.” which often included complex, conflicting medical information regarding the assessment and treatment of HIV/AIDS (p. 106). Like the healthwork performed by the Bresalier et al. study participants, lifework performed by
homeless individuals not only hinges upon their ability to read and write, but also upon their ability to remain “hooked up” to complex organizational systems.

**Homelessness Discourse: Language, Culture, and the Power of the Media**

Power relations are often wide-reaching and diverse: they may be found not only in a single, corporate organization, but they often permeate outward into related, wider relations of ruling, such as banks, governmental agencies, the media, and globalized, political systems (D. Smith, 2005, 183). Institutions use a variety of strategies in order to maintain power and privilege over subordinate groups in society. One mechanism of domination is found in the way elite organizations use the media (e.g., press conferences, public meetings, or press releases) to shape public opinion (Van-Dijk, 1996, p. 12). News and print media are a source of both social and political power, as messages found in the media are highly influential in shaping the attitudes and perceptions of the general public (Lovell, 2002).

Language employed by media sources coordinates the subjectivities of people through mediating their collective consciousness and views about the world. D. Smith (2005) analyzed media coverage surrounding the 1994 Stanley Cup riot in Vancouver, British Columbia, in which groups of inebriated individuals broke windows and vandalized storefronts after their local hockey team lost to an American competitor. D. Smith argued that media interpretation of events shaped public opinion by permeating broadcasts with a sense of imminent threat or danger (p. 94). A similar riot took place in 2011 in Vancouver following another Stanley Cup defeat. The Vancouver police chief and mayor blamed “anarchists” for the mayhem and violence that ensued (Lee, 2011). Media focus on apparent anarchist or subversive unrest served to define and shape the public’s opinion of what had occurred. During the 2010 G20 summit in downtown Toronto,
police commanders described the destructive acts of “anarchists” and “terrorists” in an attempt to legitimate the arrest and detainment of thousands of peaceful protestors, and these reports were widely disseminated by the media. “Referring to protesters in such a way left the impression that they were criminals…that attitude resulted in the decision to contain and arrest approximately 1,100 people during the weekend summit” (Seglins, 2012). D. Smith (2005) notes that actual, material events are often transformed and rewritten by the media through the employment of repeated incendiary imagery and sound bites. Community members, in turn, take up, transform, and expand these images through conversations with others (p. 94). Critical theorist Guy Debord traces this phenomenon in his analysis of a “spectacle” society. For Debord (1983), the spectacle of events in the media depicts a falsified, “unreality” of material life. Although the spectacle is largely fictional (or at the very least exaggerated), it nevertheless is transformed into a real product that permeates our actual, material lives (p. 8). Therefore, the actual events no longer exist, nor do they matter, as such events have been replaced by more imperative, inflammatory, and altogether more compelling imagery.

The spectacle functions as a means to maintain systems of social control and order in society, whereby police and government actors are able to galvanize mass audiences around the world to support a particular worldview. Debord (1983) argues that the aim of the spectacle (or media’s version of reality) is to dominate everyday, social life: “It is hierarchical society's ambassador to itself, delivering its official message when no one else is allowed to speak” (p. 12). Our perceptions of the Iraq war, for example, were mediated and interpreted through the “shock and awe” of the spectacle. The spectacle comprises our worldview, and we perceive this worldview as inherently objective and real. Debord (1983) argues: “Life is presented as an immense accumulation of spectacles. Everything that was directly lived has receded into a
representation” (p. 7). Further, our interactions with others in the real world are influenced by our shared contemplation of the spectacle. The spectacle is more than a collection of images or visual imagery: rather, the spectacle mediates the social relations between people (p. 7). Thus, the spectacle not only arbitrates our own identity formation, but it also comprises an integral part of the social process, whereby people make meaning of their place in society through a process of social interaction mediated by media imagery.

As the media has a significant capacity to shape our beliefs and perceptions, it also has direct influence upon the management and treatment of others in society. The media shapes our perceptions of individuals living without a fixed address. Reynalds (2006) identifies two primary ways in which people in society learn about homeless individuals: 1) through portrayal or representation in print and television media, and 2) through people’s own personal interactions with homeless individuals in the community (p. 2). Reynalds points out that many people live in suburban communities situated well outside of city centers, and they therefore have few first-hand experiences of homeless individuals. Thus, the media functions as a means of identifying and defining the cultural values and parameters of homelessness. It also often functions to reinforce currently held stereotypical definitions of homelessness. Daly (1996) notes that the language of mainstream news media reinforces negative perceptions regarding specific subgroups in society, including the subgroup labeled homeless. Indeed, defamatory rhetoric and imagery in mainstream media often both demeans and ultimately subjugates marginalized subgroups, including those living without a fixed address.

Common tools of manipulation include televised images, video, sound bites, and print, all of which can be employed to support messages of influence, power, and control promoted by governmental or dominant organizations (p. 6). The Center for Media and Public Affairs
(CMPA) analyzed American news media transcripts portraying homeless individuals. CMPA researchers found that the ABC, CBS, and NBC networks portrayed homeless individuals in ways that either ignored or distorted broader socioeconomic factors, such as growing poverty, income disparity, and pervasive unemployment among disenfranchised groups. For example, only 25% of homeless individuals depicted in large media-outlet portrayals were described as “unemployed,” which perhaps subtly suggests that the remaining 75% were not currently seeking paid employment (Media Monitor, 1989, p. 6). CMPA researchers argue that our failure to understand the social factors experienced by homeless individuals ultimately undermines any attempt to address their needs. Indeed, individuals’ shortcomings, failures, and inadequacies are often highlighted in mainstream media, and wider social, economic, and political factors are either not fully explicated or they are largely ignored (Levinson, 2004, p. 535).

Definitions and perceptions of homelessness are numerous and diverse. An individual’s gender, age, and level of education are factors that influence his or her perceptions of homeless individuals. For example, younger, educated females tend to be more sympathetic toward homeless individuals than are their older, male, and uneducated counterparts (Tompsett & Toro, 2007, p. 13). Negative perceptions held by older adults often stem from earlier life experiences, as many older adults have lived through periods of war, limited resources, and economic recessions. They therefore have little patience with subsequent generations’ inability to cope with financial hardships. Given their traditional faith in human courage and resourcefulness (and the ability to overcome adversity against all odds), older adults who have lived through challenging epochs often judge the current generation of homeless individuals in a judgmental and negative light (Tompsett & Toro, 2007, p. 104). Rich, Rich, and Mullins (1995) note that the term “homeless” evokes a number of derogatory images, as opposed to more sympathetic images.
of vulnerability and need (p. 1). A study commissioned by the Scottish government in 2006 found that almost half of those interviewed viewed homelessness as a personal choice: 45% agreed that “most homeless people could find somewhere to live if they really tried” (Cleghorn, Ormston, & Sharp, 2007, p. 13). Tipple and Speak (2004) discussed the widely held stereotype that depicts homeless individuals as scruffy and unkempt (p. 2). Another persistent stereotype regarding homeless individuals is that such individuals remain homeless for lengthy periods of time, whereas the reality is that many individuals experience homelessness over brief (albeit frequent) periods of time. The use of generalizing language often serves to ensure that certain individuals are viewed in negative terms by mainstream society (p. 2). At the community-level, political entities often promote the perception of homeless individuals as unkempt or dirty in order to galvanize street-cleansing initiatives. Such initiatives aim to improve the image of cities or communities and to convince the public that governmental street-cleansing initiatives are socially and ethically worthwhile (p. 2). Although charities and church organizations often assume a more sympathetic stance towards homeless individuals, language employed by such institutions may be demoralizing to the very individuals whom they seek to support. Tipple and Speak (2004) argue that there is a fine line between language that asserts power and authority over others, and language that ultimately encourages individuals to act as agents of change (p. 2). Indeed, the language employed by members of charitable organizations can inadvertently undermine both the personal agency and potential of individuals. Typical examples include the “unemployable,” the “impoverished,” the “destitute,” or the “homeless.” Few charities co-opt or include recipients of their charitable offerings in key decision-making processes. Although charitable organizations are accountable to patrons or donors, most are not accountable to recipients or beneficiaries of the charity dispensed.
Public discourse plays a significant role in producing, transforming, and perpetuating public knowledge and opinion about people living without a fixed address. Individuals make sense of the world through human interaction, dialogue, and public discourse. Foucault (1972) writes that discourse is “controlled, selected, organised and redistributed by a specific number of procedures” (p. 216). Individuals learn “how” to think through a socialization process: “In a society such as our own we all know the rules of exclusion. The most obvious and familiar of these concerns what is prohibited. We know perfectly well that we are not free to say just anything, that we cannot simply speak of anything, when we like or where we like” (Foucault, 1972, p. 216). For Foucault, discourse is inextricably linked to power. People who hold positions of power and authority and who possess the means of widespread communication produce and perpetuate human consciousness and knowledge. Discourse is often employed to manipulate the meaning and intent of textually mediated governmental or institutional policies and practices.

For example, in previous decades, psychiatric discourse traditionally governed the medical treatment of women with mental illnesses, and criminological discourse promoted punishment of homosexuals (Foucault, 1972). Public discourse creates an understanding of the culture of homelessness, and people then engage in further discourse that not only outlines disturbing social problems associated with homelessness, but that also advocates actions to resolve such problems. Pascale (2005) argues that homelessness discourse often frames visible poverty as a personal problem that is related to lack of character, as opposed to an economic problem that is related to unemployment or lack of affordable housing (p. 261). Discourse that shapes and manipulates our view of homelessness may well be constructed to serve the needs and interests of governmental or political entities, rather than those of the homeless individuals it purports to assist. Policy directives, political agendas, and social interventions often obscure or preclude the personal
subjectivities and unique lived experiences of individuals labeled homeless, and instead such policies and interventions often focus public attention on issues of governmental accountability, cost-cutting incentives, and reduced welfare spending.

**Situating the Health of Homeless Individuals in Ontario, Canada**

The Oxford dictionary states that a homeless individual “is a person without a home, and therefore typically living on the streets” (Oxford Dictionaries, n.d.). Rossi (1989) notes that the term homeless may refer to precarious or unstable housing as equally as it can to no housing at all. Health-related literature regarding homelessness often distinguishes between the minimally housed, the precariously housed, and the absolutely homeless. Individuals are deemed minimally housed if they are sheltered in long-term protective housing, such as a low-cost hotel or subsidized apartment dwelling. Individuals who find short-term, provisional housing are deemed precariously housed, whereas individuals who sleep outside in tents, vehicles, or abandoned buildings are deemed absolutely homeless (Office of the High Commissioner for Human Rights, 1996). Individuals who are either absolutely homeless or precariously housed often lack the basic necessities of life, including sanitation, protection from the elements, and personal safety. Research indicates that both groups require healthcare interventions more frequently than their housed counterparts (Cowan et al., 2007; Hwang, 2001; Kushel, Evans, Perry, Robertson, & Moss, 2003).

Churches and charitable organizations perform a key role in supporting, encouraging, and promoting the safety and wellbeing of homeless individuals, especially during the cold months of winter. Open Access in Ontario, for example, is an entirely church-run program, which relies on
generous donations from individuals in the community, rather than government subsidies or support. Indeed, Open Access performs an essential service in Toronto during the cold winter months when government-funded shelters reach capacity levels.

Individuals who are unable to secure provisional shelter and therefore sleep on the streets experience significantly high rates of mortality. The term “rough sleepers” commonly refers to individuals who sleep outside in the elements. These individuals experience high mortality rates. In a 1996 United Kingdom study, researchers found that rough sleepers living in London have an average life expectancy of only 42 years, compared with the national average of 74 years for men and 79 years for women (Grenier, 1996, p. 5). Both participants and shelter staff in the Grenier study discussed the importance of access to emergency shelter during winter months. Statistical evidence showed that accessibility to cold-weather shelters decreased mortality rates among homeless individuals. In particular, the rate of deaths among homeless individuals in the winter months did not differ significantly from deaths in the warmer months (Grenier, 1996, p. 5). Emergency shelter services, such as those offered by Open Access, may have a significant impact upon decreasing cold-related illness and death among homeless individuals in Toronto.

Income is a social determinant of health. Limited or inadequate income influences not only the rate of homelessness experienced by individuals, but also the health of these individuals. Townsend et al. (1992) found that the lowest employment-level groups in the United Kingdom experienced the greatest likelihood of dying from disease or accident at every stage of the life cycle. Barriers to employment may include lack of transportation, lack of a secure home, and lack of available jobs. A 2010 study conducted by the Salvation Army underscores the pervasive

\[20\] The City of Toronto provides limited funding for the provision of security services at each shelter. Currently such funding supports security services provided by Dixon Hall.
cycle of unemployment experienced by many homeless individuals in Canada: many individuals have difficulty both locating and retaining stable employment due to the lack of a fixed address, and the lack of a fixed address in turn correlates with increased levels of unemployment (Salvation Army, 2010, p. 3). In Canada, 72% of individuals who frequented the Salvation Army shelter system were unemployed, while the remaining 28% were under-employed in low paying or temporary positions (Salvation Army, 2010, p. 2). Researchers further noted that in 2009 (one year after the study was conducted) the unemployment rate in Canada had increased to a seven-year high of 8%, and that it was therefore likely that unemployment rates among homeless individuals had increased at a similar rate (p. 2).

In 2006, Statistics Canada released an income distribution report. The gap between the rich and the poor is widening in Canada. The 2006 Statistics Canada study found that the wealth share of the top 10% of Canadian families had consistently increased, while the wealth share of the bottom 90% of families had consistently decreased. In 1984, Canadian families in the top 10% of the wealth distribution owned 52% of household wealth, in 1999 they owned 56% of household wealth, and in 2005 they owned 58.2% of all such wealth (Morissette & Zhang, 2006, p. 5). Homelessness and poverty are inextricably linked, as are poverty and predisposition to illness (Wilkinson et al., 2003).

Research regarding homelessness and health care is often performed by community-based, non-profit research and policy institutes in Toronto. The Wellesley Institute is a non-profit, non-partisan research and policy institute that examines public policy related to health and homelessness at municipal, provincial, and federal levels. The Street Health Community Nursing Foundation also performs community-based research. In the past 10 years, the Street Health Foundation has published two significant reports: the 1992 and 2007 Street Health Reports.
Street Health employs a community-based group of nurses who provide primary health care, donations of warm clothing and sleeping bags, and assistance in acquiring mailboxes and OHIP registration. In addition to providing outreach services, Street Health also publishes a number of peer-reviewed reports regarding the current state and wellbeing of Toronto’s homeless population. A third research centre situated in Toronto is the Centre for Research on Inner City Health, located at St. Michael’s Hospital. Each of these centres works collaboratively, and findings from their published research studies are often presented in public forums at various inner-city community centres located across downtown Toronto.

Grassroots activist groups in Toronto have made considerable inroads not only in supporting the needs of homeless individuals, but also in promoting anti-poverty campaigns. The high-profile Ontario Coalition Against Poverty (OCAP) and the Toronto Disaster Relief Committee (TDRC) support poor and homeless individuals in Ontario through employing high-profile advocacy campaigns to address the crisis of homelessness in Toronto. Financial support for activist organizations is often raised by trade unions representing university and college contractual employees. For example, OCAP maintains strategic relationships with both the Canadian Union of Public Employees (CUPE) 3902 and 3903. (CUPE represents the University of Toronto and York University Teaching Assistants, Graduate Assistants, and other contractual employees.)

The review of medical literature that follows provides an in-depth, comprehensive picture of the current health of Toronto’s homeless population. However, an understanding of how specific institutional policies play out in the everyday lives of homeless individuals remains largely absent from this literature. This study aims to fill this niche. More recent medical literature revealed that homelessness increased threefold in Toronto over the 15–year period of
1992–2007, and the health of this population also deteriorated over the same period (Cowan et al., 2007, p. 8). Cowan et al. examine the current health and wellbeing of Toronto’s homeless population in the Street Health Report of 2007. Findings were based on a representative sample of 368 homeless men and women living on the streets of downtown Toronto. Researchers used random selection to recruit participants from homeless shelters, drop-in centres, and free-meal programs. The survey instrument was primarily a close-ended, quantitative questionnaire that explored not only participants’ general health and wellbeing, but also their access to health care services in Toronto. Cowan et al. (2007) found that homeless populations cope with high rates of hepatitis C, epilepsy, and heart disease (p. 23). The disparity in health between the homeless and the housed was significant: homeless individuals were 29% more likely to have hepatitis C, 20% more likely to have epilepsy, and 20% more likely to have heart disease (p. 24).

Cowan et al. (2007) argue that despite the serious health needs of this community, individuals experience significant barriers to accessing basic health care services (p. 40). Such services may include visiting a family doctor or receiving emergency medical attention. Findings from this Cowan et al. study indicate that the recent attempts by the Ministry of Health to reduce health care fraud by tightening both OHIP registration and allocation may have exacerbated this problem. Without a valid health card, a homeless individual may be legally refused free medical care. Cowan et al. found that 28% of homeless individuals were refused health care in the past year, compared to only 7% in 1992 who were “refused care at some point in their [entire] lifetime” (Ambrosio et al., 1992, p. 48). The goal of the Street Health study was to present a comprehensive analysis of the health and wellbeing of the homeless in Toronto, with a view to creating an immediate “call to action,” which might hopefully pressure community coalitions, medical providers, and policy makers to address “the devastating and growing problem” of
homelessness in Toronto (p. 50).

Homeless individuals appear to be at a higher risk of injury and assault, and therefore require more preventive and rehabilitative treatment than those in the general population. Kushel et al. (2003) presented findings from a survey of 2,577 homeless people living in San Francisco, California. The study instrument included a series of close-ended, quantitative interview questions, in which researchers assessed participants’ access to housing, history of victimization, sexual behaviour, substance abuse, mental health, and justice-system involvement over a one-year period. Kushel et al. were interested in determining the connection between homelessness and reported rates of assault. Researchers reported that homeless individuals were at higher risk of victimization than the general population, due to inconsistent shelter facilities, nearness to high-crime areas, and involvement in high-risk activities, such as drug use, alcohol abuse, and sex-trade work (p. 2492). Indeed, one in three men and women (32.3% and 27.1% respectively) reported incidents of either sexual or physical assault in a one-year study period (p. 2492). These findings show that violence and victimization are a common reality for many homeless individuals.

Cowan et al. (2007) concurred with these findings in their Toronto study: one in three homeless individuals was physically assaulted during a one-year study period, and, furthermore, a majority of these assaults occurred more than once (p. 48). Violent assault results in physical harm and emotional distress, and victims of such abuse require immediate and often prolonged medical intervention. Homeless individuals require medical attention for assault-related injuries more frequently than their general-population counterparts, and yet, conversely, these very
individuals are often excluded from basic health care services, due to the recent changes\textsuperscript{21} governing health card regulations (Cowan et al., 2007, p. 50).

While both sexes in the homeless population are susceptible to violence, homeless women and transgendered individuals appear particularly vulnerable to sexual violence. Researchers in the San Francisco study found that 9.4\% of homeless women have experienced sexual assault over a one-year study period, and that this percentage more than doubled among homeless women with a mental illness (Kushel et al., 2003). Transgendered individuals were equally as likely, and in many cases more likely, to be the victims of sexual assault than their female counterparts (p. 2495). Cowan et al. (2007) present similar unsettling findings about life on the streets of Toronto: one in five homeless women has been sexually assaulted during a one-year period (p. 4). Women in the general population are substantially less likely to experience sexual assault: less than 1\% of the general population in Toronto reported an incidence of sexual assault to the police over the same one year period (p. 17).\textsuperscript{22} The current barriers to universal health care access in Toronto are perhaps of particular significance to women and transgendered individuals, as each of these groups may require more ongoing and specific health care interventions.

Affective disorders, such as bipolar, depressive, post-traumatic stress, and panic disorders are more prevalent in homeless populations (Hwang, 2001). Cowan et al. (2007) report that 35\% of participants in their study suffer from one or more diagnosed affective disorders (p. 27). Homelessness is often associated with mental illness. Underlying or latent mental illness may be

\textsuperscript{21} OHIP replaced residents’ old red and white card with a new high-tech security card, which included a digitalized photograph and mandatory renewal requirement. These features were designed to prevent non-citizens from fraudulently obtaining health benefits in Ontario (Shu, 1996).

\textsuperscript{22} In each of these studies, it is not known if strangers or acquaintances were perpetrators of these attacks, or where the attacks took place.
triggered by the difficulties and challenges inherent to living on the streets, and homeless individuals are therefore perhaps more prone to mental illness than those in the general population (Cowan et al., 2007, p. 28). While symptoms such as chronic depression and anxiety are characteristic of many mental illnesses, these symptoms may be exacerbated by the day-to-day experience of life on the street. Living on the streets results in isolation from support networks, frequent and unwanted contact with correctional agencies, poor general health, and mental health instability (Fischer & Breakey, 1991).

Homeless individuals who experience ongoing mental illness often require frequent assistance from mental health workers. Mental illness is often effectively treated with consistent medical intervention. Such interventions include counselling services, prevention programs, and long-term prescription drug regimes. Many individuals require extended support delivered by a variety of mental-health workers, including community liaison workers, social workers, psychiatric nurses, and addiction therapists. Publicly funded addiction and mental health agencies in Ontario are covered by the Ontario Health Insurance Policy (CAMH, 2008). In order to qualify for health services in Ontario, individuals are required to have a valid OHIP card. However, many homeless individuals do not possess a valid OHIP card. Alcohol and substance abuse often accompany mental or emotional instability, as alcohol and drugs may offer brief relief from the negative aspects of affective disorders, while they may also mitigate the day-to-day realities of life on the street. Cowan et al. note that illegal drugs are often “easier to obtain than prescription medications” (p. 29). These researchers concluded that their study participants were very likely self-medicating, in an effort to relieve symptoms for which they were unable to gain medical treatment, as they were often unable to gain ready access to health care services, counselling, or substance abuse interventions. Mental illness comprises a daily reality for many
homeless individuals. Because mental illness often initiates and perpetuates homelessness, ongoing research is needed in order to explicate in greater depth the correlation between mental instability and homelessness.

This study examined the experiences of 27 individuals who frequented a homeless shelter in downtown Toronto, Ontario. A primary aim of the study was to shed light upon the ways in which organizational literacy (or the lack of literacy) shapes the experiences of individuals who attempt to gain access to basic health care. This study highlighted a combination of social, economic, and political factors that affect and mediate individuals’ ability to access health services in Toronto. The overarching aim of this study was to investigate the nature of power and authority inherent in the processes of administration and governance, and the role that text and language play in both standardizing and coordinating the everyday activities of health-seeking individuals in society. The review of related literature shows that the income gap between the rich and the poor in Canada has steadily increased in recent years. Further compounding this issue are the high rates of violence and victimization experienced by vulnerable individuals, and the ongoing mental health needs of marginalized populations. Homeless individuals arguably require more consistent and ongoing health interventions than their housed counterparts. However, many participants interviewed in this study either lacked an Ontario Health Insurance Card, or they expressed little interest in acquiring one. This study asked: How does this actuality come to be? How essential is literacy to individuals seeking access to health care? How are institutional health policies evidenced in the everyday, material lives of real people? Are such institutional policies potentially exclusionary? The Methods chapter that follows describes the ways in which institutional ethnography was employed to explicate these questions.
Chapter 4

Methods

I’ve never used the computer. I’ve never drove the car. Quite frankly, it wouldn’t be fair to society. Would you like to see me driving down Highway 69?

Ben, Interviewee

Introduction

This study utilized a number of techniques common to ethnographic research, including semi-structured interviews, field observation, and text analysis. In total, 27 participants were recruited from one Open Access homeless shelter located in Greater Toronto. There are approximately 19 faith-based Open Access organizations that provide emergency overnight shelter for homeless individuals in downtown Toronto. Participants were selected using a snowball sampling technique, which involved asking initial participants to recruit future potential participants from their network of acquaintances. The timeline of the interview and text collection phase spanned approximately four months. The average length of each interview was 30 minutes to one hour. Semi-structured interview questions drew upon participants’ first-hand knowledge and personal experience and were designed to encourage complete and contextualized responses. Analysis of research data involved substantial analysis of institutional text and documents. Textually mediated actions and activities were mapped as logical, complex sequences, in an attempt to unearth the dynamic (and often invisible) relations between people in institutional settings. The employment of first-hand ethnographic accounts provided a means to contextualize individuals’ experiences within the broader sociopolitical and socioeconomic
environments in which public institutions operate.

**Conceptual Framework: Marx’s Method of Analysis**

The design of this study is grounded in institutional ethnography (D. Smith, 2005). People’s routine social interactions, and in particular, the class relations that ensue as a result of such interactions, provide the primary focus of institutional ethnographic investigation. The term “social organization” in institutional ethnography refers specifically to the patterns of social interaction that constitute people’s interrelated experiences within institutionalized settings. Institutional ethnography provides researchers with a means to investigate the organization of the social world through the use of mapping techniques, which trace or connect the complex set of relations embedded within social organizations. Researchers attempt to grasp the multifaceted features of the social world, and, in doing so, to unmask a deeper understanding of the relationships that guide human action and interaction within organizational settings. Institutional ethnography draws insights from the work of Marx and Engels. Marx believed that human history is moved or activated by the physical, material world. Thus, the world is moved by people acting within a material setting. People are central to institutional ethnographic research, as they are perceived as active agents of social action. Like their Marxist predecessors, institutional ethnographers unravel relations of class-based ruling practice and challenge authoritative ways of knowing.

**Institutional Ethnography**

As a method of analysis, ethnography is defined as both a process and a product of research. The process involves observing and documenting the routine, daily lives of a group of
individuals. The product involves producing a detailed, accurate account of the ways in which these individuals interpret the world around them (Agar, 1980, p. 53). “We begin with our own interpretations of what our informants are up to, or think they are up to, and then systematize those” (Geertz, 1973, p. 14). Geertz sees ethnography as a means to understand the cultural idiosyncrasies of specific groups of individuals: “A good ethnography is an interpretation that gets to the heart of another culture, or a part of another culture, at a particular time” (p. 16).

Like ethnography, institutional ethnography is concerned with the activities, events, and interactions that comprise people’s everyday experiences. However, institutional ethnography places a specific emphasis upon both exploring and recording in concrete and systematic ways people’s experiences in organizational or institutionalized settings (Campbell & Gregor, 2002, p. 87). This method attempts to explicate everyday social interactions that are not readily visible or transparent, or more especially, it attempts to explicate wider institutional processes, known as translocal relations of ruling (D. Smith, 2005, p. 191). In this study, individuals’ personal accounts serve to shed light upon the invisible or translocal relations of ruling that shape, standardize, and govern the provision of health care delivery in Ontario. When viewed collectively, these personal accounts led to a cumulative understanding regarding the potentially exclusionary practices inherent to the provision of health care in Ontario.

Using institutional ethnography as a method of inquiry, this study explicated the organizational power structures that coordinate and direct homeless individuals’ lives within bureaucratic settings. Such power structures are maintained and promoted within the complex social interactions and interrelationships that exist between people who operate in institutionally mediated bureaucracies. The notion of social relations is at the crux of institutional ethnography: the focus of research not only concerns the communal lives of individuals, but also each unique
individual’s activities in relationship to the activities of others (D. Smith, 2005, p. 59). An overarching goal of this study was to examine how institutionally mediated patterns of social interaction mediate individuals’ access to health care. Institutional ethnographers begin with people’s real experiences in the social world as a point of entry for subsequent research. Like phenomenology (Merleau-Ponty, 1945), institutional ethnography ensures that participants’ experiences remain central to investigation. Institutional ethnography attempts to tap into the lives of people and their daily work routines, and to bring into view the social organization inherent to these experiences (D. Smith, 2005, p. 129). People’s everyday experiences are examined in a methodical and systematic manner: “The conceptual framing of everyday experiences heard or read about, or observed, constitutes one of the distinctive features of an institutional ethnography” (Campbell, 2006, p. 92). It should be noted that institutional ethnographers rarely, if ever, lay claim to interpreting events or experience. Stories may be told and transcribed, but the overall aim of an institutional ethnography is not to produce stories that are subsequently interpreted and reconstructed by researchers. Further, institutional ethnographers do not seek to generalize an individual’s experience or to discover thematic threads indicative of the human experience. Instead, researchers seek to discover and describe social processes that have a generalizing influence on people’s lives (D. Smith, 2005, p. 131). People’s experiences are not organized theoretically or pulled into thematic accounts: rather, knowledge gained from people’s experiences is mapped in the form of a sequence of events and activities, without additional subjective interpretation (p. 211). Institutional ethnographers often choose to gather information regarding individuals’ first-hand experiences through in-depth interviews with participants. Interviews are not geared towards establishing a participant’s subjective, idiosyncratic stance: rather, they are geared towards acquiring a cumulative
understanding of the inner workings of institutional processes (DeVault & McCoy, 2006, p. 18).

In this study, inquiry was focused on the standpoints or viewpoints of individuals. Institutional ethnographic researchers stand alongside their participants, and employ the viewpoint of participants to guide subsequent research direction. Drawing upon the standpoint of individuals, researchers aim to step outside their established scope of traditional scholarly knowledge, and to seek knowledge specifically from the information and first-hand experiences of participants (p. 206). Throughout this study, homeless individuals’ experiences were viewed both as the impetus to begin research inquiry, and the means by which to explore tangential avenues of inquiry. Framing individuals’ experiences not only provided the researcher with a standpoint, or a place to begin research inquiry, but it also provided a real-life backdrop or context through which to explicate the ways in which institutional or governmental practices impacted the lives of individuals in concrete and perhaps exclusionary ways.

Challenging or restrictive aspects of homeless individuals’ activities and relationships within institutional settings (commonly referred to as organizational disjuncture in institutional ethnography) directed the focus of inquiry. Organizational disjuncture is usually a text-based, systematic phenomenon indicative of many bureaucratic systems (G. Smith, 2006, p. 167). Organizational disjuncture creates a sense of disquiet or unrest in individuals. Such disjunctures often reveal incoherence or separation between the artificial realities promoted by institutional settings and the real-life actualities of people’s first-hand experiences of

23 The researcher developed the initial set of qualitative research questions used in the interviews. Participant responses during the interview process guided subsequent research direction. At various junctures of the study, participants provided follow-up information and clarification.
bureaucratic processes. 24 Organizational disjuncture yields a “problematic” (D. Smith, 2006, p. 38). A problematic may be framed as a subsequent set of research questions or puzzles (Campbell & Gregor, 2002, p. 53).

D. Smith (2005) describes ruling relations as the translocal lineages of administrative, governmental, and managerial entities that mediate, shape, and control people’s experiences. However, such an examination extends further than the local lives of research participants. Institutional ethnographers look for the ways in which people’s experience is coordinated with another person’s experience, and the ways in which these social relations are “hooked up” to wider relations of ruling within social organizations (D. Smith, 2005, p. 132). The Ontario Health Insurance Plan is one example of a ruling relation. The notion of “relations” is at the crux of institutional ethnography: the focus of research not only concerns individuals’ experiences, but also their activities in relationship to others’ activities (D. Smith, 2005, p. 59).

One aim of institutional ethnography is to invite participants to trace their everyday experiences. Through the employment of interviews, as well as an in-depth analysis of OHIP-related texts and forms, this study attempts to piece together how institutionalized relationships operate in concert, and how such interactions mediate outcomes for individuals attempting to access health care. In this study, the researcher sought to reach beyond the locally observable events as discussed and explored in transcribed interviews, and instead sought to link these events to wider, translocal, institutionally-mediated relations of ruling and governance.

24 Examples of organizational disjunctions that emerged in this study were participants’ inability to secure housing located in the downtown core, lack of secure storage for medication or personal identification, and difficulty obtaining ongoing health or dental care.
Research Design

This study followed a systematic research procedure, which included developing sample research questions, conducting interviews with participants, and performing in-depth analysis of interview responses, field observation, and text analyses. Institutional ethnography is grounded in research that draws upon the standpoint of individuals. Researchers identify a real problem, they locate a standpoint that guides the direction of inquiry, and they interact with real people who stand outside of bureaucratic ruling regimes25 (D. Smith, 2005, p. 32). Working in a homeless shelter provided a starting point, or a place to begin inquiry, where the actualities of how individuals’ lives become mediated by institutional relations were examined. The specific focus of this study concerned the everyday, local experiences of homeless individuals attempting to secure health services within the larger, translocal social organization of the Ontario Health Insurance Plan.

Research Setting

The research setting in this study was an Open Access shelter located in Toronto, Ontario. Open Access is an entirely faith-based program that offers food and overnight shelter to homeless individuals. Because each Open Access site is only open one night each week, individuals must travel to different sites throughout the week in order to secure shelter on a continuing basis. There are 19 Open Access programs dotted around the Toronto area, all of which are housed in church and synagogue basements. The program is supported by donations from both faith-based congregations and surrounding communities. Rigorous funding campaigns

25 D. Smith (2005) writes that assuming the “standpoint” or perspective of another individual enables the researcher to gain a more complete and comprehensive picture of human experience through entering the everyday, “local actualities of people’s lives” (p. 25).
are undertaken in order to provide the majority of funding for the program. The City of Toronto provides limited funding for the provision of security services at each shelter. Security services are currently provided by Dixon Hall.

The Open Access program is designed to provide food and shelter for homeless individuals throughout 23 weeks of the winter season (opening in November and closing for the season in April). As each location offers shelter for only one night, individuals must travel from location to location during the cold winter months. A typical day at one Open Access shelter begins at 4:00 p.m., when soup and bread is served. The main-course dinner is served at 5:00, which is followed by a late-night movie and dessert. Breakfast is served each morning at 6:00 a.m. At 7:00 a.m., the doors of the shelter close until the following week, and guests are asked to vacate the premises.

Open Access was started in 1987 by Sister Susan Moran from St. Michael’s School in Toronto. During the cold winter months of 1987, Sister Susan and a group of her students befriended a man named George living in a wooded area adjacent to St. Michael’s School. However, their relationship with George was short-lived: one night George sustained a prolonged and brutal beating and died from internal injuries. George’s death motivated Sister Susan to open the first Out the Cold shelter in Toronto, with a view to ensuring other homeless individuals received not only adequate food over the cold winter months, but also a safe place to sleep. Open Access has grown from one small program started by Sister Susan 35 years ago, to 19 extensive faith-based programs located across the Toronto area. Although Sister Susan’s initial program was limited in scope, the program has since grown to include various churches, synagogues, and temples located across Ontario. Currently, Barrie, Cambridge, New Market, Brantford, and Peterborough offer Open Access programs during the winter months.
Plans to transform church-basement spaces into provisional shelter beds have not always boded well with local communities. In 2006, members of St. Aidan's Anglican Church (located in Toronto’s upscale Beaches neighborhood) planned to provide 12 shelter beds. Plans to establish the emergency shelter were stymied after residents of the Beaches enclave threatened St. Aidan's Church with a legal injunction. However, after a significant public outcry in favour of the Open Access program, the church was able to move ahead with its plan to join the Open Access program. Currently, St. Aiden’s offers 16 beds during the winter season.

**Research Population**

Homeless individuals in this study were drawn from an Open Access shelter located in Toronto during the months of February, March, April, and December 2011. Every attempt was made to include individuals from different cultural or racial backgrounds. Ages of participants ranged from 25 to 65. In total, only six out of 27 individuals in this study were female. As homeless females are often less visible than males, it was difficult to locate homeless females at the Open Access shelter. Women experience homelessness differently than men. Women’s health needs are different from those of their male counterparts, as they include a diversity of reproductive health needs, and they are especially vulnerable to sexual violence and exploitation. The responses provided by the six women interviewed in this study shed light upon a number of health-related challenges experienced by homeless women (including negotiating pre-natal and post-natal intervention, seeking support after sexual and physical assaults, and managing blood-borne diseases such as HIV/AIDS).

**Participant Inclusion Criteria**

- Homeless (sleeping overnight at Open Access for more than 1 month)
• 21 – 65 years of age
• Able to speak and understand English
• Living in downtown Toronto

Exclusion Criteria

• Sleeping overnight in stable housing, such as a low-cost hotel or apartment
• Intoxicated or mentally unstable

Data Collection

The consent process. Prospective participants were informed of the nature of the research, what information would be collected, and how that information would be utilized. The risks and benefits of the study were explained to participants, which enabled them to make an informed decision regarding their willingness to participate.

1. Participants who indicated they were interested in participating were provided with the specific details (both verbally and in writing) regarding the nature of the study.
2. The researcher ensured that prospective participants were given adequate opportunities to ask questions, discuss their concerns, and consider their willingness to participate.
3. Once the participants had been briefed regarding the purpose of the study and the consent form had been fully explained, participants were asked to sign the consent form.

Interviews. Interviews were conducted with 27 individuals using a specific set of questions (see interview questions that follow). This investigation drew upon a variety of sources
and perspectives. Participants were questioned regarding their knowledge of the ways in which they gain access to a variety of health services in Toronto. Each interview was completed in approximately 30 minutes to one hour and was semi-structured in nature (main prompting questions, probing where necessary). With permission from each participant, interviews were recorded on audiotape and were transcribed at a later date. The following questions were used as a springboard for the interviews:

**Interview Questions**

1. How long have you been with Open Access?
2. What are some examples of your health care needs?
3. What happens when you get sick? Where do you go?
4. Do you have a health card? If not, how do you get help without a card?
5. Have you ever lost your health card? How do you go about getting a new health card?
6. Do you have a family doctor? If not, why not?
7. Have you ever had any problems getting health care? If so, how?
8. Do you feel that it has been harder (or easier) to receive health care services in recent years? If so, in which specific ways?
9. Do you have access to a computer with an Internet connection? What kinds of things do you use the computer for?
10. If you could change something about the health care system, what would it be?
11. Is there any way I can contact you in the future (e.g., email)?

**Ethnographic field collection.** Ethnographic fieldwork provided a view of “real-world”
conditions experienced by individuals frequenting the Open Access shelter. Fieldwork included interviews, observations, and document collection. In order to supplement this fieldwork, institutional documents were gathered and subsequently analyzed in the analysis phase of this study.

The following guidelines were closely followed throughout the ethnographic field collection process (Hammersley, 1990):

1. Key informants (interviewees) were asked to discuss their insights regarding the provision of health care in Toronto.

2. Data were gathered from health-related documents (e.g., Ontario Ministry of Community and Social Services press releases, Ontario Works policy literature, and OHIP-approved agency forms), as well participant’s first-hand accounts. Fieldwork was corroborated through discussions with multiple participants (Open Access shelter personnel, health care personnel and reception staff, OHIP representatives, and OHIP-approved agency staff).

3. Direct quotations were referenced as much as possible, as the intent was to capture participants’ views in their own words. Audiotaped recordings of each interview allowed the researcher to maintain clear, precise records of each participant’s contribution.

Data Analysis

Text analysis. The Ontario Health Insurance Plan (OHIP) is governed by the Health Insurance Act, which, in turn, is mandated by the Ministry of Health Canada. These bureaucratic organizations employ templates, form letters, and legal documents in order to manage the health
needs of Canadian citizens. The kind of planning that is introduced and legislated determines not only who will receive benefits, but also who will be excluded from such benefits. Few individuals are privy to the regulatory planning associated with OHIP, the Health Act, or other health care mandates generated by the Ministry of Health Canada. Through tracking and mapping the sequence of OHIP’s forms, cards, templates, and texts, the power of texts in organizing and operationalizing the political decisions made by policy makers, planners, and governmental agencies is brought into view. (For a more detailed discussion of texts, see Chapter 3: The Social Inequalities of Health).

This study examined the ways in which texts coordinated people’s activities across place and time. The ways in which texts enter, coordinate, and activate individuals’ activities is at the crux of institutional ethnography (D. Smith, 2005, p. 170). Of particular interest in this study was the specifics of text-act-text sequences that reveal an institutionally mediated course of action. Texts that were discussed with participants during the interviews were later located and examined during the analysis stage. Copies of documentation were gathered directly from the OHIP branch or from an Internet website.

This study was particularly concerned with the nature of accessing textually mediated health services, and the problems that may ensue as a result of OHIP’s stringent regulations. The aim of this investigation was to examine the ways in which institutional texts and documents coordinate homeless individuals’ activities across place and time. How are people’s everyday lives embedded in organizational processes? How do things get “written up” or “worked up” in institutional settings? How do large institutions such as OHIP use texts to accomplish their work? Throughout the interview process, the following questions were addressed (DeVault & McCoy in D. Smith, 2006, p. 37):
1. How did the participant come to use the text (or form) and where is the text now headed?

2. What does the participant need to know in order to complete and/or understand the text?

3. What does the participant do (or expect) as a result of completing the text?

4. How does the text depend on other texts (or intersect with other texts)?

5. What is the overarching institutional or organizational framework for the text?

**Mapping.** Mapping is a form of institutional analysis that assists researchers to locate and connect actual events and experiences within institutional settings. Such connections are sometimes invisible to people who work and live within these settings. Texts are material forms of language, and, as such, they may be mapped in logical, complex sequences that reveal the underlying interests of an institution. Turner (2006) argues that an analysis of texts produces an account of the daily work activated by the dynamic relations between people in institutional settings (p. 143). Further, in the mapping process, texts may be analyzed, deactivated, and thereby stripped of their institutional power (p. 142). Mapping in this study helped to explicate the ways in which ruling entities mediate, shape, and standardize people’s attempts to gain access to basic health care services in the Province of Ontario.

**Narrative exhibits.** Selected segments from these interviews are presented in this thesis in first person format (see Appendix A). These accounts were not organized as thematic accounts: rather, information and knowledge were mapped in the form of a sequence of events and activities (see Results and Exhibits). As such, these accounts serve as exhibits of
organizational disjunctures\(^{26}\) (D. Smith, 2006, p. 41). Individuals’ first-hand, personal accounts provide a first-hand portrayal of the ways in which such individuals navigate a variety of health services in Toronto. These stories were particularly useful when seeking holistic, descriptive, and personal portrayals of an individual’s experiences when accessing health care services. Gubrium and Holstein (2008) recommend situating participants’ ethnographic accounts within specific social contexts (p. 252). This method seeks to capture in first-person and descriptive format the social, relational, and interactive lives of research participants. Participants are perceived as active agents, interpreters, and storytellers who construct their reality of life and their understanding of the world around them through the process of sharing stories. In this study, the process of documenting homeless individuals’ personal accounts explicated the collective realities of life for one group of homeless individuals in an Open Access shelter. These stories revealed the “relational selves” of storytellers, whereby individuals’ lives are shaped by their social interactions and experiences with others (Gubrium & Holstein, 2008, p. 244). Individuals interviewed at the Open Access shelter shared stories about living without a fixed address. They discussed poverty, unemployment, ill health, and feelings of social exclusion. They also discussed the human need for acceptance, and feelings of fear and resignation commonly experienced in the face of sickness and poor health.

**Summary**

In sum, the procedure of this institutional ethnographic study is described below:

\(^{26}\) An example of organizational disjunctures that emerged in this study include participants’ inability to secure housing located in the downtown core, lack of secure storage for medication or personal identification, and difficulty obtaining ongoing health or dental care.
Research Preparation

1. The researcher developed a sample set of research questions.

2. A standpoint or position or entry into the inquiry was located. In this study, the standpoint of homeless individuals guided the direction of inquiry, which enabled the researcher to gain a more complete and comprehensive picture of the everyday experiences of individuals who frequented one Open Access shelter.

Data Collection

3. An understanding of the problematic was co-constructed with the participants in an informal interview setting. Ethnographic descriptions were delineated from interpretive analyses. 27

4. A “problematic” was developed, which was based upon a series of organizational disjunctures, or a challenging or restrictive experience in the lives of interviewees. The organizational disjuncture that emerged in this study may be seen in the significant barriers experienced by homeless individuals when attempting to access basic health care services.

Data Analysis

5. Interviews were recorded and fully transcribed.

6. Texts that subsumed individuals’ actions and activities into an institutional framework (i.e., text-act-act sequences) were identified and analyzed.

27 Although participant-observation was not directly employed as a research strategy in this study, the researcher nevertheless participated in everyday activities and routines at the Open Access shelter (e.g., cooking, serving, cleaning).
7. The social relationships between individuals were mapped and thereby made visible, with specific emphasis upon the ways in which relations were coordinated with wider relations of ruling within institutional settings.
Chapter 5

Results and Participant Summaries

The following chapter answers five research questions posed at the outset of the study. The overarching research question is as follows: How are health care services socially organized with regard to homeless individuals’ access to mainstream health care services?

- Mapping and organizing the intent of text-based documents (including health cards, agency letters, OW [Ontario Works] statements, and online forms and documents) explicated the coordination and interrelatedness of people’s activities and actions across place and time.

- Organizational literacy was an essential focus of this study: in order to “hook up” successfully to institutional regimes, individuals must be able to negotiate, understand, and engage effectively with organizational and administrative forms of knowledge (e.g., regulations, contracts, policies, licenses, procedures, and text-based dialogues).

- Informal health services offer individuals non-intrusive, inclusive, and patient-friendly care, and do not require the completion of lengthy paperwork or the rendering of proof of identification. Individuals in this study who had disengaged from institutional processes were largely able to function adequately outside the mainstream apparatus.

- Many individuals interviewed in this study sought care from either hospital emergency rooms settings or informal health providers (such as church drop-in centres or traveling health-service buses), in an effort to circumvent or avoid
bureaucratic regulations that may otherwise discourage them. 66% of interviewees (18 out of 27 individuals) specifically chose informal health care or emergency room services (as opposed to seeking either family-physician or specialist care).

- Among those interviewees with access to health cards (either on their actual person or stored at a local drop-in centre), 9 out of 14 individuals preferred either emergency room or informal care services, and they did not use their health cards to access regular, preventive, or specialist care. In the event of a pressing illness or injury, many individuals in this study relied upon informal nursing stations situated in churches and drop-in centres, none of which requires completion of lengthy paperwork or the rendering of proof of identification.

- Among those interviewees without health cards, approximately 4 out of 13 individuals indicated that they had no plans to seek reissuance of their health cards.

- Many interviewees either implicitly or explicitly excluded themselves from participation in mainstream health care services that, although useful to them, might be perceived as regulating, controlling, and thereby subordinating their interests to those of the dominant institution.

- Exclusion was often mutually established: individuals both “dropped out” and were “pushed out” by the structures of health care policies and regulatory processes that often perpetuate unequal access to services.
The subset of research questions are as follows:

1. What problems, if any, emerge for homeless people when seeking care without a valid health card?

   - Many individuals in this study required follow-up or specialist care, which was difficult to obtain without a health card. Follow-up or specialist care is essential for individuals with ongoing, or life-threatening health care needs. 37% of participants interviewed (10 out of 27 individuals) discussed managing at least one serious health care need, such as HIV, hepatitis C, liver disease, cancer, diabetes, heart disease, emphysema, or persistent drug and alcohol addiction.

   - Approximately 50% of participants interviewed in this study (13 out of 27 individuals) either did not possess a health card, or expressed little interest in acquiring one.

   - Only 26% of individuals (7 out of 27 individuals) had a health card on their actual person.

   - 14% of participants (4 out of 27 individuals) had opted out of mainstream health services and had no immediate plans to obtain a health card.

2. How does organizational literacy, or the lack of such literacy, affect homeless individuals’ attempts to gain access to basic health care? How do current governmental policies and directives impact homeless individuals’ access to health care?

   - Participants’ capacities to perform their everyday lifework often hinged upon the ability to access, decipher, and navigate complex organizational systems. Individuals
who have organizational literacy skills are able to “hook up” successfully to benefits offered by bureaucratic or institutionalized health organizations.

- Text-based documents exerted considerable regulatory power and control over individuals interviewed in this study. Organizational texts were readily replicated (in print or online formats) and may be employed to manage, regulate, and coordinate people’s actions, everyday activities, and relationships with each other.

- Organizational literacy often played a pivotal role in the management of participants’ healthwork, as organizational literacy mediated participants’ ability to navigate or decipher text-based health care information. Those who held a valid health card received fully insured health care services, while those who did not hold a valid health card were subsequently either excluded from receiving such services, or they encountered considerable difficulties when attempting to do so.

3. How does technological literacy, or the lack of such literacy, facilitate or mediate access to health care?

- Individuals’ capacity to perform their everyday lifework often hinges upon the ability to operate a number of technologically mediated devices and systems. For many people, dedicated access to cell phones, computers, and Internet connections not only comprise the necessities of modern life, but access to such devices also facilitates lifework and healthwork activities.

- Approximately one half of interviewees used the Internet located at various shelters and drop-in centres. Individuals used a computer occasionally for entertainment or social networking purposes. These individuals used free computer services at
downtown drop-in centres to access emails, social networking websites, online dating websites, or YouTube videos.

- Health literacy (which draws heavily upon technological literacy) is defined as the ability to locate and access information related to health. Few individuals in this study used the Internet to conduct health queries, which was due either to the lack of access to a dedicated home computer or the time-consuming demands of everyday lifework.
**Table 1:** Introducing the Participants.

<table>
<thead>
<tr>
<th>Name</th>
<th>Has a physical card on actual person:</th>
<th>Has a physical card in storage:</th>
<th>Has a life-threatening health need:</th>
<th>Has no health card:</th>
<th>Seeking OHIP reissuance:</th>
<th>Services used in Toronto (mainstream, informal or ER):</th>
<th>Has a health card, uses informal or ER services:</th>
<th>Uses a computer at a drop-in centre:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allan</td>
<td>Lost/stolen</td>
<td>No</td>
<td>Informal</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Antonio</td>
<td>Lost/stolen</td>
<td>Mainstream CHC</td>
<td>NA</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Judd</td>
<td>* Yes</td>
<td>Lost/stolen</td>
<td>Informal</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Robert</td>
<td>Friend</td>
<td></td>
<td>Mainstream Drop-in Clinic</td>
<td>NA</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peter</td>
<td>Lost/stolen</td>
<td>Mainstream CHC</td>
<td>NA</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dennis</td>
<td>Lost/stolen</td>
<td>No</td>
<td>Informal</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ray</td>
<td>Yes</td>
<td></td>
<td>Mainstream FD</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ben</td>
<td>* Yes</td>
<td>Lost/stolen</td>
<td>None / ER</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lynn - F</td>
<td>Friend</td>
<td>Yes</td>
<td>Informal</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lee</td>
<td>* Yes</td>
<td>Lost/stolen</td>
<td>Informal</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maria - F</td>
<td>Yes</td>
<td></td>
<td>Informal</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mac</td>
<td>* Yes</td>
<td>Lost/stolen</td>
<td>Informal</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stacey - F</td>
<td>Lost/stolen</td>
<td>Mainstream FD</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tom</td>
<td>Drop-in</td>
<td>Yes</td>
<td>None / ER</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tony</td>
<td>Drop-in</td>
<td>Yes</td>
<td>Informal / ER</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eric</td>
<td>Drop-in</td>
<td></td>
<td>ER</td>
<td>NA</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trevor</td>
<td>Lost/stolen</td>
<td></td>
<td>ER</td>
<td>NA</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sean</td>
<td>Drop-in</td>
<td></td>
<td>Informal</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mick</td>
<td>Drop-in</td>
<td></td>
<td>None / ER</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Donald</td>
<td>Yes</td>
<td></td>
<td>Mainstream</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ida - F</td>
<td>* Yes</td>
<td>Lost/stolen</td>
<td>ER</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fred</td>
<td>Yes</td>
<td></td>
<td>ER</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laura - F</td>
<td>Yes</td>
<td></td>
<td>Mainstream FD</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tanya - F</td>
<td>Lost/stolen</td>
<td>No</td>
<td>None / ER</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jake</td>
<td>Yes</td>
<td></td>
<td>Mainstream FD</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lyle</td>
<td>Lost/stolen</td>
<td></td>
<td>ER</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walt</td>
<td>Yes</td>
<td></td>
<td>Informal</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>14 (approx. 50%)</td>
<td>11 (41%)</td>
<td>13 (approx. 50%)</td>
<td>4 (14%)</td>
<td>Informal or ER: 19 (70%)</td>
<td>9 out of 14</td>
<td>14 (approx. 50%)</td>
<td></td>
</tr>
</tbody>
</table>

- F = female
- * = Life threatening health need and no health card
- CHC = Community Health Centre. (Many require a valid health card only for the first visit. Many also ask that applicants live in designated catchment area. Waitlists are common).
- FD = Family Doctor
- NA = Information not available
Participant Summaries

The following participant summaries include selected portions of individuals’ interviewees. These segments were selected based on two criteria: 1) they explicated the social organization of health care in Ontario with specific regard to homeless individuals’ access to such care, and 2) they explicated the coordinative and operationalizing nature of health care texts and bureaucratic processes. Interviewees shed light upon broader relations of ruling that mediated and coordinated not only their interactions with bureaucratic agencies, but also their subsequent access to health care services. When viewed collectively, individuals’ summaries led to cumulative understandings of a complex, mutual form of exclusion from mainstream health care services, which is referred to as “mutually established exclusion” through this thesis. In many cases, a complex form of self-imposed exclusion was evidenced by individuals’ lack of participation in a wide range of mainstream health care options.

Allan. Allan has no health card. He lost his card, and subsequently chose not to replace it. Allan presents a “sheet” (likely a temporary OHIP health card or an OHIP agency letter) when attempting to gain access to health care services. However, Allan recognizes that his sheet is viewed as inadequate paperwork by mainstream health care entities. Allan views the health care system as two-tiered and unequal, in which one tier serves tax-paying “working people”, and a second, informal tier serves poor, disabled, and unemployed people. Allan believes an unkempt or disheveled appearance has exacerbated his difficulties when attempting to gain access to health care services.

28 Mutually established exclusion in this thesis refers to the ways in which marginalized individuals at once “dropped out” and were “pushed out” from institutional and bureaucratic mainstream health care services.
Antonio. Antonio has no health card. Antonio’s account illustrates the bureaucratic hindrances encountered by individuals attempting to access mainstream health services. Antonio discusses the prolonged institutional waiting period governing health card registration. For individuals who do not meet the criteria governing accessibility to OHIP health care coverage, the registration process includes locating an OHIP-approved agency, receiving an agency letter, submitting the agency letter in person to an OHIP office, fulfilling the digital photograph renewal requirement at the OHIP office, arranging for the health card to be mailed to a proxy address, and periodically visiting this proxy address in order to check if the reissued health card has arrived. Antonio seeks care from informal health care services that do not necessitate the use of a health card. Antonio was recently billed $800 at a hospital emergency room, as he did not have a health card in his possession. Antonio did not pay this bill. He also left the hospital before receiving a diagnosis (or subsequent treatment) for his chest ailments. Antonio’s account illustrates the difficulties encountered by individuals managing “all the running around” (or daily travel from one location to another) inherent to shelter living.

Judd. Judd has no health card. He lost his health card and has postponed the onerous re-registration process. Judd’s everyday lifework is further complicated by a life-threatening illness. Judd’s account illustrates the ways in which texts (i.e., computerized records) mediate and coordinate interactions between people operating in institutional settings. Judd believes he has been labeled “homeless” and therefore singled out in mainframe hospital computer systems. He

Ontario citizens must present proof of a permanent address, a birth certificate or passport, and photo identification in order to obtain a health card (Ontario Health Insurance Plan, n.d.).
further believes that computerized coding systems not only label him, but also diminish the level of treatment he ultimately receives from institutional entities. Judd therefore remains mistrustful of mainstream health care organizations.

**Robert.** Robert has a health card. Robert chooses to store his health card with a friend, as the Open Access shelter that he frequents offers no secure storage facilities. Robert’s account highlights the difficulties encountered by individuals without a fixed address who must manage both the demands of survival lifework and the challenges of long-term addiction. Robert’s discussion illustrates the problems encountered by homeless individuals who must cope with housing and financial problems while also dealing with bureaucratic, text-based, and regulatory health care processes.

**Peter.** Peter has no health card. He is planning to use an OHIP-approved agency in order to acquire a new card. Peter believes an unkempt or disheveled appearance has exacerbated his difficulties when attempting to gain access to mainstream health care services. Peter discusses giving up or being “denied” when attempting to access institutional mainstream services without a health card. He also discusses being “dissed” by service providers. Although Peter indicates an interest in obtaining a health card, it remains unclear if he will seek mainstream care in the future. Peter’s account illustrates the hindrances and barriers encountered by homeless individuals without health cards, especially where such individuals are attempting to negotiate or manage bureaucratic regulatory processes. Peter no longer uses the computer or the Internet. Although he had at one time used advanced computerized drafting programs in his work as a construction foreman, he has found little use for the computer or the Internet in recent years.
**Dennis.** Dennis has no health card. He has no plans to acquire a health card in the near future. Dennis’ account illustrates the problems encountered by homeless individuals managing basic survival lifework. Without a door to lock or secure storage, his belongings (i.e., money and shoes) have been stolen. Although Dennis has disengaged from mainstream health care services, he nevertheless is able to obtain basic nursing care in drop-in centres located outside the mainstream ruling apparatus. (Each Friday, a volunteer nurse administers basic nursing care at his local drop-in centre.) He remains suspicious or mistrustful of organizations that require regulatory information or personal identification, such as a health card number. Dennis employs the computer as a social networking tool, and he employs a pseudonym in order to protect his online identity.

**Ray.** Ray has a health card, which he carries on his actual person. Ray’s account highlights the difficulties encountered by homeless individuals balancing both housing and health needs. Ray discusses the necessity of rendering a valid health card when attempting to access psychiatric or addiction treatment. Ray believes that homeless males encounter more difficulties or societal pressures than do homeless females. Ray has continuous, dedicated access to the Internet through his smartphone, which also includes GPS, email, digital camera, and MP3 technologies.

**Ben.** Ben has no health card. He does not plan to acquire one in the future. Ben sees no need to acquire a health card. Ben has decided to remove himself from bureaucratic or regulatory health care processes, and thus to abandon any attempts to access mainstream health care
services. Although Ben does not see any need to obtain a health card, he has experienced difficulties accessing care in an emergency room setting without a health card. Ben does not know how he would acquire a health card at this time. Ben rarely, if ever, needs to navigate or decipher bureaucratic paperwork in his everyday life. He does not use computer, know how to drive a car, or complete tax forms. Ben also chooses not to use a bank account, as he has established an informal relationship with a convenience store owner, who distributes his Ontario Works payments in small, periodic cash sums.

**Lynn.** Lynn has a health card, which she stores in the trunk of a friend’s car. Although Lynn has a health card, she nevertheless grapples with a bureaucratic and largely unresponsive health care system. Lynn wonders why some health providers are able to retrieve her health card number in a computerized database, while other providers seem unable to access this number. Lynn’s account illustrates the difficulties of living without a fixed address, while also managing life-threatening disease. Lynn also discusses homeless females’ vulnerability to physical and sexual attack. Lynn’s account describes not only the onerous nature of her everyday survival work, but also the difficulties she encounters when dealing with bureaucratic paperwork.

**Lee.** Lee has no health card and has experienced difficulties obtaining a new card. Lee discusses the prolonged institutional waiting period governing health card registration. (He has been waiting for over two months to receive his new health card.) Although Lee received a triple heart bypass ten years ago and has since “dropped dead” on two occasions, he is not seeking specialist medical intervention at this time. Lee’s account illustrates the difficulties encountered by homeless individuals who must manage lifework survival issues, while also negotiating and
managing bureaucratic regulatory processes. He discusses the problems encountered when living on the streets and attempting to retain or secure personal belongings. Without a door to lock or secure storage, his belongings (i.e., money and identification cards) are frequently stolen. Thus, he often has to undergo the onerous re-registration process associated with health card acquisition. Lee does not use a computer, and he feels “too stupid” to learn how to use a computer keyboard.

**Maria.** Maria has recently acquired a new health card. Maria discusses the prolonged institutional waiting period governing health card registration. (In order to obtain a health card, Maria needed to locate an OHIP approved agency, obtain the necessary paperwork, bring the paperwork to OHIP, wait for the new card to be issued, and periodically visit the proxy address where her card would eventually be delivered.) Maria’s account illustrates the difficulties encountered by homeless individuals managing basic survival lifework, while also attempting to navigate bureaucratic regulatory processes. Maria’s health has deteriorated while living on the streets (e.g., she now experiences dental and feet problems). Maria believes that she is permitted only one government-funded, emergency tooth extraction. Thus, she will avoid seeking further extractions of abscessed teeth in the future.

**Mac.** Mac has no valid health card. He is planning to use an OHIP-approved agency in the future in order to obtain a new card. Mac’s account illustrates the coordinative and regulatory nature of bureaucratic processes, whereby texts and regulations both coordinate and mediate individuals’ relations with institutional entities. Mac explains that not having an address poses significant problems for him, as “they [OHIP] won’t let you pick it [health card] up.” Mac
believes that in recent years, a new level of technologically mediated bureaucracy (i.e., a security enhanced card) has negatively impacted his access to health care. Mac’s account also highlights the prolonged institutional waiting period governing health card registration. For example, Mac is resigned to waiting one full year for an OHIP-approved agency to return to his local drop-in centre, at which time he plans to visit the agency in order to initiate OHIP health care registration.

Stacey. Stacey has no health card. She is planning to use an OHIP-approved agency in the future in order to initiate the re-registration process. Stacey’s account illustrates the difficulties experienced by homeless individuals when balancing survival lifework activities with the demands exerted by bureaucratic regulatory processes. Stacey’s account also explicates the sense of engendered powerlessness experienced by individuals interacting with rigid or depersonalized institutional entities. She has experienced problems when attempting both to regain custody of her child and secure long-term housing. (Securing housing would support her appeal for maternal custody.) When giving birth to her child, Stacey attempted to pump breast milk for her premature baby, although she was discouraged from continuing to do so by Children’s Aid Society. Stacey’s account illustrates the somewhat unyielding and rigid nature of bureaucratic institutions.

Tom. Tom has a health card, which he stores in a locker at a drop-in centre. Although Tom possesses a health card, he does not receive specialized medical attention for his hepatitis C condition. Tom discusses one occasion in which he had difficulties obtaining health care without having a health card in his possession. He uses street drugs in an effort to self-medicate an
underlying anxiety disorder, rather than seeking ongoing and monitored prescription drug
treatment.

Tony. Tony has a health card, which he stores in a locker in a drop-in centre. Although Tony has a health card, he often chooses to access informal services or emergency room services when seeking medical assistance. Tony is largely dissatisfied with the level of care he has received in emergency rooms. His concept of reasonable care is inconsistent with the kinds of services offered in emergency-room settings (as opposed to those commonly depicted on television). Tony expresses compliance with bureaucratic, institutional demands and regulations. His account explicates the difficulties encountered by homeless individuals who must manage both the demands of healthwork with the demands of a life-threatening alcohol addiction. His alcohol addiction not only impacts his healthwork, but it also negatively impacts his interactions with hospital service providers.

Eric. Eric has a health card, which he stores at a friend’s home. Eric has lost his health card approximately five times and has undergone the reregistration process repeatedly. Eric’s account highlights the difficulties encountered by homeless individuals who must manage survival lifework activities, while having no secure place in which to store belongings or personal identification. Eric’s interactions with his OW [Ontario Works] caseworker are mediated by the employment of text-based lists, forms, and documents. For example, Eric is only eligible for dental treatment of an abscessed tooth if his problem is subsumed under OW coverage. Dental extraction is also the only option available to him under OW coverage.
**Trevor.** Trevor has no health card. He is planning to use an OHIP-approved agency in the future to obtain a new card. Trevor’s account explicates the onerous nature of survival lifework and healthwork. He has experienced problems when attempting to secure long-term housing. Trevor left a low-cost rooming house when it became an uninhabitable drug-dealing house. Trevor not only grapples with the lack of permanent housing, but he is also managing the poor health of his girlfriend. Trevor’s account illustrates the bureaucratic hindrances encountered by individuals attempting to access mainstream health services, and the ways in which organizational literacy (or the lack of such literacy) impacts his ability to access to institutional services.

**Sean.** Sean has a health card, which he carries on his actual person. Sean feels that the onerous nature of completing extensive paperwork discourages many individuals from complying with the bureaucratic regulatory processes necessary to obtaining a health card. Sean discusses the regulatory function of text-based identification cards. He theorizes that an individual must be registered with a bureaucratic entity in order to be recognized as an established person in society. Although Sean possesses a health card, he nevertheless has largely opted out of mainstream health care services in favour of informal nursing care. While Sean prefers informal care, he points out that many drop-in centres only offer basic cleaning or bandaging services. Sean feels he receives inferior treatment in mainstream health care settings. Sean discusses a negative security presence in emergency waiting rooms, which he views as judgmental and intimidating. Although Sean is not computer savvy, he views technology as an important and useful tool.
**Mick.** Mick has a health card, which he stores in a locker at a drop-in centre. Mick’s account highlights the difficulties encountered by individuals without either a fixed address or a reliable location in which to store personal belongings. Although Mick has access to a health card, he has largely opted out of mainstream services, and instead seeks care only in hospital emergency settings. Mick discusses being singled out by security personnel in emergency waiting rooms, which he attributes to security staff assumptions that he is attempting to “abuse the system.” Mick attempts to comply with bureaucratic rules and regulations: he memorizes his OHIP card number, he does not “cause trouble,” and he waits “patiently” in waiting rooms.

**Donald.** Donald has a health card, which he carries on his actual person. Donald’s account describes not only the onerous nature of his everyday survival work (which also includes managing a number of life-threatening diseases), but also the difficulties he encounters when dealing with the regulatory demands of living in an institutionalized shelter setting. The shelter facility that Donald recently frequented did not permit bed rest during the day, due to limited operational hours at the shelter. Despite having multiple chronic diseases, Donald climbed three flights of stairs each day in order to reach his sleeping accommodation. Donald does not use computers or technological tools to support his everyday lifework.

**Ida.** Ida has no health card. She is planning to use an OHIP-approved agency in the near future in order to acquire a new card. Ida’s account highlights the difficulties encountered by homeless individuals without a fixed address, who must manage both the demands of survival lifework with the demands of coping with a life-threatening illness. Ida often finds herself engaging in negative interactions with hospital security personnel.
Fred. Fred has a health card. He keeps his health card on his actual person. Although Fred has a health card, he nevertheless chooses informal medical services that do not necessitate the rendering of a valid health card. Fred uses both drop-in and emergency room facilities. However, he expresses a preference for emergency room care, as he believes that health services are more immediate in such settings. Fred uses computers at the library or drop-in centres for social networking purposes.

Laura. Laura has a health card, which she carries on her actual person. Laura’s account highlights the ways in which institutionally initiated plans of action shape, mediate, and coordinate interactions between individuals in bureaucratic settings. Laura describes her recent experience in a hospital setting, in which she gave birth to a son who was immediately apprehended by Children’s Aid Society. Laura’s account also highlights the multiple difficulties faced by individuals living without a fixed address who must manage both onerous daily lifework (accessing food banks, doing laundry, finding shelter accommodation) and healthwork (prenatal care, routine STD testing), while also coping with life-threatening disease or addiction.

Tanya. Tanya has no health card, and she has no immediate plans to acquire one. Tanya views her interactions with service providers as both unrewarding and negative. She believes a clean, respectable appearance elicits positive responses from health care providers, and that her apparent “homeless” appearance elicits negative responses from health care providers. Tanya believes she is at times viewed as a “piece of virus” in institutional settings. She therefore remains suspicious or mistrustful of mainstream health care organizations.
**Jake.** Jake has a health card, which he carries on his actual person. He chooses comprehensive, patient-friendly health services found in one location: Sherbourne Health Centre, a community-based health clinic that caters to individuals living without a fixed address (i.e., no health card is required). Jake believes certain aspects of his appearance (most notably tattoos and needle marks) negatively impact attitudes and responses displayed by some mainstream health care providers. Jake has had negative experiences attempting to access health care in some institutional settings. Jake uses computers not only for social networking purposes, but he also performs health-related Internet searches.

**Lyle.** Lyle has no health card. He is planning to use an OHIP-approved agency in the future in order to obtain a new card. Lyle’s account highlights the lengthy institutional waiting period that he must endure before obtaining a new health card. (During a six-week period during this research study, Lyle had been unable to acquire an OHIP-approved agency letter in preparation for a subsequent request for OHIP approval.) Lyle’s account also sheds light upon the difficulties encountered by individuals living without a fixed address who must manage survival lifework activities while having no secure place in which to store belongings and personal identification. Although Lyle at one time possessed advanced computer skills, he no longer uses computers to facilitate his everyday lifework.
**Walt.** Walt has a health card, which he carries on his actual person. Although Walt has a health card and full access to mainstream health care services, he instead chooses to access only informal, drop-in health care services. Walt nevertheless suggested that he might visit a mainstream doctor “just for spite” in the near future. It remains unclear if he will actually do so. Walt’s account illustrates the lifework problems encountered by individuals frequenting both shelter accommodation and low-cost rooming houses. He explains that his personal belongings are at risk of being stolen at the Open Access shelter. Walt left a low-cost rooming house when it became an uninhabitable “drug house.”

**Conclusion**

This institutional ethnographic study highlighted the bureaucratic and institutional policies, directives, and structures that affect and mitigate individuals’ access to health care services in Ontario. Participant summaries presented in this chapter provide an explanatory glimpse into the routine, everyday lives of one group of individuals who frequented an Open Access homeless shelter. Individuals’ personal experiences explicated the ways in which organizational literacy (or illiteracy) is expressed and constituted in institutional settings. When viewed thematically, these personal accounts led to cumulative understandings of the exclusionary practices that often exist within institutional settings. Many participants interviewed in the study either lacked an Ontario Health Insurance Card, or they expressed little interest in acquiring one. Individuals who had chosen not to seek reissuance of their health cards either implicitly or explicitly self-excluded themselves from participation in programs and services that, although useful to them, might be seen to regulate, control, and thereby subordinate their interests to those of the dominant institution.
Table 2: Mapping the Coordination of Text-Based Documents.

<table>
<thead>
<tr>
<th>Individual</th>
<th>Reviews Documents</th>
<th>Obtains Documents</th>
<th>Visits Proxy Address</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allan</td>
<td>Opted out</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peter</td>
<td>In progress</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Antonio</td>
<td>Completed</td>
<td>In progress</td>
<td></td>
</tr>
<tr>
<td>Judd</td>
<td>In progress</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mac</td>
<td>In progress</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lee</td>
<td>Completed</td>
<td>Completed</td>
<td>In progress</td>
</tr>
<tr>
<td>Dennis</td>
<td>Opted out</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stacey</td>
<td>In progress</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trevor</td>
<td>In progress</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ben</td>
<td>Opted out</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tanya</td>
<td>Opted out</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ida</td>
<td>In progress</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lyle</td>
<td>In progress</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: Many participants discuss the prolonged institutional waiting period governing health card registration, which often took months, and in some cases (see Mac’s narrative exhibit in Appendix A), years to complete. Mapping and organizing the intent of text-based documents (including health cards, agency letters, OW [Ontario Works] statements, and online forms and documents) explicates the coordination and interrelatedness of people’s activities and actions across place and time.
Chapter 6

Politics, Power, and Praxis: A Study of Organizational Literacy in the Provision of Health Care Delivery in Ontario, Canada

Why don’t they see the person, and then deal with the health [card] stuff later? It must be in the system somewhere. A database system, or can’t they just pick up a phone, and phone? I think OHIP is kind of stupid, the carrying around the card thing.

Lynn, Interviewee

One essential aim of this study was to investigate the nature of power and authority inherent to the processes of administration and governance, and the role of organizational literacy in both standardizing and coordinating bureaucratic regulatory policies, practices, and directives. Organizational literacy is the ability to navigate, negotiate, and interpret organizational processes, policies, structures, and texts in ways that often elude individuals who are not privy to such organizational knowledge (D. Smith, 2005, p. 183). In this study, individuals’ personal accounts explicated not only the complexity of institutional policies, processes, and practices that mediated and controlled their interactions with health care services, but they also explicated the ways in which individuals take up, interact with, and navigate such processes. Darville (1995) believes that people can learn to negotiate dominant forms of literacy (e.g., regulations, contracts, policies, licenses, procedures, and dialogues) if they are equipped with organizational literacy skills “…the difficulty is not in reading skills in a rudimentary sense, but practical knowledge about how certain information is organizationally relevant, [and] how it will be used” (p. 257). Organizational literacy not only assists individuals to engage effectively with dominant forms of literacy, but it also assists them to locate their place within wider
institutional systems. Rather than focusing upon developing the personal attributes of the adult learner, organizational literacy enables individuals to explore the context of their actions and experiences, and to understand the nature of their relationships to external bureaucracies.

One aim of this study was to investigate the role of organizational literacy in both standardizing and coordinating the everyday activities or lifework of individuals seeking health care. The acquisition of organizational literacy is a challenging undertaking, and even marginal competency eludes many individuals. It is not enough to be able to interpret and analyze institutional forms, documents, and pamphlets. Individuals must also be able to “read into” and thereby unpack and digest the power structures that direct and control policies and procedures governing their lives. Individuals who have organizational literacy skills are able to “hook up” successfully to benefits offered by health organizations. Those who do not posses organizational literacy skills are often rendered organizationally illiterate when faced with the complexities and nuances of institutionalized or bureaucratic regulations and procedures, and they therefore often fail to avail themselves of the benefits or services offered by institutional organizations.

The transient and unstable nature of living without a fixed address presents significant challenges for individuals living on the streets. Lifework includes securing emergency health or dental care, obtaining food, showering, doing laundry, using the telephone or Internet, retrieving belongings from storage facilities, and relocating lost or stolen identification. The everyday work of basic survival (or lifework) consumed a significant part of participants’ everyday lives. At the particular Open Access shelter from which participants in this study were drawn, guests were supplied with one TTC [Toronto Transit Commission] token after breakfast, and any subsequent travel was conducted on foot. Thus, participants often spent a significant portion of their day travelling by foot to various shelters, drop-in centres, and travelling clinics located across the
city. Mick explained that after Open Access ends for the season spent a significant portion of his time searching for food: “I get sleeping bags and find a nice place outside. I have a routine that I do. I’ll find food if I can find it. Usually I just eat during the day and at night I go without.”

There are 19 Open Access shelters located in a churches, synagogues, and temples across the Greater Toronto area (see Figure 5). Each of these faith-based organizations opens its doors one night each week throughout the winter season (see Figure 6 for an example weekly lifework map of available Open Access shelters). Each Monday, for example, individuals may locate a bed at St. Margaret’s Church (Etobicoke), St. Bridgit’s Annex (The Danforth), Beth Emeth (North York), or St. Aiden’s (the Beaches). The unavoidable and relentless pursuit of daily lifework exacerbates the problems and challenges encountered by individuals. Additional to these demands are those exacted by drop-in centres or travelling clinics, each of which necessitates its own regulatory policies and procedures.
### OUT OF THE COLD SITE SCHEDULE 2010 - 2011

<table>
<thead>
<tr>
<th>SUNDAY</th>
<th>MONDAY</th>
<th>TUESDAY</th>
<th>WEDNESDAY</th>
<th>THURSDAY</th>
<th>FRIDAY</th>
<th>SATURDAY</th>
</tr>
</thead>
<tbody>
<tr>
<td>St. Patrick's 136 McCaul St. (Dundie/McCaul) 75 Guests Nov 21 to Apr 15 4:00 pm to 7:00 am</td>
<td>Lake Shore 80 St. Margaret's Church 116 6th St. (4th Ave/Bathurst) 20 Guests Nov 22 to Apr 13 6:00 pm to 8:00 am</td>
<td>Evangel Hall 552 Adelaide St. E. of Bathurst 25 Guests Nov 10 to Mar 28 5:00 pm to 7:00 am Tickets for mats given at 12:30</td>
<td>Yorkminster Park Baptist 1500 Yonge St. (N of St. Clair) 40 Guests Nov 4 to Apr 6 7:00 pm to 8:00 am</td>
<td>Holy Blossom Temple 150 Bathurst (N of Eglington) 45 Guests Nov 5 to Mar 29 6:30 pm to 8:00 am</td>
<td>Eastminster United 310 Danforth Ave. (W of Chester) 55 Guests Nov 6 to Mar 29 6:00pm-8:00am</td>
<td>Blythwood Rd Baptist 60 Blythwood Rd. (N of Yonge/Eglington) 55 Guests Nov 6 to Mar 29 6:00pm-8:00am</td>
</tr>
<tr>
<td>St. Matthew Our Lady Peace 3629 Boor St W. Shaver 25 (Men only) Nov 21 to Mar 27 3:00pm - 5:00 am</td>
<td>St. Brigid's Annex 1096 Danforth (Donlands/Danforth) 60 Guests Nov 15 to Apr 11 4:00 pm to 6:00 am</td>
<td>Beth Shalom 1445 Eglinton W. (Allen Expressway) 40 Guests Jan 11 to Mar 29 5:15 pm to 7:00 am Tickets for mats given at 12:30</td>
<td>First Interfaith St. Matthew's 729 St. Clair Ave W 45 Guests Nov 4 to Mar 31 4:00 pm-6:00 am</td>
<td>All Saints Kingsway Anglican 2650 Boor W (Royal York) 20 Men Only Nov 18 to Apr 1 6:00pm-8:00am</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Beth Emeth 160 Eider St. Wilmington/Shapard 30 Guests Jan 10 to Feb 28 6:00 pm to 7:00 am</td>
<td>Chinese Gospel 456 Duncia St West 15 Men Only TBA 6:00 pm to 7:30 am</td>
<td>Knott United 1599 Midland Ave Midland/Shoppard 20 Guests Nov 5 to Mar 25 6:30 pm - 8:00 am</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>St. Aidan's 70 Silverthorn Ave 16 Guests Nov 6 to Mar 28 4:00pm - 8:00pm</td>
<td>University Settlement House* 23 Grange Rd. (McCall N of Queen) 65 Guests 5:30pm - 7:30am</td>
<td>University Settlement House* 23 Grange Rd. (McCall N of Queen) 65 Guests 5:30pm - 7:30am</td>
<td>University Settlement House* 23 Grange Rd. (McCall N of Queen) 65 Guests 5:30pm - 7:30am</td>
<td>St. Michael's Cathedral* 66 Bond St. 60 Guests TBA</td>
<td>Dixon Hall Resource and Support Services for Out of the Cold Phone 416.699-0062 Fax 416.691-0024</td>
<td>Mosaic Interfaith York Region* 1.866.392.3777 416-948-6682</td>
</tr>
</tbody>
</table>

Programs not serviced by Dixon Hall:
- University Settlement House
- University Settlement House
- University Settlement House

---

Out of the Cold is a volunteer initiative by Toronto area synagogues, churches and faith communities to serve as Host Sites that offer shelter, hospitality and refuge to people who are homeless in the City of Toronto.

Out of the Cold host sites reach out to marginalized individuals and extend a warm invitation to enjoy food, shelter and hospitality. This is made possible through the dedication and support of the many volunteer groups that offer their time, energy and perseverance.

Out of the Cold Resource and Support Services provided by Dixon Hall are funded by the City of Toronto.
Eric’s Lifework

My day – do you want to know how it is? I wake up at 7:00, and I go for coffee. Then I walk to the next place I have to go - to another Open Access. I may not eat lunch. Sometimes I’ll go to another drop in to eat lunch. Like today there is a place on Church where you can have a shower. Showers are big, like finding a place to have a shower. Then I make my way to the next Open Access and eat around 5:00. It takes up your day.

Eric’s Sample Week

Monday (M): St. Brigid’s Annex (Donlands Ave. and Danforth Ave.)
Tuesday (T): Evangel Hall (Bathurst St. and Adelaide St.)
Wednesday (W): Yorkminster Park Baptist (Yonge St. and St. Clair)
Thursday (Th): Holy Blossom Temple (Bathurst St. and Eglinton Ave.)
Friday (F): Eastminster United (Danforth Ave. and Chester Ave.)
Saturday (S): Blythwood Road Baptist (Yonge St. and Eglinton Ave.)

Sunday (Su): St. Patrick’s Church (Dundas St. and McCaul St.)

Individuals’ capacity to perform everyday lifework largely hinged upon the ability to access, decipher, and navigate bureaucratic organizations, such as drop in-centres, shelters, OHIP-approved agencies, travelling clinics or hospital emergency rooms. The employment of organizational literacy enables individuals to “hook up” successfully to benefits and services offered by bureaucratic organizations (such as drop-in shelters and clinics), while those without such knowledge and skills often encounter barriers or difficulties when seeking assistance.

Of particular interest in this study were textually mediated, organizational disjunctures or challenges that mediated individuals’ everyday experiences. Such disjunctures often resulted in feelings of helplessness or powerlessness for interviewees. Tony, one interviewee, experienced a sense of organizational disjuncture when receiving emergency room treatment. Tony’s sense of disjuncture was expressed in his discussion of the disparity between the real-life actualities of his first-hand experiences in emergency rooms and the artificial realities depicted in televised emergency room dramas. Tony was managing long-term alcohol addiction, and he had sustained a number of head injuries following heavy bouts of drinking in recent months: “Half the time you go to the emergency, you’re drunk and you’re intoxicated, and you’re passed out in some snow bank or something.” Although Tony had a health card in storage, he invariably sought care from emergency rooms or informal drop-in centres (none of which offered ongoing preventive care, counseling services, or treatment for alcohol addiction). In particular, Tony’s concept of care was largely inconsistent with the kinds of services offered in emergency-room settings: “One thing I don’t believe is that they haven’t fully checked me out, ’cause a few times I totally
blacked out. I passed out because I had a huge thing on my head. I looked like John Merrick [Elephant Man]… And then they said, ‘Everything is fine.’ But they didn’t show me anything. You know how on TV they show you, you know, ‘This is what’s wrong, and this is what it should look like.’ They didn’t do that at all.” Tony grappled with a health care system that in many ways he viewed as incomprehensible, or at the very least, inconsistent with the health care practices commonly depicted in the entertainment media. This study explicated not only individuals’ challenges gaining access to mainstream care, but it also explicated how such challenges come to be in the everyday, material lives of individuals. The acquisition of organizational literacy assists individuals to understand the intent, inner workings, and common practices of institutional or bureaucratic systems, which, in turn, assists individuals to understand their place with such systems. In sum, organizational literacy makes the world more comprehensible to people.

This study explored the coordinative nature of dominant texts (e.g., identification cards, informative pamphlets, documents, forms, and letters), and the ways in which individuals both initiate and operationalize such coordination. Of particular interest in these first-hand accounts were discussions of textually mediated processes of control and governance promoted by bureaucratic institutions. Personal accounts illustrated the ways in which texts both coordinate and operationalize the everyday activities and actions of homeless individuals. Eric, another interviewee, required immediate dental care for an abscessed tooth. However, without appropriate documentation (i.e., an Ontario Works statement or “pay stub”) his care had been delayed: “You have to get a Tylenol. I have to wait until the end of the month to get my pay stub, so I can go see a dentist for free. For people on OW [Ontario Works] and Social Assistance, for people on Street Allowance, same thing. They basically will pull it [the tooth]. But you need
your OW statement and your health card. There’s a big list of dentists, but I’m still gonna have to wait a week and a half.” Eric’s dental problems must be subsumed and subsequently addressed under a standardized (and fully OW insurable) list of emergency, rather than non-urgent, dental complaints. In order for Eric to receive free emergency dental care, his abscessed tooth must qualify for treatment in an emergency hospital setting (see Figure 7). As Ontario Works in Toronto will only insure extractions (as opposed to fillings, root-canals, or crowns), the only option available to Eric was full extraction of his tooth. Eric’s health issues were entirely subsumed under Ontario Work bureaucratic regulatory policies and procedures. Organizational literacy hinges upon the ability to draw upon informed understandings of the inner, procedural workings of institutional systems. Eric lacked the “inside” knowledge or informed understandings necessary to either confronting or manipulating the governmental processes with which he was engaged or enmeshed. He therefore remained resigned to enduring continued pain before undergoing tooth extraction.
Figure 7: Ontario Works Dental Coverage.

Note. Individuals receiving Ontario Works may receive free dental care if it deemed as “emergency” case. There is currently no public dental insurance in Ontario and only minimum dental coverage for those on social assistance. Complete removal of the tooth is therefore the only option for individuals with no means of paying for dental cleanings, fillings, root canals, or crowns.
The management of serious, life-threatening health conditions consumed a significant portion of many individuals’ everyday lifework. Bresalier et al. (2002) extended the notion of lifework to include “health work”, or more specifically, the health-related work undertaken by individuals living with HIV/AIDS. In this study, healthwork is defined as obtaining health care insurance, accessing pharmaceuticals, and managing illness and addiction. Many interviewees managed one or more life-threatening health issues: approximately 40% of participants interviewed (11 out of 27 individuals) discussed coping with at least one major health care need, such as HIV, hepatitis C, liver disease, cancer, diabetes, heart disease, emphysema, or drug and alcohol addiction. Judd had lost 110 pounds over the course of only a few months, perhaps largely due to self-treating his diabetes condition: “I lost 110 pounds in the past four months. I was diabetic type 2. Now I think I’m starting to be type 1. I stopped taking my type 2 diabetes [medication] because it’s making me more sick.” Although Judd would benefit from specialist medical attention (such as receiving guidance from a qualified dietitian and treatment from an endocrinologist), he struggled to cope with the bureaucratic or regulatory processes governing health card reissuance and related care. “I had that card for a while, and I guess that was the old version with this one picture on it, ’cause they tell me that one is invalid. So I had to get another one, a new version, which has two pictures on it, right? I should go pretty soon, but I keep putting it off.” Judd had lost his health card at an Open Access shelter over three months ago. When asked how the system could be made better for him, Judd discussed the institutional waiting period governing health card reissuance: “If you go down to 777 Bay Street, it still takes six weeks. I thought you’d be able to get it right there and then.” As Judd grappled with the bureaucratic or regulatory procedures and policies governing health card reissuance and related care, he had postponed the onerous health card re-registration process. The inability to navigate
mainstream health care regulatory processes in effective and resourceful ways had significant consequences for interviewees in this study, and those consequences were particularly perilous for those who managed life-threatening illness.

Technology is an essential facet of organizational literacy. For many individuals, cell phones, computers, and Internet connections comprise the necessities of modern life. People’s ability to function in the world today hinges not only on their ability to purchase and utilize technology, but it also hinges on their ability to adapt to a world in which technology plays an increasingly pervasive role (Haste, 2008). Mick, for example, avoids mainstream health care settings, although he did indicate that he was interested in learning more about Ontario Telehealth (a free, confidential telephone service that enables individuals to receive health advice or general health information from a registered nurse). Such a service might feasibly benefit Mick, particularly as individuals are not required to have a valid health card in order to be the recipient of telephone health advice. However, individuals who use the service require a dedicated telephone number through which to receive a “call back” from a registered nurse. As Mick has no cell phone or dedicated telephone line, he is unable to access Telehealth.

Interviewees in this study had limited access to computers, no time to devote to computer usage, and no economic means to pay for technology equipment.

Women experience homelessness differently from men. Women’s lifework differs from men in two key ways: women are more susceptible to sexual violence, and they also have uniquely female sexual and reproductive issues. Lynn, one study participant, had been raped in a downtown Toronto stairwell. Although Lynn feels more secure sleeping at the Open Access shelter, she nevertheless finds herself deflecting unwanted sexual advances from men on a daily basis: “You have to know who to be around, and how long to stay if somebody’s around. And
learn to recognize the signs. Because I have been raped. I have been attacked. I have been stabbed - on the streets, in the stairwell.” The management of serious, life-threatening health care consumed a significant portion of women’s everyday lifework and healthwork. Lynn’s everyday healthwork involved managing advanced-stage HIV/AIDS. Lynn discussed her difficulties obtaining a health card, and her subsequent problems accessing specialist medical care:

I have to go get one [a health card]. I’m going to try to go without, but I’m probably going to be forced through that process again. It frustrating - that’s why I give up. I have nodules in my right lung. I don’t even care… They’ve taken two of my left lobes out. But I just avoid doctors ‘cause it’s so much hassle, and that’s wrong because I don’t want to die.

Bureaucratic processes (such as visiting clinics, making and keeping specialist appointments, and completing health-related paperwork) proved onerous for many women. For these individuals, the arduous work of managing basic survival needs often took a back seat to that of essential health care. Organizational literacy played a pivotal role in the management of participants’ healthwork, as organizational literacy mediated their ability to decipher, navigate, or manage bureaucratic processes or demands. Understanding the inner workings, operations, and expectations inherent to institutional bureaucracies may feasibly facilitate Lynn’s efforts to manage or circumvent the regulatory demands when seeking health care.

In order to obtain a health card, individuals need to decipher, navigate, or “hook up” to institutional entities. Interviewees who possess organizational literacy skills are able to obtain fully insured health care services with relative ease, while those without such skills often encounter difficulties when attempting to access fully insured services. Many participants
interviewed in this study experienced difficulties obtaining an Ontario Health Insurance Card, or they expressed little interest in acquiring one. Allan, one study participant, had no valid OHIP health card, and he was not currently seeking such coverage. Allan’s situation was not unique: 50% of participants interviewed in this study (13 out of 27 individuals) either did not possess a health card, or were not motivated to acquire one. These findings have serious implications for individuals attempting to access ongoing or specialized health care (as opposed only to immediate or emergency care). Allan stated that he occasionally visits the Rotary Club of Toronto Health Bus, a travelling health bus that offers mobile, on-the-spot nursing care. The Health Bus does not require participants to show identification or to produce a health card. “I go to drop-ins. Drop-ins within very concentrated areas of crime. Prostitution, drugs, where help is needed. Or they have buses. These are buses that come by in concentrated neighborhoods. Again, places with random acts of all sorts of not appropriate living styles.” When asked if he has ever had a health card, Allan explained: “Yeah, I’ve had them, yeah, but I’ve lost them. Lost them.” Allan expressed views common to many individuals in this study: he was stymied by the onerous, time consuming, and often difficult regulatory processes that typically govern health card reissuance.

Organizational literacy is more than an acquired skill: it is the ability to decipher, analyze, and understand the covert power structures inherent to institutional policies and processes. Organizational literacy enables individuals not only to select which personal information to disclose, but also which information it might be advantageous to withhold. Judd, for example, felt that the responses he elicited from interactions with institutional service providers were negatively impacted by his lack of a permanent address. Judd usually attempts to conceal his homeless status: “They treat you different if you have a place. Then they find out
you’re homeless. ‘OK, give him what he needs, and then get him out of here.’ Rush you out.”

Judd understood that a large, computerized, data-management system administers patient information: “It’s on my card or something. On my file. Fixed address or something. I tried before, but it’s all on their computer. ‘What’s your postal code?’ Then they find out. I don’t know postal codes; [telephone] numbers I’m good at.” Judd’s discussion explicates the ways in which organizational literacy, or the lack of such literacy, curtails individuals’ attempts to access mainstream health care service. In Judd’s case, this was demonstrated by routine and standardized record-keeping requests that directed and mediated his activities and actions in institutional settings. The apparent extent and intractability inherent to governmental regulatory demands and policies discouraged and ultimately deterred Judd. He expressed a sense of marginalization within the health care institution to which he was seeking entry.

One aim of this study was to investigate the ways in which individuals engage in, take up, and thereby activate regulatory control processes in bureaucratic settings. Anyone may be rendered powerless (or organizationally illiterate) if faced with an unfamiliar or oblique institutionally mediated course of action. Stacey recounted the birth of her son, who was apprehended by Children’s Aid Society immediately after his birth. Children’s Aid Society had mounted a case for complete removal of Stacey’s maternal rights, which would allow no future contact with her newborn child. Stacey did not explore the specifics of the infant’s apprehension, although she did discuss her disappointment when informed that she would not be permitted to provide breast milk for her premature infant. Children’s Aid did not allow her to pump milk for her infant, and neither hospital staff nor Children’s Aid explained to her why she was prevented from doing so. Further, Stacey was not consulted regarding a number of institutional decisions regarding the birth process and the subsequent apprehension of her child: “The doctor looked at
me and says, ‘You either give birth to this baby right now, or we’re putting you out.’ So I said, ‘Whatever’s best for the baby.’ I wasn’t thinking about me or anything. I woke up, and there’s my baby. I was scared.”

Institutional plans of action, put into motion by health care policies and procedures, had significant consequences for women in particular. Interviewees discussed not only negotiating labour and birthing processes, but they also discussed dealing with subsequent apprehension of their infant children. Darville (2005) argues that organizational literacy is a dominant form of literacy that is “part of the power of those who have power,” and that such power supports the interests of those with the background knowledge of the inner workings of systems designed to perpetuate and replicate power (p. 250). Individuals who do not possess this knowledge are thereby rendered illiterate, or uninformed regarding the policies, objectives, or ideologies inherent to specific institutional plans of action. As Stacey was not consulted regarding a number of institutional decisions surrounding the birth process and the subsequent apprehension of her child, she was therefore rendered organizationally illiterate, and thus without either personal or operational power regarding decisions related to the welfare of her infant son.

Many interviewees sought to circumvent institutional power structures. Lynn’s HIV/AIDS condition necessitated daily adherence to a complex antiretroviral drug regime. A local shelter (not associated with Open Access) had recently withheld Lynn’s antiretroviral medication, in an effort to persuade Lynn to remove seven bags of personal belongings that she had left at the shelter: “Yeah, I have been taking my medication regularly, but this is the problem. I was at a shelter… and it’s probably a great place for some people, but I couldn’t handle it. They packed my stuff into seven bags. I brought it in two [bags]. They don’t know how to pack obviously. I had to fight with them for a [TTC] token. They didn’t want to release
my medication without me taking all of my belongings. They don’t have the storage space. But that’s wrong, so I had a doctor from the health centre. It’s all women, and they do what they can. The doctors are female - so the doctor called the shelter and said, ‘It’s a matter of life and death. Maybe not death, but it’s crucial that she has her medication, so can she pick up just her medication and leave her belongings?’ They didn’t care. Out of their shelter is all they care. I will never, ever go back there.” Lynn recognized the intractable and unyielding nature of the regulatory policies enforced by the shelter organization. In order to circumvent the rules and regulations enforced by the institution, Lynn sought assistance from an intermediary (a doctor working within an informal health setting) to help retrieve her antiretroviral medication. Lynn utilized her knowledge of institutionalized systems in order to resist domination and control by people, practices, and policies: she grasped that in order to confront intractable, institutional regulatory policies of one shelter, the support of a reputable medical professional from another institution would further her interests and deflate any opposition she might face. Nevertheless, she continues to struggle with bureaucratic rules and regulations, and with a view to avoiding any further problems, Lynn currently stores any personal belongs in the trunk of a friend’s car.

The process by which an individual is rendered organizationally illiterate and thereby potentially marginalized within bureaucratic health care institutions was evident in individuals’ first-hand accounts. The acquisition of organizational literacy is a multifaceted undertaking. It is not enough to interpret and analyze organizational forms of knowledge. Individuals must also be able to ‘read into’ and thereby unpack and digest the power structures that are inherent to dominant literacies. Darville (1995) believes that all types of literacy are powerful tools that can at once liberate or dominate. “The task of understanding the patterns of domination that underlie daily experience forces an engagement with forms of literacy that are part of the power of those
who have power - for example, regulations, applications, contracts, invoices, identification cards, licenses, business letters, memoranda, laws, and judicial decisions” (p. 250). Individuals who have organizational literacy skills are able to decipher, navigate, and thereby “hook up” to benefits and services offered by health care organizations, while those without organizational literacy skills often encounter challenges when attempting to access such benefits and services. This study examined the relationship between organizational literacy and access to health care benefits. It also explored how inclusion and equality may be promoted in the health care system. When asked how the health care system may be made better in Ontario, Lynn discussed the regulatory problems associated with text-based identification cards: “Why don’t they see the person, and then deal with the health [card] stuff later? It must be in the system somewhere. A database system, or can’t they just pick up a phone, and phone? I think OHIP is kind of stupid, the carrying-around the card thing.” The findings from this institutional ethnographic study, drawn from explicit information provided by informants, indicate that bureaucratic organizations may perhaps unwittingly operate to exclude or marginalize those whom they purport to serve: all Canadians residents, including those without the essential knowledge necessary to navigating ongoing, mainstream care.
Chapter 7

Mapping Neoliberal Ideology: The Translocal and Invisible Realm of Bureaucratic Health Care Delivery and the Everyday Lives of People

It’s become a little bit harder. I guess, back in the day, you could go in and basically if you knew your number you were good. But now they have the magnetic strip and everything’s on that. They’re into this new mentality. They have a set of rules that they have to follow. If you don’t have a card that they can swipe, sorry, we don’t have procedures for people without health cards. Here’s where you can get one. OK, yeah. Back to that place again, right.

Mac, Interviewee

This chapter seeks to map, locate, and make visible the local, everyday experiences of 27 individuals at an Open Access shelter, and to situate that map within the translocal and often invisible realm of broader neoliberal ideologies and their related bureaucratic health care policies and directives. In Das Kapital, Marx (1867/1996) argued that the root causes of economic and social inequalities in contemporary society are a direct consequence of capitalism. Marx and Engels argued that class differences in society denote individuals’ capacity to purchase productive property and employ a means of production. Marx and Engels (1932/1970) further argued that the ruling classes not only possess the material means of production, but they control the production and distribution of intellectual ideas: “The class which has the means of material production at its disposal, has control at the same time over the means of mental production, so that thereby, generally speaking, the ideas of those who lack the means of mental production are subject to it” (p. 64). Thus, the ruling or dominant class may work to promote values or attitudes
that serve its own ends, and to diffuse or deny divergent or alternative ideas that may serve to threaten those ends. Neoliberalism not only references the doctrine of capitalism or free market exchange, but it also infers a social and moral philosophy espoused by the mainstream dominant institutions. Thompson (2005) writes: “Neoliberalism is the intensification of the influence and dominance of capital; it is the elevation of capitalism, as a mode of production, into an ethic, a set of political imperatives, and a cultural logic” (p. 23). Martinez et al. (1997) describe neoliberalism as a set of economic policies employed by conservative governments to reframe conservative policies as progressive, fiscally responsible, and socially advantageous, rather than as conservative, politically motivated, or non-advantageous to poor or marginalized demographic groups (p. 1). The main tenets of neoliberalism include the support of free enterprise, the reduction of social services, the privatization of state enterprises, and the reduction of welfare benefits, all of which are promoted as “individual responsibility”30 or the moral responsibility of ethically inspired citizen (p. 1). More specifically, neoliberal policies include cost-effective restructuring of public health care and education systems, privatization of public entities, and the reduction of welfare spending, all of which ultimately contribute in significant ways to creating both economic hardships for marginalized groups and the associated social determinants of health for these groups.

Broader social determinants of health (poverty, socioeconomic disparity, and social status) predetermine the extent to which certain societal groups are predisposed to illness (Wilkinson et al., 2003). Materialist theorists attempt to explicate how social detriments or inequalities come to

30 Health institutions are able to frame health care inequalities and reductions in benefits in terms of the promotion of the responsibility of the individual. In doing so, unwanted attention is shifted away from any public debate of such inequalities and is focused more specifically on the individuals’ responsibility for maintaining his or her own health.
be. They specifically seek to explicate the causes and effects of unequal distribution of economic resources among diverse socioeconomic groups (Eckersley et al., p. 94). In keeping with the materialist approach, this study explores the role of neoliberal political structures, policies, and practices in coordinating and controlling both the everyday, material lives of people and their ability to maintain good health. One effective means of explicating political power structures is to map the wider distribution of power, money, and resources located at all levels of governance, and to examine how the distribution of resources, benefits, and privileges impacts the everyday, local lives of individuals.

This study sought to make visible the ways in which neoliberal discourse (for example, discussion regarding the cost-effective restructuring of public health care) is promoted and operationalized in institutional settings through the employment of dominant texts.31 Institutional texts are not static entities: they are read, listened to, examined, and operationalized by people. From an institutional ethnographic perspective, text-based documents are neither static nor benign entities: rather they are control-based mechanisms that play an active role in both mediating and managing the actualities of people’s everyday lives (D. Smith, 2005, p. 105). D. Smith draws a distinction between text and discourse: meaning derived from discourse (as opposed to texts) is constituted by human interaction and ongoing dialogue.32 Informative, persuasive discourse is further promoted through texts and printed dialogue.

Texts manage and control our lives in multiple and unavoidable ways. Neoliberal philosophies and ideologies (e.g., cost-cutting accountability and the privatization of social

31 Dominant texts are as defined as regulations, contracts, policies, licenses, procedures, and text-based dialogues.
32 D. Smith (2005) draws upon Foucault’s notion of discourse. Foucault (1972) writes that concepts and ideas gain meaning and shape through human interaction and dialogue (p. 32). Discourse is promoted and manipulated through textually mediated institutional rules and practices, as evidenced in both medical treatments for women with psychiatric disorders (psychiatry discourse) and punishments for homosexuals (criminology discourse).
services) are often both implicitly and explicitly expressed, stated, or discussed in governmental text-based documents, policy papers, royal commissions, and research papers. Mapping and organizing the intent of text-based documents reveal the coordination and interrelatedness of people’s activities, actions, and plans across place and time. D. Smith (2005) argues: “Replicable and replicated texts are essential to the standardizing of work activities of all kinds across time and translocally. It is the constancy of the text that provides for standardization” (p. 166). The employment of standardized texts in institutional settings often ensures that order, objectivity, and accountability are maintained effectively within an institution. Organizational texts are replicated (in print or online formats) and are employed by governing entities not only to manage, regulate, and coordinate people’s everyday actions and activities, but also to coordinate their relationships with each other. Texts coordinate people’s lives in one key way: texts describe, outline, or mandate sequential order or linear processes in the organization of people’s actions and activities (D. Smith, 2005, p. 166). This results in the removal of the individual as an active, empowered agent in the bureaucratic process in which he or she is engaged or enmeshed. “The ruling relations are a complex and massive coordinating of people's work. Intentions, desires, opportunities, impediments, blockages, and powerlessness arise within them” (Smith, 2005, p. 183).

Neoliberal ideologies and polices are often evident in the implementation and promotion of sophisticated, text-based, computerized data-management systems. Peters (2001) theorizes that neoliberalism has opened new avenues for surveillance and citizen monitoring, which enable governments to record personal data, consolidate and share information, and implement increased accountability measures. The development of high-tech computerized monitoring systems has brought about an increased security presence throughout all aspects public life,
including video surveillance on the streets, security systems in buildings, high-tech retina or fingerprint scans in airports, and the mass-digitalization of personal data through the use of “smart” or high-tech identification cards (Peters, 2001, p. 92). In Ontario, high-tech smart cards were implemented in an attempt to reform public health care accessibility (in order to ensure only those eligible received health care). OHIP replaced residents’ old red and white cards with new smart cards, which include several security features, such as a digitalized photograph and a 5-year mandatory renewal requirement. These features were designed to prevent non-citizens from fraudulently obtaining health benefits in Ontario (Shu, 1996). Ontario Health Insurance Plan [OHIP] further expanded the criteria governing accessibility to its universal health care coverage: citizens must now present proof of a permanent address, a birth certificate or passport, and photo identification in order to obtain a health card (Ontario Health Insurance Plan, n.d.). However, tightened bureaucratic regulations designed to reduce fraud and counterfeiting have also resulted in preventing many individuals from either seeking or receiving mainstream health care, due to the arduous and time-consuming nature of the health card registration process. Thus, neoliberal policies framed as a means to prevent fraud and reduce reckless spending may equally be framed as a means to monitor individuals’ personal information and to direct and control their activities and actions within institutional settings.

Another essential tenet of neoliberalism is that the reduction of welfare spending not only reduces taxation, but that it also promotes personal responsibility in its citizens. In Ontario, systematic welfare reductions are evident in recent changes to welfare subsidies. Many participants in this study had previously benefitted from the Special Diet Allowance, a subsidy administered through the Ministry of Community and Social Services, which was designed to ensure that low-income individuals living with a medical condition receive increased welfare
benefits. Initially, Special Diet requests were listed on an open-ended form, which allowed medical practitioners to design special diets based on their patients’ unique health needs. In 2005, the Special Diet subsidy was dramatically scaled back, whereby only 43 medical conditions were then deemed valid prerequisites to receipt of the Special Diet Allowance, and in 2011 it was further scaled back, whereby only 29 medical conditions were deemed valid prerequisites. In an attempt to implement further accountability or cost-cutting measures, the Ontario government eliminated the Special Diet Allowance and replaced it with the Nutritional Supplement Program. This program is administered through the Ministry of Health, rather than the Ministry of Community and Social Services. The Ministry of Health has not only expressed plans to remove a number of medical conditions deemed incommensurate with the subsidy, but it also plans to implement a tracking system that will identify any “questionable” trends in the referrals submitted by physicians (Ontario Ministry of Community and Social Services Newsroom, n.d.). Thus, the Province of Ontario has not only encouraged a reduction in Nutritional Supplement referrals, but it has also encouraged employment of greater caution by physicians when listing medical conditions deemed as valid prerequisites. The elimination of the Special Diet welfare subsidy is one example of reduction of welfare spending that seriously impacts health outcomes for marginalized individuals. It is also an example of how neoliberal ideologies and their implementation has had a direct impact upon mainstream policies and practices in current health care circles today.

This study sought to make visible the translocal linkages of health care practice in the everyday, local lives of people, through mapping the intent and employment of text-based documents in directing people’s lives. The OHIP health card is one such text-based document. It coordinates and facilitates the relationship between an individual and the Ontario Ministry of
Health. Under legislated law, an individual must present a physical, valid card in order to receive health benefits. Those who hold a valid health card may receive fully insured health care services, and those who do not hold a valid health card are subsequently either excluded from receiving such services, or encounter considerable difficulties when attempting to do so. Health care policies differ significantly across the provinces, as provincial jurisdiction (rather than federal) largely governs provincial health care policy. In Ontario, in order to obtain a health card, one piece of prerequisite identification must include either a passport or a birth certificate, either of which may prove time-consuming or difficult to replace if lost or stolen (see Figure 8). British Columbia has more lenient policies regarding prerequisite identification regulation than those imposed in Ontario, although these policies are currently under review. Current British Columbia policies are perhaps more conducive to supporting individuals without a fixed address. British Columbia, for example, does not require its residents to update health cards or to provide picture identification. Furthermore, British Columbia residents may obtain replacement health cards using a simple online form, which does not require proof of residency status (see Figure 9). Ontario residents must obtain a replacement health card in person. Policies designed to eliminate fraud and counterfeiting, such as those commonly promoted by conservative neoliberal governments, have a significant impact upon individuals’ attempts to gain access to fully insured health care services in Ontario, as such policies invariably bring with them increased bureaucracy and regulatory demands.

33 The British Columbia government announced in May 2011 that it plans to introduce a new “smart” card. Residents will be required to renew their new health cards on a regular basis, in order to be eligible for fully insured health services.
**Ontario Health Insurance Coverage Document List**

You will need one document from each list. All documents must be originals. The Ministry of Health and Long-Term Care and its agents, ServiceOntario, reserve the right to request additional documents.

**List 1** - Proof of Citizenship or OHIP-Eligible Immigration Status:
A document to prove you are a Canadian Citizen or hold another immigration status that makes you eligible for Ontario health insurance coverage.

**List 2** - Proof of Residency in Ontario:
A document that displays your name and current home address and confirms that your primary place of residence is in Ontario.

**List 3** - Support of Identity:
A document that displays both your name and your signature.

### List 1: Proof of Citizenship / OHIP-Eligible Immigration Status

- **Canadian Citizens**
  - Birth Certificate from a Canadian province or territory (issued under the Vital Statistics Act)
  - Canadian Certificate of Registration of Birth Abroad
  - Certified Statement of Live Birth from a Canadian province or territory
  - Certificate of Canadian Citizenship or Certificate of Naturalization (paper document or card, not commemorative issue)
  - Certificate of Indian Status (paper or plastic card)
  - Registered Indian Record (certified)
  - Valid Canadian Passport or Canadian Passport expired not more than 5 years
  - Permanent Residents / Landed Immigrants
    - Canadian Immigration Identification Card
    - Confirmation of Permanent Residence (IMM 5292)
    - Valid Permanent Resident Card or Permanent Resident Card expired not more than five years
    - Record of Landing (IMM 1000)

### List 2: Proof of Residency

- **Child Tax Benefit Statement**
- **Employer record (pay stub or letter from employer on company letterhead)**
- **Income tax assessment (most recent)**
- **Insurance policy (home, tenant, auto or life)**
- **Monthly mailed bank account statements for savings or checking accounts (does not include receipts, bank books, letters or automated teller receipts)**
- **Mortgage, rental or lease agreement**
- **Ontario Motor Vehicle Permit (plate or vehicle portions)**
- **Property tax bill**
- **School, college or university report card or transcript**
- **Statement of Direct Deposit for Ontario Works or for Ontario Disability Support Program**
- **Statement of Employment Insurance Benefits Paid**
- **Statement of Old Age Security T4A (OAS) or Statement of Canada Pension Plan Benefits T4A(P)**
- **Statement of Registered Retirement Savings Plan (RRSP), Registered Retirement Income Fund (RRIF) or Registered Home Ownership Savings Plan (RHOSP) from a financial institution (bank, trust company, credit union)**
- **Utility bill (phone, internet, cable TV, public utilities commission, hydro, gas, water)**
- **Ontario Driver’s Licence or Temporary Driver’s Licence (only if accompanied by photo licence card with the same address)**
- **Workplace Safety and Insurance Board Statement of Benefits**
- **Your Canada Pension Plan Statement of Contributions**

### List 3: Support of Identity

- **Canadian Immigration Identification Card**
- **Certificate of Canadian Citizenship (plastic card)**
- **Certificate of Indian Status (paper or plastic card)**
- **Confirmation of Permanent Residence (IMM 5292)**
- **Credit card**
- **Current employee ID**
- **Current professional association licence**
- **Old Age Security card**
- **Ontario Motor Vehicle Permit (plate portion)**
- **Passport (Canadian or foreign)**
- **Permanent Resident Card**
- **Record of Landing (IMM 1000)**
- **Student ID card**
- **Union card**
- **Valid Ontario Driver’s Licence or Temporary Driver’s Licence**

### Need more information?
For Health Card Services OHIP locations, check the blue pages of your phone book under ServiceOntario or Health or call:
- 1 800 268-1154 (Ontario only)
- 416 314-5518 (Toronto only)
- 1 800 367-5555 (for TTY)
or visit our website at:
[www.health.gov.on.ca](http://www.health.gov.on.ca)
Note. British Columbia residents applying for a replacement health card (or CareCard) can use an online form available on the Medical Services Plan (MSP) website. The web form is simple and straightforward, and it also does not require the submission of additional documentation.
Neoliberal doctrine may be seen in the process through which the state apparatus both seeks to expand and centralize its underlying power base. In Canada, conservative ideologies have increasingly driven provincial health care policy and directives in recent years. One example is the current federal government’s insertion into the discourse surrounding the implementation of harm-reduction programs in the treatment of drug addiction. Governmental linkages of power and authority are linear and hierarchical. A recent landmark court case revealed the extent to which the federal government is willing to assert its political ideologies in the implementation of provincial mandates. In 2011, the Ministry of Health Canada (under the auspices of the federal Conservative government) appealed to the Supreme Court of Canada to transfer management of Insite (a safe injection site located in Vancouver’s Lower East Side) to federal government jurisdiction, rather than provincial jurisdiction. The Supreme Court rejected the appeal. This case revealed the lineages of power and authority inherent to bureaucratic governance. Harm-reduction advocates applauded the Supreme Court decision (which supported continued operation of Insite under provincial, rather than federal, jurisdiction, and which therefore ultimately supported continued operation of Insite). Health advocates in both Canada and the United States have continued to confront neoliberal policies and directives in recent decades, all of which are often grounded far more in issues of control and power than they are in evidence-based research or socially democratic principles.

Few individuals are privy to the regulatory planning associated with OHIP, the Health Act, or other health care mandates generated by the Ministry of Health Canada. Bureaucratic organizations rely heavily on templates, form letters, and legal documents in managing the health

34 The Harper government is ideologically opposed to Insite’s harm-reduction model of decreasing adverse health consequences of drug use, without requiring abstinence from drug use.
needs of the public. These documents are created in settings outside of the everyday experiences of individuals seeking primary health care in local settings. Legislation is passed down from one entity to another, and, over time, acts and policies passed down in one setting inevitably impact people’s lives across other, or more distant, settings. Although provincial jurisdiction permits the Ontario government to determine and implement the health care policies deemed best for its citizens, provinces are dependent upon federal cash contributions in order to supplement provincial health costs. The Ontario Health Insurance Plan is governed by the Health Insurance Act, which in turn, is mandated by the Ministry of Health Canada. Thus, an extensive and hierarchical lineage of governmental control governs health care policy and implementation in Ontario, Canada today. Neoliberal ideologies are increasingly evident in health care policies and directives, as the linear lineages of political control pass these ideologies from one governmental level to another.

Text-based identification cards wield considerable regulatory power and control over individuals throughout the course of their lives. Government and private organizations require government-issued identification as a prerequisite for securing housing, opening bank accounts, or obtaining health cards. Sean, one interviewee, understood that valid identification personified and actuated his existence in the world: “Documentation is important for a lot of people. It shows their existence. ’Cause they’re always losing their ID. Out of the people I know right now, and I’m saying a small group of just say 20, approximately 12 to 14 of them are missing their ID. The other percentage has one piece of an ID, or a part of an ID, so they’re still not in the system. They are more out of it.” Text-based documents exerted considerable regulatory power and control over individuals interviewed in this study. Many interviewees found it difficult to overcome the text-based regulatory processes governing the acquisition of personal identification
documents. For example, the health card registration process often included locating an OHIP-approved agency, receiving an agency document, submitting the agency document in person to an OHIP office, fulfilling the digital photograph renewal requirement at the OHIP office, and arranging for the health card to be mailed to a proxy address. For Sean, documentation not only wielded considerable power and control over individuals, but such documentation also held the power either to provide or deny services to individuals seeking access to such services.

Many participants interviewed in this study lacked an Ontario Health Insurance card, or they expressed little interest in acquiring one. Allan, for example, had no health card in his possession, although he stored a “sheet” (most likely an agency letter or a temporary OHIP statement) in a mailbox at a local drop-in centre. When asked why he didn’t use his sheet to obtain the services of a family doctor, Allan articulated his place within the complex and pervasive ruling apparatus of the Ontario health care system: “When she [the doctor] sees my sheet, she wouldn’t take care of me, as she does for you. As soon as she sees that sheet, I get half the attention that you get.” Allan perceived the sheet as a reflection of his marginalized social standing and his lack of economic status. For Allan, the sheet both represented and instigated the use of regulatory power: it operationalized the activities, actions, and intentions of others, while it also diminished his own sense of social entitlement. However, although Allan grasped the limitations inherent to rendering a sheet (rather than a health card), he nevertheless avoided seeking reissuance of his previous card. Increased or tightened regulations have dissuaded Allan from seeking health card reissuance. In oblique, although entirely traceable ways, neoliberal, policies (designed to reduce fraud and address health costs) have mediated Allan’s choices regarding acquisition of a health card. He has elected to avoid increased regulatory demands and
instead to render only a sheet (which he nevertheless views as stigmatizing) when seeking health care.

The bureaucratic process of repeatedly obtaining replacement identification proved onerous for many individuals interviewed at the Open Access shelter. Participants in this study used OHIP-approved agencies (also known as kiosks or ID clinics) to obtain agency letters in lieu of providing documentation determining citizenship and residency. Participants commonly referred to these official letters as “affidavits.” Mac, one interviewee, explained that counsellors working at OHIP-approved agencies assisted individuals with this process: “What the deal is, basically, if you’re homeless, and you don't have a lot of ID, as long as one of the counsellors knows you, they will actually sign an affidavit for you, and you can use that as ID to get the health card, and then they [OHIP] mail that to you at your shelter, and three weeks later you can get it back at your shelter.” There is no centralized OHIP-approved agency in Toronto, and many interviewees discussed “looking out for” travelling agencies temporarily located at certain local drop-in centres. Maria, another interviewee, explained that a significant portion of her day was often spent in the search for an agency: “They move all over the place. Sometimes they will be at this drop-in or this drop-in on a certain day, so you just have to figure out… walking, and if it’s raining or snowing, you’re screwed.” Maria had lost her identification cards on numerous occasions in recent months, and she was therefore well acquainted with both the health-card replacement process and the search for OHIP-approved agencies.

Interaction with OHIP-approved agencies added another layer of bureaucracy to the already complex and bureaucratic nature of obtaining health insurance. The use of agency letters may also limit the period of time in which subsequently issued health cards are viewed as valid. This, in turn, increases the number of times individuals need to reapply for replacement health
cards. For example, an applicant who uses an agency letter to confirm citizenship will receive a health card that is valid for only a one-year period, following which time the applicant must provide original citizenship documentation in order to obtain a card with the three to five-year standardized expiry date. Individuals who use OHIP-approved agencies are required to bring paperwork to OHIP in person. Allan is unable to receive a reissued health care card, as he has avoided visiting OHIP: “Oh, yes, you had to wait in line for three hours. I know. I know. I was down there too, but I said you’re not catching me in that line up. It’s like you’re in an aquarium.”

Additional bureaucratic processes and related paperwork considerably prolong the institutionally mediated health card replacement process. Lyle’s wallet was stolen six weeks ago at an Open Access shelter when he had inadvertently left his knapsack unattended. Prohibitive line-ups at an OHIP-approved agency had discouraged Lyle from reapplying for a new health card during the past few weeks. The use of agencies not only prolongs the institutionally mediated waiting period incurred when employing this approach, but it also ensures only short-term solutions to long-term accessibility issues. Mac, another interviewee, relied heavily upon OHIP-approved agencies and was unmotivated to explore other options when seeking replacement identification. Locating agencies on a consistent basis has nevertheless proved problematic for him. Mac was waiting for a travelling agency to make its yearly rounds to his local drop-in centre: “You just wait until you find out where the next kiosk is. At the Meeting Place, they have them once a year, because they have them all over the city. There may be one next month, but it may be in Scarborough or Mississauga. I guess it’s about a year until it makes it back.” Mac appeared resigned to the inevitability of this prolonged waiting process.

Many interviewees observed that increased regulatory, bureaucratic demands had been exacted in more intractable and challenging ways in recent years. Lynn, for example, discussed
recent increases in bureaucracy: “I think it’s just the bureaucracy. Follow the paper trail. You need this to get that. You used to be able to open a bank account with just one piece of ID. You can’t even do that anymore. The OHIP card – the only place that will take you without the OHIP card is St. Mike’s, and I think that drop-in clinic, I’m not sure. But pretty much other than that you’re SOL [shit outta luck] if you don’t have a health card.” Mac, another interviewee, no longer had a health card in his possession: “It’s become a little bit harder. I guess, back in the day, you could go in and basically if you knew your number you were good. But now they have the magnetic strip and everything’s on that. They’re into this new mentality. They have a set of rules that they have to follow. If you don’t have a card that they can swipe, sorry, we don’t have procedures for people without health cards. Here’s where you can get one. OK, yeah. Back to that place again, right?” Mac spends the warmer months in an off-the-grid\textsuperscript{35} home located in a nearby wooden ravine: “There’s all kinds of construction up there so it’s basically almost the size of a car - plywood, pink Styrofoam installation, and more plywood.” Mac’s home does not constitute Ontario residency: “They [OHIP representatives] actually want you to have stuff to prove your address, because they mail it to your address. So if you go in there and say, ‘Hey, I’m a homeless guy.’ ‘Well,’ they say… ‘We don’t do pick-ups. We mail it to your address. So… Next!’ Right? ...You know, ’cause it’s just some lady. It’s not like, you know, she can change the rules or make exceptions. She basically has to do what she has to do, and one of the things is that they mail them out to you. Yeah, most street people don’t bother with anything over there [OHIP office].”

Neoliberal ideologies (explicitly expressed as efforts to reduce costs and increase accountability) have instigated a drive to implement highly effective, computerized, regulatory

\textsuperscript{35} The term off-the-grid refers to living in a self-sufficient manner, without relying on the use of public utilities.
encoding systems in government-issued health cards. Such systems ensure that the process of health card reissuance remains efficient, standardized, and resistant to fraudulent applications. The version code is an essential regulatory element of the health card. Mick has been homeless for twenty years, and he has lost his health card on numerous occasions. Although his card number remained the same, the version code (two letters following the card number) has changed each time his card has been reissued. As Mick often chose not to carry his card on his person, he had wisely memorized his health card number. However, Mick had difficulties remembering the version code, as this security code changed each time his health card was lost or stolen. “I know my OHIP health card in my head. Because I don’t have it, I’ll memorize the number in my head. Because I don’t always have it. I try to remember as much as I can in my head… I always forget the two numbers on the end [the version code]. That always changes.” The drive to implement cost reduction, anti-fraud measures has undoubtedly yielded increased bureaucratic regulatory controls associated with OHIP approval. Mick, like many other participants in this study, struggled to cope with these increased regulatory controls.

This study sought to make visible not only the impact of broader neoliberal ideologies upon the everyday lives of people, but also the ways in which such ideologies have influenced current political thinking regarding social welfare spending. Marx and Engels (1867/1996) argued that capitalism produces inequality of wealth and power. Little has changed over the past century. Harvey (2007) writes that neoliberal policies and practices reflect a deeper penetration of capitalism into political and social institutions, and that such trends have infiltrated our cultural consciousness. Women, children, minorities, and low-income earners largely shoulder the social consequences of neoliberal ideologies (Harvey, 2007, p. 170). In particular, lower-class women working in contractual, disposable, and flexible jobs (e.g., the service industry, care
work, and the sex trade) suffer from reductions to social welfare support systems (p. 170). Neoliberal conservative policies and practices are designed both to promote private enterprise and reduce social welfare expenditures. As such, they benefit the wealthy and marginalize the poor. Chomsky (2007) sees such policies and practices as inherently grounded in issues of wealth and power: “one conclusion seems fairly clear: the approved doctrines are crafted for reasons of power and profit” (p. 39). Neoliberalism benefits a select few in society. Wealthy individuals can purchase seductive consumer goods, which contribute to their sense of identity, worth, and entitlement in society, while those without economic means find themselves at greater risk of exploitation and marginalization.

For participants in this study, neoliberal policies and practices have done little either to improve the quality of their lives or their access to health care. It is the poor who have largely shouldered the social welfare detriments inherent to the cost-effective restructuring of public health care, privatization of public entities, and the reduction of welfare spending. Tightened institutional policies, practices, and regulations (designed to reduce fraud and increase accountability) had considerable impact upon interviewees’ attempts to access health care. Approximately 50% of participants interviewed in this study (13 out of 27 individuals) either did not possess a health card, or were unmotivated to acquire one. Interviewees who had access to health cards (either in storage or on their physical person) often chose not to access services covered by OHIP and instead gravitated towards informal health services, such as those offered by the Rotary Health Bus. The Rotary Health Bus does not require the rendering of a valid health card. For example, Sean possessed a health card but preferred informal health care services. He was able to articulate why he, and many of his associates, shunned mainstream health care institutions: “Most of these people [in the Open Access shelter] don’t have the tolerance or
capability to go through application after application. Even if you go to the doctor, you have to fill out some kind of application, some kind of medical form again, some kind of a history.”

Informal services are non-invasive, inclusive, patient-friendly, and do not require the need for the completion of lengthy paperwork or the rendering of proof of identification. The current Ontario provincial government continues to promote policies designed to reduce welfare spending and implement cost-cutting measures. However, the impact of neoliberal reform has had a significant impact upon the health and wellbeing of vulnerable individuals in Toronto. In particular, regulatory, cost-cutting, accountability measures have not only undermined the moral purposes of universal care, but such measures have also impacted vulnerable individuals’ access to effective health care.
When you’re poor and on disability they only want to check your blood pressure to see when you’re going to keel over. They want to know how long it’s going to be. The synopsis is, when you’re poor, you’re in a basket. So what? So what? You got no life anyway. You’re just poor. So what?

Allan, Interviewee

The first-hand, personal accounts provided by interviewees in this study highlighted the complex nature of exclusion from mainstream health care services. Many individuals perceived themselves as “pushed out” or excluded by the structures of health care services that purported to support and service them. However, individuals interviewed in this study were also active agents in a complex, mutually accepted form of exclusion (referred to as mutually established exclusion throughout this thesis). Mutually established exclusion refers to the ways in which individuals both “dropped out” and were “pushed out” by the structures of health care policies and regulatory processes that may serve to promote unequal access to health care intentionally or otherwise. In this study, mutually established exclusion was evidenced not only in the ways in which interviewees chose to withdraw either partially or fully from multilayered, bureaucratic governance and mainstream health care services, but also in the ways in which mainstream health care institutions either discouraged or hindered interviewees’ attempts to access such services. Many individuals in this study perceived health care institutions as exerting power and control, and they subsequently attempted to subvert, avoid, or redirect this imposed control by
dropping out, or opting out, of such institutions. A number of interviewees either implicitly or explicitly excluded themselves from participation in programs and services that, although useful to them, might otherwise have been seen to regulate, control, and thereby subordinate their interests to those of the dominant institution.

Health care in Ontario is a multi-layered entity. Wealthy individuals are able to finance private, exclusive, and highly personalized health care, which remains largely inaccessible to the vast majority of individuals. Medcan is one example of a “private and executive” top-tiered health provider located in Toronto that offers “head-to-toe” health services for approximately $2495 per visit (Medcan, 2012). Patients commit to five hours of micro-managed health care, performed at approximately 12 preventive health stations, each operated by a team of medical specialists (see Figure 10). Services include: ankle brachial indexes, fitness appraisals, nutrition evaluations, hearing and vision tests, pulmonary lung test, and chiropractic and massage therapy. Patients’ test results are tracked and monitored on an ongoing basis. Results are emailed to both patients and their general practitioners in preparation for further follow-up. Individuals who can afford private health care services support a specific ideology regarding how they administer, manage, and govern their health care: an ideology that encompasses entitlement, self-value, and personal empowerment in regards to their overall health and wellbeing. Medcan is only one of a number of private clinics successfully operating in Canada, which are supported by payments obtained from individuals or corporations (as opposed to mainstream health care, which is financed by the Ontario Insurance Plan). Private, for-profit executive health care providers such as Medcan offer select individuals top-level health care services. Such services remain in sharp contrast to free, informal health care services offered in drop-in shelters or the Rotary Health Bus (see Figure 11), although ironically, like the Rotary Health Bus, Medcan does not require that a
valid health card is presented before treatment is initiated.
Figure 10: Private and Executive Health Care.

Note. Medcan offers private and executive health care services, with an emphasis on preventive care. Medcan’s “head-to-toe” health services total $2495 per visit (Medcan, 2012).
Figure 11: Free Health Care Services Available on The Rotary Health Bus.

Note. The Health Bus offers free nursing care, hygiene supplies, information and referral health care services, with an emphasis on not needing a health card.
Charitable, non-profit organizations do not require completion of lengthy paperwork or the verification of health insurance. Individuals in this study often gravitated towards flexible, casual, non-bureaucratic health care that exists outside of standardized, mainstream services. While many interviewees expressed difficulties obtaining OHIP health cards, others had little interest in obtaining cards and had actively withdrawn from mainstream health services. Sixty-six percent of interviewees (18 out of 27 individuals) consistently chose informal health care or emergency room services (as opposed to seeking either family-physician or specialist care). Among those interviewees without health cards, approximately 4 out of 13 individuals indicated that they had no plans to seek reissuance of their health cards. Among those interviewees with access to health cards (either on their actual person or stored at a local drop-in centre), 9 out of 14 individuals preferred either emergency room or informal care services, and they did not use their health cards to access regular, preventive, or specialist care. In the event of a pressing illness or injury, many individuals in this study relied upon informal nursing stations situated in churches and drop-in centres, none of which requires completion of lengthy paperwork or the rendering of proof of identification.

Allan, one study participant, had been homeless for three months, and although he had no valid OHIP health card, he was not currently seeking OHIP coverage. Allan discussed why he avoided visiting conventional doctors located in mainstream health settings: “When you’re poor, all they want to know is how high your blood pressure is. They’re waiting to see how long until you keel over. So what? You got no life anyway. You’re just poor.” His views regarding the Ontario health system were unequivocal: he saw the Ontario system as two-tiered and unjust, consisting of one system that services professional working people, and a second, somewhat inferior, system that services those on social assistance programs. Allan explained: “They tend to
want to shoo you away. They look at you as scatterbrains or crazy.” Interviewees often encountered negative experiences when attempting to obtain mainstream care in institutional health care settings. A number discussed negative or judgmental reception in health care settings, which they largely attributed either to their unkempt appearance or their apparent homeless status. Many also attributed the difficulties they encountered when accessing health care services both to increased institutional, bureaucratic demands and the intimidating presence of security personnel.

For many interviewees, an unkempt appearance exacerbated their difficulties. Peter (who was waiting for a new health card to be forwarded to a mailbox at his local shelter) discussed the need to appear presentable before visiting a mainstream health clinic, particularly as he was unable to render a valid health card. When asked if it has been harder or easier to obtain care in recent years, Peter responded: “It’s harder now. There is way more rejection, way more. It takes me 15 minutes to clean myself so I can go into a clinic to be presentable. But there are no showers at this shelter. I am disrespected when I go to a doctor. They have dissed me. I know it.” Peter maintained that all Canadian residents, even those without a health card in their possession, should receive equal access to health care: “There should be equality for all, even if you’re homeless. All OHIP people should be taken care of, even if you don’t have a physical card.”

A number of interviewees often found the security presence in institutional settings intimidating. For example, Mick’s experiences in hospital emergency rooms have been largely negative, due to unwelcome interactions with security personnel. For Mick, despite having legitimate reasons for seeking emergency services, a disheveled appearance has resulted in security personnel singling him out for expulsion: “Usually it’s security who gives me a hard time if I’m just sitting there waiting, and waiting, and waiting with everyone else. I don’t like
security guards… They say: ‘You’re still waiting. You’re still waiting.’ I’m not going to go outside bleeding, just to keep your little room cleaner.” When asked why security personnel targeted him specifically, Mick surmised: “They [security personnel] think I’m there to abuse the system.” Participants used a variety of informal health care services, including church drop-in centres, informal nursing stations, and travelling health buses, as these settings were not monitored by extensive security services. There were valid and compelling reasons for selecting informal, rather than mainstream services. Sean provided a persuasive argument for the use of informal health care services:

I know a lot of the people here, and I’ve talked to them, [they] don’t like going there [emergency rooms] because there’s a security presence in there that intimidates them. For some of these people, they fade in, fade out. Hygienically they aren’t smelling the best, or looking the best. People are putting them down. It’s a morale-type thing, so they don’t want to go there. The only thing they have to work with are the vans [travelling health buses]. They’ll do a cleaning or put a bandage on it. There are two levels of society, and unfortunately they’re not involved in the first one. The first one is always going to step on people, and it’s usually them. Treatments that they need – emotional, psychological, mental – it’s not available. They’re insecure.

Sean maintained a vocal and influential presence at the shelter. Although he had a health card in his possession, he was a strong advocate of informal health care services, due to both the decreased emphasis on bureaucratic paperwork and the lack of intimidating security personnel found in such settings.

The onerous and relentless nature of lifework was a pervasive theme that emerged
throughout many discussions with interviewees. Lynn explained that she often forgot important appointments, due to the chaotic nature of her everyday lifework: “Yeah, if you could just drop-in that would be great. I have a hard time keeping my appointments. ’Cause I have enough shit to remember everyday. Then you forget what day it is sometimes, so you lose track.” Tanya, another interviewee, saw little use in obtaining a health card when living on the street: “I don’t really want one. When everything else gets settled, I will think about it. But day-to-day, when you are on the street, you can’t really think about that. Like a health card, what am I gonna do with that?” Eric discussed the constant search for food and showering facilities that constituted much of his daily lifework: “I may not eat lunch - sometimes I’ll go to another drop-in to eat lunch. Like today there is a place on Church where you can have a shower. Showers are big – like finding a place to have a shower. Then I make my way to the next Open Access and eat around 5:00. It takes up your day.” For many individuals, basic survival lifework (securing food and shelter) took precedence over attempts to obtain ongoing health care. Mick also often went without food during the day:

I’ll eat during the morning and that will be it for the day. I’ll find food if I can find it.

Usually I just eat during the day, and at night I go without. The ones [vans] that are at night – you have to be at a certain spot, ’cause there are vans that go around, but they are not always reliable. If I am nowhere near the vans, I just say, forget it. I’ll say OK, I won’t be eating until tomorrow, and I’ll just go to sleep.

Although exclusion from mainstream health care services was commonplace throughout interviewees’ first-hand accounts, so too were themes of noncompliance and withdrawal. While participants in this study discussed their sense of exclusion from mainstream health benefits and
programs, many individuals also discussed their self-imposed withdrawal from multi-layered, bureaucratic governance. These individuals avoided participating in regulatory processes, such as completing paperwork, obtaining identification, and complying with scheduled timelines. Dennis had been denied mainstream health care in the past, due to having an expired health card: “I didn’t know that it had expired, so I couldn’t get treatment at that moment. And the nurse says, ‘No, you can’t, ’cause you’d have to pay for it.’ So, they says, ‘Go to this place.’ And they gave me the address, so I went there. They paid for my health card. And I went to the health card place with my little slip of paper, and they said, ‘OK, that’s the temporary number.’ You’re covered. You’re paid for. You see it’s all about the money. I was kind of mad.” Dennis has since surrendered any attempts to maintain a valid health card.

Many individuals had chosen to ignore, avoid, or circumvent bureaucratic or regulatory health care demands, and thus had abandoned efforts to receive fully insured health care. Tanya had withdrawn from mainstream health care services, as the regulatory demands exacted by such services discouraged her compliance. Although Mick had access to a health card in a storage locker, he often avoided seeking bureaucratic health care services: “If I get sick, I just rest and make sure I’m warm. I only see a doctor if I’m bleeding or broken.” Mick sprained his foot on three occasions last winter while walking on black ice. However, he chose to forgo medical assistance, and he instead chose to sleep off his injury on the streets of downtown Toronto: “I didn’t go anywhere. I found a place to stay down for a couple of days. I gathered some food and stayed put for two to three days. When I felt better, I walked around.” Both Tanya and Mick had

36 There is no fee for health cards in Ontario. However, applicants must pay a fee in order to receive replacement documentation to support citizenship (e.g., a replacement Canadian SIN card costs $10 or a replacement birth certificate costs $35). Dennis likely used an agency letter in lieu of providing supporting documentation. An applicant who uses an agency letter in lieu of citizenship documentation will receive a health card that is valid for only a one-year period, following which time the applicant must provide original citizenship documentation in order to obtain a card with the three to five-year standardized expiry date.
chosen to withdraw from mainstream health care services. Tanya saw little use for a health card while frequenting shelters, and Mick more often favoured sleeping off his ailments on the streets.

Participants who had disengaged from institutional processes were nevertheless able to function adequately outside the mainstream apparatus. Ben, for example, had no health card, nor did he use a bank account to manage his ODSP [Ontario Disability Support Program] payments: “You know what I have to do with my disability cheque? There’s a lovely old man, there’s two of them actually. They’re brothers. They run a convenience store. You know what? As soon as I get my cheque, I’m so fucking irresponsible, I have to give him my money, because I trust him.” When asked if he could use a health card, Ben explained: “I can’t even do my income taxes. Well, I could. But I don’t even care.” Ben had no interest in seeking ways to improve bureaucratic organizations that purport to assist him. When asked how the system could be made better for him, Ben paused briefly before replying: “Honestly, I don’t have a frigg’n clue. You want me to lie to you? You want me to give you a song and dance?” Ben has abandoned any attempts to access mainstream health care services. When asked if would use a health card if he had one, Ben responded: “I’m not sure. I haven’t got to that.” Ben operates successfully outside the confines of mainstream institutional processes, and he expressed little interest in realigning himself with these processes.

Informal drop-in health services such as those offered by church run or non-profit organizations, although favoured by many individuals interviewed in this study, provided only limited care. Individuals who opted out of mainstream health care instead chose to frequent informal health services such as those offered by church-run or non-profit drop-in organizations. Although informal health providers do not necessitate the completion of onerous paperwork or the verification of health insurance, most informal providers offer only basic nursing care, such
as hygiene or bandaging services. Dennis had no health card in his possession, nor was he planning to acquire one in the near future. Although the care he received in informal settings was basic (rather than ongoing, diagnostic, or specialized), he remained satisfied with such care:

“And there’s nurses and doctors we see on the street. I don’t know who they work for. There’s one lady who is retired who works there every Friday. I met her in a drop-in. I saw a sign that said, ‘The doctor is in’. So I spoke to a guy who knows me from many years ago. And I said, ‘Do I have to have a health card?’ And they says, ‘No.’ So, I told her my problem, and she gives me some cough candies.” Acts of non-compliance, avoidance, or resistance have significant consequences for individuals. The decision to obtain medical services only in the event of an emergency, and to avoid or resist ongoing or mainstream care, meant that all attempts to secure preventive or comprehensive care have been largely abandoned.

The non-bureaucratic nature of the Open Access shelter appealed to individuals seeking admission to flexible and non-regulatory programs and services. Unlike other shelters that require guests to complete paperwork or show valid identification, the Open Access shelter has no prerequisites to access. Anyone can use the Open Access shelter, and the use of pseudonyms is also permitted. The non-bureaucratic nature of the shelter perhaps narrowed the participant group recruited for this study, as individuals who specifically preferred non-governmental and non-regulatory shelters naturally gravitated to Open Access. It is feasible to assume interviewees drawn from a more bureaucratic institution may have represented a cohort more compliant with bureaucratic or governmental controls than those found at Open Access, and therefore more motivated to comply with governmental or regulatory prerequisites to health care. Dennis explained that he avoids homeless shelters that require identification as a prerequisite to access:

“But like here [Open Access] they say, ‘What’s your name? Dennis? Here’s your ticket for the
supper. Here’s your ticket for the meal.” If you go to the Sally Anne to get a place to stay, you have to give a health card number, and you have to sign a release of information. Now, they want to know the last time you had a poop, and everything else, and I’m not telling them that. If you’re a nurse or a doctor, then I have to give you permission to go and check it. So when you want to get a bed, you have to go through murder. They’re all about numbers.” When asked what happens if he is unable or unwilling to show proof of identification, Dennis explained: “You don’t get a bed then, unless you got a birth certificate and a driver’s license, and a passport and all that other stuff. They say this: ‘Do you have government photo ID?’ Most people don’t have a driver’s license. And I say, ‘I don’t have to give it to you by law. You’re not a doctor.’ And they say, ‘Sorry, I can’t help you.’ But they don’t say it blunt outright. They say you have a choice. They don’t say, ‘Give me the number.’ If I brought you there as a counsellor, you would freak right out at what they say.”

Dennis’ discussion explicates the complicated nature of engagement with institutional entities. Dennis understands his place within institutional organizations, and his right to assume or surrender that place. The organization exerts power and control, and Dennis confronts, negates, or subverts this imposed control by dropping out of the organization. Many individuals in this study excluded themselves from participation in programs and services that, despite being useful to them, might ultimately be viewed as wielding intrusive control. Dennis’ lack of valid identification (and his refusal either to obtain or show identification) not only limited his access to certain shelters and mainstream health services, it also limited his access to a variety of other governmental services that might be advantageous to him. When asked how long he had been living at Open Access, Dennis was quick to establish his independence: “I don’t live here. I live on the streets.” Dennis’ withdrawal from mainstream health care services limited his options and
narrowed the range of services available to him. Dennis nevertheless remained independent and resilient, and, in many ways, personally empowered.

The notion of empowerment is an essential component of Freirean philosophy. Freire’s message of self-empowerment encouraged individuals to resist domination and oppression perpetuated by governmental organizations and large corporations through collective organization, power sharing, and collegiality. Giroux (1987) argues self-empowerment is often realized by the acquisition of critical, analytical skills that encourage individuals to examine and assess the socially and institutionally mediated nature of their everyday experience in critical ways (p. 6). Dennis understood both the institutionally mediated nature of his everyday experiences and the intrusive nature of the regulatory processes exacted by institutional entities. Drydyk (2006) asserts that empowerment results in active agency, in which individuals promote autonomous decision-making, as opposed to passive acceptance of the decisions of others (p. 13). Mick and Tanya, although potentially disadvantaged by their self-removal from mainstream health care services, nevertheless demonstrated both autonomous decision-making and active agency (as opposed to accepting the decisions of others and passively engaging in the services and programs promoted by others).

Empowerment is a complex, culturally grounded, and value-laden notion, which has radically different meanings for different members of society. In this study, personal empowerment was evidenced in individuals’ active withdrawal or disengagement from institutional health care processes. Many interviewees chose not to carry essential identification on their person, and instead chose to store their identification in a security locker at a shelter. Only 26% of individuals (7 out of 27 individuals) had a health card on their actual person. Mick, for example, stored his identification at a local drop-in centre, in an effort to avoid being tracked
or monitored by the Canadian Police Information Centre: “People don’t care about having ID, because if they don’t have ID, they can’t get c-picked… Checked out by the police. CPIC [the Canadian Police Information Centre]. It’s an actual acronym. You can give any name you want. Since you don’t have anything with your name on it, they have to believe you. And if they don’t believe you, they know you by sight. Then you’re SOL [shit outta luck]. But if they don’t know you, and you don’t have any ID, you can just say you’re Joe Blow. They don’t know.” Mick not only avoids being controlled, tracked, or monitored by authoritative entities by choosing not to carry personal identification documents, but he also feels that he gains increased autonomy and self-reliance through such acts of non-compliance. However, without valid identification, Mick is unable to receive fully insured, mainstream health care. This is a price he appears willing to pay.

The findings from this study, drawn from explicit information provided by homeless participants, indicate that health care organizations may unwittingly operate to exclude or marginalize those whom they claim both to serve and assist. Interviewees discussed encountering negative experiences when attempting to obtain mainstream care in institutional health care settings, which they attributed both to their unkempt appearance and their lack of a fixed address. Many interviewees discussed being stymied by obstructive or discouraging bureaucratic demands, while others discussed the intimidating presence of security personnel. While many interviewees expressed difficulties obtaining OHIP health cards, others had actively withdrawn from organized health services. Many individuals chose informal and non-profit health services such as those offered by travelling health buses. Charitable, non-profit organizations do not necessitate the completion of lengthy paperwork or the verification of health insurance. The modes of non-compliance discussed by individuals at the Open Access shelter highlighted the
complex nature of self-imposed exclusion from mainstream health care services. In this study, individuals who “dropped out” of mainstream institutional processes often framed their resistance as a response to differential and unequal treatment in society. However, those who “dropped out” of mainstream health care services may equally be seen as having been pushed out by health care policies that institutionalize and perpetuate unequal access to services. Those who actively dropped out of mainstream institutional health care services may perhaps be viewed as refusing to be subordinated by the vast and complex relations of ruling inherent to institutional entities. Mick, for example, gains a sense of empowerment when he forgoes the care of emergency hospital services in favor of a sheltered stairwell. Yet empowerment is never absolute. Mick’s sense of empowerment was limited, if not somewhat self-defeating. When asked if he would ever like a health check up, Mick paused briefly before answering: “No. If I’m sick, I don’t want to know. I’d rather die ignorant.” One overarching aim of socially just health care policy aims to protect and support the most vulnerable and marginalized among us. This aim is facilitated by the provision of effective and equal access to social benefits. This study highlights not only the institutionally mediated inequality of access to health care services, but it also highlights the unsettling resistance to services expressed by those most in need of such assistance.
Chapter 9

Conclusion

Things for me are progressing. The more normal you look and the more active you are in the normal mainstream, the more people treat you better. You gotta go with the normal. I feel better for myself, which makes me progress even more.

Tanya, Interviewee

Summary of Research

This study is grounded in institutional ethnography, a method of inquiry that provides a means to investigate the organization of the social world through mapping human interactions and activities as they occur within institutional settings. In total, 27 individuals were drawn from one Open Access shelter in Toronto, Ontario. This study found that homeless individuals, unlike their housed counterparts, are perhaps excluded and sidelined by institutional health care policies and practices that may to serve to facilitate and promote unequal access to health care. People were central to this investigation. Interviewees’ first-hand accounts revealed organizational disjunctures or challenges that mediated their everyday experiences. Particular attention was paid to text-based control mechanisms that managed, regulated, and coordinated individuals’ interactions with others in both local and translocal institutional settings. In order to understand these relationships more fully, this study attempted to map the ways in which institutionalized interactions and relationships operate in concert.

The setting of this study took place in an Open Access shelter during the months of February, March, April, and December 2011. In total, 27 participants were drawn from one particular Open Access shelter located in Greater Toronto. Participants were viewed as
knowledgeable informants and co-researchers throughout the course of the study. Individuals provided both anecdotal evidence and examples of texts (agency letters, cards, forms, and documents), all of which were employed to direct the evolving course of this investigation. Many individuals had experienced homelessness for lengthy periods of time. Over time, these individuals had accrued valuable, first-hand, and “ground-up” knowledge regarding access to health care services for homeless individuals in Ontario. This institutional ethnographic study aimed to examine and understand inequities that may exist in gaining access to mainstream health care in Ontario, Canada.

A number of research methods were employed in this study, including interviews, field observation, and text analyses. Although participant observation\(^{37}\) was not extensively employed as a research strategy in this study, the researcher nevertheless participated in everyday activities and routines at the Open Access shelter (e.g., cooking, serving, cleaning). Working in a homeless shelter provided a starting point by which the actualities of life for one group of individuals living without a fixed address were examined. Participants were recruited using a snowball sampling technique, which involved identifying one individual and asking that individual to recruit other members of his or her network of associates. Each interview followed a semi-structured format (main prompting questions, probing where necessary) and spanned approximately 30 minutes to one hour in length. Interview questions served as a framework for exploring potential avenues of discussion and were flexible, open-ended, and fluid in nature. In this study, discussions with interviewees are presented in the form of narrative exhibits.

\(^{37}\) There are two types of participant observation: covert observation and overt observation. An example of covert participant observation in institutional ethnographic research is Timothy Diamond’s (1992) examination of the institutional health care practices evidenced in three nursing homes located in Chicago. Diamond dropped out of academia, trained as a nursing home assistant, and secured employment in three nursing homes. During the period of his employment, he collected data through surreptitiously taking notes on scraps of paper.
Examples of these accounts may be found in Appendix A.

The ways in which texts entered and coordinated individuals’ experiences characterized one main direction of research. During the interview process, interviewees often referenced institutional forms, documents, cards, and letters. These texts may be perceived as modern day technologies of ruling practice, which serve as powerful control devices designed both to coordinate and operationalize the activities of individuals across different locations and times. The close examination of texts undertaken in this study assisted with mapping the organizational power structures that coordinated and directed homeless individuals’ interactions and activities within bureaucratic settings. Throughout the course of this investigation, the examination of texts also provided a springboard for subsequent avenues of research.

**Study Limitations**

Snowball sampling, in which individuals recommend members of their cohort group, offered an effective method to access hard-to-reach populations. This technique nevertheless presented study limitations. Participants tended to recommend members of their own cultural or ethnic groups. While a willing interviewee was never turned away, every effort was made to interview a diversity of participants. A diverse range of ethnically and socio-culturally diverse individuals was interviewed, which included the aged and the young, and the long-term and the newly homeless.

Women were underrepresented in this study. Of the 27 individuals interviewed, only six were female. Locating enough women to constitute a representative sample proved difficult during the course of research. As homeless women are generally not as visible as their male counterparts, their experiences are often underrepresented in the research literature. Although
these six female interviews constituted only a limited sample, their personal accounts were not only compelling, but also served to shed light upon a number of health-related challenges specific to homeless women.

Another limitation of the study concerned the research setting itself. The all-access, inclusive nature of Open Access appealed to individuals seeking admission to non-bureaucratic programs and services. Unlike other shelters that require guests to complete paperwork or to show valid identification, the Open Access shelter has no prerequisites to access. Anyone can use the Open Access shelter, and the use of pseudonyms is also permitted. The non-bureaucratic nature of the shelter narrowed the participant group recruited for this study, as individuals who prefer non-governmental and non-bureaucratic services naturally gravitate to Open Access. It is feasible to assume that if this study were conducted in another institutional setting, findings may reveal both a greater preponderance of health card possession, and a greater tolerance of bureaucracy than that found in the Open Access cohort.

**Study Strengths**

The status of the researcher as both a student and volunteer within the shelter (as opposed to a medical professional) perhaps resulted in interviewees feeling more willing to share their experiences and personal opinions during the interview process. This study also reached a specific population that has not been captured fully in the medical literature. Rather than draw participants from a health care setting, participants were drawn from Open Access, a completely non-institutionalized homeless shelter. Not only did this study capture a unique segment of the homeless population in Toronto, but it also shed light on the essential role of informal health care organizations, many of which are church-run or community funded. Open Access receives only
peripheral government funding, and has secured few, if any, strategic ties with government entities.\(^3\)

This study contributes to the field of both qualitative and quantitative health-related research. Although this institutional ethnographic study was largely qualitative in nature, it nevertheless sought specific quantitative findings. From a medical standpoint, quantitative research studies have traditionally comprised a significant and useful contribution to literature that specifically pertains to the health of underserved populations. Qualitative ethnographic research, however, brings another dimension to research studies in this field, particularly as in ethnographic study, individuals maintain an active and integral voice in the research and academic scholarship that purports to represent them.

**Significant Findings**

This study revealed the impact of broader neoliberal ideologies upon the everyday lives of people. The fundamental underpinnings of neoliberal doctrine include the reduction of social services and welfare benefits, the promotion of free-market competition, and the facilitation of an economy in which autonomous producers and consumers drive growth. This study also explicated the ways in which such ideologies have influenced current political thinking regarding social welfare. Neoliberal doctrines have also been evidenced in recent health care reforms, which have included reduction in welfare spending and social subsidies, centralization of federal power and authority over provincial mandates, and the implementation of high-tech computerized monitoring and management systems designed to reduce fraudulent access to

\(^{38}\) Open Access receives the majority of its funding from community members, and only Dixon Hall overnight security staff is funded by the government.
health care. Findings from this study indicated that the introduction of neoliberal policies and directives into the political agenda has not only created significant economic hardships for marginalized individuals, but has also mediated the social determinants of health for marginalized groups. Although neoliberal doctrines are created and operationalized in translocal (and often invisible) settings, such doctrines have significantly impacted the everyday lives of marginalized individuals.

A number of quantitative results emerged at the conclusion of this research study. Findings suggest that a significant number of homeless individuals do not have health cards in their possession. Approximately 50% of participants interviewed (13 out of 27 individuals) did not possess a physical health card, and only 26% of participants interviewed (7 out of 27 individuals) had a physical health card on their actual person. Individuals with no physical health card had either experienced difficulties obtaining a new health card or they expressed no interest in acquiring one. In the event of a pressing illness or injury, many individuals visited a hospital emergency room, or relied upon informal nursing stations situated at churches and drop-in centres, neither of which necessitated the use of a valid health card.

It should be noted that a significant number of interviewees managed at least one life-threatening health need. Approximately 40% of participants interviewed (11 out of 27 individuals) discussed managing either one or a number of the following conditions: HIV, hepatitis C, liver disease, cancer, diabetes, heart disease, emphysema, or long-term drug and alcohol addiction. Participants also discussed unaddressed dental issues, as few welfare subsidies are available to treat dental problems. Dental problems must be subsumed and subsequently treated under a standardized (and governmentally insurable) list of emergency dental complaints. As Ontario Works in Toronto will not insure dental fillings, crowns, or dental fillings, the only
option available to individuals is full extraction of damaged or infected teeth. Many interviewees required follow-up or specialized medical and dental care, which was difficult to obtain without the proper identification or paperwork (e.g., valid health card, identity documentation, drug card, or Ontario Works cheque stub).

Participants in this study often discussed self-initiated withdrawal from mainstream health care services. Individuals participated as active agents in a complex, mutually tolerated form of exclusion, which was referred to as “mutually established exclusion” throughout this thesis. Individuals who had actively withdrawn or disengaged from institutional health care processes often perceived themselves as personally empowered, self-reliant, autonomous decision-makers. Mutually established exclusion was evidenced in individuals’ preference for either partial or full withdrawal from multi-layered, bureaucratic governance. Individuals who had disengaged from institutional processes were nevertheless able to function adequately outside the mainstream ruling apparatus. Individuals who had chosen to opt out of mainstream health care services received limited care from informal health providers operating in non-profit travelling buses or church drop-in centres. Opting out of mainstream services was not without consequences: individuals received only basic health care from informal health care stations, as opposed to comprehensive, ongoing or diagnostic care.

The onerous nature of lifework was a pervasive theme that emerged throughout many discussions with interviewees. Lifework is defined as everyday survival activities. For example, individuals often crisscrossed the city in order to shower, shave, do laundry, obtain emergency health or dental care, use the telephone or Internet, retrieve belongings from storage facilities, and relocate lost or stolen identification or paperwork. Individuals’ lifework was often made more difficult by the lack of both a fixed address and personal identification. An essential
component to lifework is health work, or the management of health care needs. Individuals’
capacity to manage both lifework and health work hinged not only upon their ability to read,
write, or use a computer, but also it hinged upon their ability to remain “hooked up” to complex
organizational systems.

This institutional ethnographic study revealed that health care is a multi-layered entity,
which includes both standardized, mainstream care and informal, charity-run care. Many
participants in this study did not seek routine care from mainstream health care services. In an
effort to circumvent or avoid bureaucratic regulations that mediate and control access to
mainstream health care services, these individuals instead sought care from informal health care
providers located in church drop-in centres, or non-profit traveling buses. In the event of serious
accident or illness, individuals also often sought care from hospital emergency rooms. A specific
focus of this study concerned not only the everyday, local experiences of individuals, but it also
sought to shed light upon the translocal lineages of administrative, governmental, and managerial
entities that mediated, shaped, and controlled individuals’ experiences. Organizational literacy
plays a pivotal role in this process: those who are organizationally literate are able to navigate
institutional, textually mediated processes, while those without such essential skills experience
considerable difficulties when attempting to navigate such processes.

The overarching aim of this study was to map the social organization of health care in
Ontario, with particular regards to the ways in which organizational literacy (or the lack of such
literacy) either facilitates or hinders individuals’ access to health care services. Organizational
literacy (Darville, 1995) draws upon a Freirean critical standpoint, which acknowledges that
knowledge and power are inextricably interconnected. This study explored the ways in which
organizational literacy is employed and reproduced in institutional settings. Individuals who
possess expert organizational literacy skills are able to “read into” texts for their implicit understandings, directives, and power structures. Furthermore, they are able to translate and decode texts as potential pretexts for coordination and control.

It is important to note that organizational literacy skills include more than the ability to decipher or navigate printed material. Individuals require technological literacy skills in order to access, navigate and decipher online documents. Accessing web-based information hinges upon the ability not only to read and write, but also to operate a computer. Interviewees in this study had limited access to computers, no time to devote to computer usage, and no economic means to pay for technology equipment. However, interviewees in this study nevertheless used computers for entertainment or social networking purposes. These individuals used free computer services at downtown drop-in centres to access email, social networking websites, online dating websites, and to watch YouTube videos. This finding suggests that the Internet is a potentially viable means to reach marginalized or inaccessible populations. Online, health card replacement services (similar to those offered to residents of British Columbia) would prove useful to individuals seeking a more efficient and accessible means of obtaining replacement health cards in Ontario. A number of recommendations emerged during the course of this study. These recommendations, augmented with participants’ first-hand experiences, are provided below.

**Recommendations**

Findings from this study may perhaps be employed to stimulate increased support for more progressive and inclusive policies, education, and legislation designed to assist marginalized individuals. Although this study did not set out to present solutions to the problems encountered by individuals in their efforts to access health care, a number of possible policy
recommendations emerged during the course of investigation. The following recommendations emerged throughout the course of research:

**Recommendation 1: Change OHIP policy.** Limit the prolonged institutional waiting period governing health card registration through:

a. Enabling residents of Ontario to enroll in OHIP by registering from the address of a friend or family member, with no need to prove residency.

b. Establishing online registration, which enables individuals to apply for replacement OHIP cards directly on the OHIP website.

c. Designating a computer at each Open Access shelter, specifically designated for OHIP-card registration.

d. Allowing individuals to obtain OHIP-approved agency letters directly from OHIP offices.

**Recommendation 2: Change Ontario Works Policy.** Extend the dental benefits available to Ontario Works recipients to include preventive care (i.e., routine check-ups) and basic restorative care (i.e., dentures).

**Recommendation 3: Extend Telehealth Options.** Enable individuals to contact Telehealth directly, without the need to receive a “call back” from a health care professional.

**Recommendation 4: Establish a Computer Centre.** Enable individuals to use the Internet at Open Access in order to perform their everyday lifework.
Individuals’ Personal Accounts: Problems, Observations, and Recommendations

Mac lived in an off-the-grid home in a wooded ravine in Toronto and was unable to receive mail at his address. His discussion highlights the necessity of having a registered address for OHIP registration:

They [OHIP representatives] are like: “Well, you’ve got to have an address for us to mail it to you. I don’t know what to tell you, Buddy. Next!” [Laughs]. Right? You know, ’cause it’s just some lady. It’s not like, you know, she can change the rules or make exceptions. She basically has to do what she has to do, and one of the things is that they mail them [OHIP cards] out to you. Yeah, most street people don’t bother with anything over there [OHIP office].

Judd felt that individuals should be able to obtain health cards “right there and then,” which would reduce lengthy institutional waiting periods:

I guess they could put your thumbprints on the card. If you go down to Bay Street, it still takes six weeks. I thought you’d be able to get it right there and then. I should go pretty soon, but I keep putting it off.

Mick indicated that he was interested in using the Ontario Telehealth, a free, confidential telephone service that enables individuals to receive health advice or general health information from a registered nurse:

I don’t mind going to the hospital, but I just don’t like the waiting. I want to learn more about the Telehealth option. You can go online or you can call. I saw it on T.V.
Jake felt that the exceptional care he received from the Sherbourne Health Centre should serve as a model for supporting and monitoring marginalized individuals:

If you know the circuit, you don’t need a health card, like on Sherbourne. I don’t think I’ve shown my health card in three years. Years ago when I lost the red and white card, it was a pain in the ass. They have everything at Sherbourne. They even have an infirmary. They monitor people who are under-housed or homeless. They monitor you. Sometimes a doctor can be pretty callous. So quick, like get you out of there. I try not to go in there [another health care centre]. I try to go to Sherbourne. Your health is ongoing. You need a log. Like when I go in and they see all my tattoos: “Oh, look: he’s a drug addict. Here we go again.”

Finally, Peter maintained that all Canadian residents, even those without a health card in their possession, should receive equal access to health care:

There should be equality for all, even if you’re homeless. All OHIP people should be taken care of, even if you don’t have a physical card.

It should be noted that a number of interviewees somewhat conversely called for increased surveillance and citizen monitoring, which perhaps reflects the extent to which neoliberal ideologies have pervaded people’s everyday lives and thinking. Sean and Judd believed that retina scans and fingerprinting would eliminate the need to carry essential identification. Lynn felt that an extensive tracking system would be helpful when using a variety of health care services. Neoliberal ideologies and polices are often evident in the implementation
and promotion of sophisticated, text-based, computerized data-management systems, including high-tech computerized monitoring systems, high-tech retina or fingerprint scans, and the mass-digitalization of personal data through the use of “smart” or high-tech identification cards. Neoliberal principals may be identified and then mapped in logical, complex sequences, which are evidenced in people’s everyday lives. Such policies are passed down from one entity to another, and, over time, policies passed down in one setting inevitably permeate people’s lives in smaller, more localized settings. Translocal social entities have the capacity to mediate, shape, and control not only our local, everyday experiences, but also our views about the world. In this study, translocal neoliberal principals were further “taken up” by participants in far more localized settings, whereby participants conceptualized and interpreted the purported benefits of such principals.

**Suggestions for Future Research**

As homeless women are not generally as visible as their male counterparts, their experiences are often underrepresented in the research literature. Women were underrepresented in this study. Of the 27 individuals interviewed in this study, only six were female. Although this sample is limited, it nevertheless shed light upon a number of health-related challenges experienced by homeless women (including negotiating pre-natal and post-natal intervention, seeking support after sexual and physical assaults, and managing blood-borne diseases such as HIV/AIDS). Both Stacey and Laura, for example, discussed not only negotiating labour and birthing processes, but they also discussed dealing with subsequent apprehension of their infant children. One future research study might include interviewing only homeless women at an Open Access shelter, with a view to explicating more fully the unique experiences of this
underrepresented group. Such a study might ask: How are health care services socially organized with regard to homeless women’s access to health care services? How do women living without a fixed address manage their sexual or reproductive health care issues or needs? How do women negotiate institutional health care directives, policies, or processes with regard to obtaining prenatal and postnatal care? How do specific texts (legislation, regulations, policy directives, and standard paperwork) mitigate women’s social relationships with institutionalized social agencies?

A second potential avenue for future research study might include an examination of the roles assumed by informal health providers in Ontario. Neoliberal policies have increasingly shaped the social democratic landscape, by introducing cost-effective restructuring of public health care and by reducing welfare spending. If this trend continues, it is feasible to assume that non-profit, faith-based organizations in Ontario will maintain a prominent role in caring for poor and disenfranchised groups (who are perhaps inadequately supported by social welfare programs). In many cases, non-profit organizations were historically formed in response to a specific need in a community that was overlooked or inadequately addressed by governmental service providers. Many interviewees in this study sought care from informal health care providers located in church drop-in centres, homeless shelters, or non-profit traveling buses, in an effort to circumvent or avoid bureaucratic regulations that mediate and control access to governmental or mainstream health care services. Open Access in Ontario, an entirely faith-based program, largely relies on donations from individuals in the community, rather than

39 Faith-based organizations and charity groups offset widespread poverty in the early years of the Great Depression. Although the Canadian government eventually mounted an effective response to the growing economic crisis, Berton (2001) writes that the government initially responded in a somewhat ambivalent and apathetic manner (p. 50).
government subsidies or support. Faith-affiliated, non-profit organizations add another
dimension to the provision of informal health care. Although non-profit organizations fill a
crucial role in providing care to vulnerable groups, little is known about the inner workings of
such organizations. Such a study might ask: What makes informal health care the preferred
choice for marginalized individuals? What support (funding or service augmentation) does the
government provide for non-profit health care organizations? Do non-profit organizations
support or diminish their governmental counterparts? What role do faith-based organizations
play in the provision of health care in Ontario? How are faith-run, non-profit service providers
and recipients (volunteers, parishioners, sponsors, and service recipients) socially organized?
What is the socio-political context in which such institutions operate?

**Implications for Future Practice**

Print and broadcast media often discuss the problems encountered by homeless
individuals living on the street. Most of us are surprised to learn about the large numbers of
homeless individuals who frequent the shelter system (approximately 100 individuals on any
given night at an Open Access shelter), or of the burgeoning rate of tuberculosis currently
reported in homeless populations across Canada today (St. Michael’s Hospital, 2011). Better
access to affordable downtown housing, cash-assistance programs, and outreach programs will
not only reduce the number of homeless individuals living on the streets, but such interventions
may also feasibly reduce the health problems experienced by homeless individuals.
Homelessness and health share a cyclical relationship: poor health contributes to homelessness,
and homelessness further exacerbates poor health.\textsuperscript{40}

Addressing individuals’ ability to navigate bureaucratic processes and thus gain access to health care will not address the root causes of homelessness. It may, however, improve the quality of life for the hundreds of homeless individuals currently living on the streets of Toronto. The aim of institutional ethnographic research is to locate individuals in the everyday world, and, in doing so, to explicate how everyday life is organized. This study aimed to explicate “how things work” regarding the provision of universal health care in Ontario. The results of this study may very well be of interest to policy makers. Multi-level support processes that focus both on implementing more inclusive mandates and on reducing textually mediated bureaucratic processes may facilitate participants’ access to health care services. Such directives or policies may also bring about increased social integration and cohesion, specifically through encouraging marginalized individuals to avail themselves more fully of social services accessible to them and to participate on a more equal footing with mainstream populations. The Canadian socialized health care mandate asserts that all residents, regardless of their economic status, have equal rights to curative and preventive health care services. However, findings from this study found discrepancies between homeless individuals’ access to mainstream health care and the access available to their housed counterparts.

The Freirean approach to critical literacy education situates literacy skills outside the confines of the traditional classroom, and instead connects literacy education to broader, sociopolitical themes that have a direct impact upon individuals’ actual lives. In particular,

\textsuperscript{40} Income is a social determinant of health. Thus, insufficient income plays a significant role not only in homelessness, but also in the health of homeless individuals. Townsend et al. (1992) found that in the lowest employment-level groups experienced the greatest likelihood of dying from disease or accident at every stage of the life cycle.
disenfranchised individuals may gain empowerment through critical literacy education that promotes democratic and emancipatory change (Freire & Macedo, 1987). In many ways, the seeds of activism have already perhaps taken root at the Open Access shelter. Sean, for example, maintains a prominent and influential presence at the shelter. Although he has a health card in his possession, he is a strong advocate of informal health care services, due to the decreased emphasis on bureaucratic paperwork found in such settings. Further, both Allan and Dennis critique unequal structures of health care practices, and they also discuss how others in their community often choose to subvert or resist services that they perceive as unequal. The provision of more inclusive social policies, in conjunction with decreased regulatory, bureaucratic demands, is perhaps at the crux of efforts to improve the health and wellbeing of homeless individuals living in Ontario. Such provisions may result in a more equitable, socially just, and consistent adherence to Canada’s universal health care mandate.
References


Carvin, A. (2000). More than just access: Fitting literacy and content into the digital divide


Hwang, S., Ueng, J., Chiu, S., Kiss, A., Tolomiczenko, G., Cowan, L., Levinson, W., &


Appendix A: Narrative Exhibits

Participants’ first-hand narrative exhibits are presented below. These exhibits are not organized thematically. Rather, information and knowledge is mapped in the form of a sequence of events, actions, and activities. In particular, these accounts serve as exhibits of organizational disjunctures\(^\text{41}\) (D. Smith, 2006, p. 41). Individuals’ first-hand, personal accounts provide a first-hand portrayal of the ways in which individuals navigate the institutional health care system in Ontario. These exhibits were particularly useful when seeking a holistic, descriptive, and personal illustration of individuals’ experiences when accessing health care services.

Allan

*How long have you been staying with Open Access?*

Oh, six months. Roughly two months. Two and a half months in this program, in this Open Access Program. I had a fire in the summer. I lost all of my belongings.

*Do you have an actual OHIP card?*

No, I do not.

*So, what happens if you wake up with a terrible fever?*

Most people here try to drink a lot of alcohol and kill it by drinking alcohol to the point that they black out.

*Have you ever had a health card?*

Yeah, I’ve had them, yeah, but I’ve lost them. Lost them.

*What if you don’t have a card?*

There are certain places all over the city that nurses come in, like a Tuesday or a Thursday. And you can see them. And if you have an emergency, you can go to any hospital. If you’re bleeding, hit by a car, they will treat you.

\(^{41}\) An example of organizational disjunctures that emerged in this study include participants’ inability to secure housing located in the downtown core, lack of secure storage for medication or personal identification, and difficulty obtaining ongoing health or dental care.
What happens when you get sick?

You also go to drop-ins, free drop-ins. They analyze you. They care about you. Drop-in people, like you [indicating the researcher]. Because drop-in people, like you, who come to work for the poor, you want to care. You want to find out what's making people sick. But people who are set up as practitioners, their wives are telling them to take the money. You know, “We need a new car. UPS is coming... I'm a doctor, but my wife needs this.” No, when you’re poor, all they want to know is how high your blood pressure is. They’re waiting to see how long until you keel over anytime or not. [Laughs.] You’re poor. You’re a scoundrel. They’re making $70 per hour. When you’re poor and on disability they only want to check your blood pressure to see when you’re going to keel over. They want to know how long it’s going to be. The synopsis is, when you’re poor, you’re in a basket. So what? So what? You got no life anyway. You’re just poor. So what?

So, I have a health card. To get it, I had to show three pieces of identification.

Oh, yes, you had to wait in line for three hours. I know. I know. I was down there too, but I said you’re not catching me in that line up. It’s like you’re in an aquarium.

If you need to see a doctor, do you go to a special place for people without health cards?

I go to drop-ins. Drop-ins within very concentrated areas of crime. Prostitution, drugs, where help is needed. Or they have buses. These are buses that come by in concentrated neighborhoods. Again, places with random acts of all sorts of not appropriate living styles. I don’t like them.

You don’t like them?

Listen, you’re young. But in society, if you get branded, you get branded. Some cops come to some areas fast, some cops come in two hours. ’Cause they know the area is concentrated like a ghetto. And they don’t care. But they don’t care. They think: “We’ve been working day and night, and they’re just hanging around day and night.” So they don’t want to come. Now those areas with the health buses, they’re set in those areas, because they know those people are out of mind, out of state. They don’t necessarily care about anything except for booze or a hit, like Hastings in Vancouver. So they set up buses there to kind of patrol the neighborhood to make sure for the country’s well being, not for the people, for the country’s well being. How it looks as an overall picture. To keep the overall picture clean. They don’t want to be responsible for the dirtiest, nastiest neighborhood. They want to rule the land. Whether you’re down-and-out sick, they’re thinking, “We can’t make ourselves look bad. Let’s send some wagons down there.” But for your care now, as a health care person who’s private, under OHIP, you’re working under the fact that you’ve been working for years. So you’re getting the benefit from the CPP, all the taxes that you’re paying. So that gives you OHIP. We’re not on OHIP. We’re on disability.

So, are you saying that because you’re on ODSP, you can’t go to my doctor?

That’s right. When she sees my sheet, she wouldn’t take care of me, as she does for you. As soon as she sees that sheet, I get half the attention that you get.

What does the sheet look like?
I don’t have it. I’d have to call you and get a place to meet you.

*Have you ever had any problems getting health care?*

Yes, you have the attention deficit [sic] where people don’t pay attention to you. You actually become despised.

*By health care people?*

No, by everybody. Like if your ass is dirty, or your shoes are dirty, or they see you’re weary and tired. They tend to want to shoo you away… OHIP private doctors… they look at you as scatterbrains or crazy.

*Do you ever use a computer?*

Why would you need to use a computer when you can go to Islington and Bloor? There’s no computer needed for that, ’cause there’s enough centres around to help poor people.

**Antonio**

*How long have you been staying with Open Access?*

I’ve been homeless a long time. Even before I was in jail I was doing Open Access. Yeah, before I was in jail I was doing Open Access, too.

*Do you have a health card?*

I lost it. You leave it somewhere or it falls out of your pocket.

*How many times have you lost your card?*

Two or three times.

*So, how do you get help without a card?*

I’m registered with a drop-in.

*Do you need an actual card?*

Some places do, but not this place.

*Does it cater to people on the street?*

Yeah, they cater to people on the streets. They give you everything there. They even have a room especially for the drug paraphernalia. They give you fresh pipes, needles. Everything you need if you’re a druggy.

*When you were in jail, did you get a health card?*

No, they can’t do that, because they need a picture of me. I got my social insurance card.

*You couldn’t have had an OHIP application done?*
I tried to get it done. I got my social insurance done.

But you need picture ID?

No, you need a picture for your health card.

They don’t have your picture on file at OHIP?

Yeah they do, but when your card runs out after the 5-year period, they want a new one [picture].

OK, so... you need an OHIP card. Have you been down to 777 Bay to do it?

Nope. I just need… there was a drop-in on Cummer Street. I went there, and he gave me a paid thing [an OHIP-approved agency letter] to go and have it paid for.

Have you ever had any problems getting health care without a card?

The only thing is that I got billed at the hospital. I just said, “Thank you” and left.

What happened?

I went to the hospital the other day. And they sent me a bill for $800.

Did you explain that you were homeless?

They knew where they picked me up [a homeless shelter]. They took the blood work. They did the EKG [electrocardiogram], but I didn’t want to stay until the blood work was over.

Why did you not want to stay?

Because I was scared. It’s weird, eh?

No, it’s not weird. You were worried.

Yeah, a little bit.

In the past few years, has it been harder or easier to get health care?

Easier. They don’t ask me any questions at the hospital.

How do you feel?

Stressed out from doing all the running around. Another place, another place, another place …

So what do you do at 6:00 a.m?

6 eat. 7 you’re at the next place. And then at 11:30 you’re at another place.

You can’t stay at the same place?

No, they close. There are different locations you have to go to throughout the day that are open. They give you one bus token when you leave in the morning. You go to that place and then that place and then back to Open Access. It’s like a circle. Same circle everyday. It’s a little tiring. I got some pains going on, like chest pains.
I’m not one of these guys who drink and do drugs and do this and that. I’m trying to get my shit together. I don’t want to do this. I used to be a bad druggie. I’m not a druggie anymore. The only thing I do is smoke weed. It’s better than doing the crack and the heroin. That’s why I got my shit together – I gotta dress good and smell good. I come from a good family.

**Judd**

*How long have you been staying with Open Access?*

15 years. Different churches. I was in the hospital a couple days ago. Different Open Access programs. If I had bus fare to get there, I would book into the Good Sheppard or Salvation Army. There’ll all the same. Crap.

*Do you have a health care card?*

No, I don’t have one. I just have to reapply for it, to get a new card. I just got it last year.

*How long have you been without a card?*

Three months. I lost it at the Grange.

*How do you get a new one?*

They have kiosks. They take a picture of you and put it on the computer and mail it to you. So sign the paper, take the mug shot. It’s only available certain periods of time. Every drop-in centre I always look for a little OHIP kiosk. I had a card for a while, and I guess that was the old version with this one picture on it, ‘cause they tell me that one is invalid. So I had to get another one, a new version, which has two pictures on it, right?

*Who told you it was invalid?*

I was told when I went to the hospital. They still took me. I had dropped from 250 pounds and was feeling really sluggish. So I went into the hospital, and they pumped me with IV’s, and gave me a couple sandwiches and juices, and [said] “OK, you’re free to go.” But in St. Mike’s you can spend eight hours in there waiting. “OK, you can go now.” Toronto Western, I like that one, because they get you right in.

*When you get really sick, where do you go?*

I go to a drop-in centre. They have a clinic Tuesday and Thursdays. They have nurses there.

*Do you have any suggestions for making the system better?*

I guess they could put your thumbprints on the card. If you go down to Bay Street, it still takes six weeks. I thought you’d be able to get it right there and then.

*Can you get a temporary card when you are there?*

I should go pretty soon, but I keep putting it off.
Have you ever had any problems getting health care?
No.

In the past few years, has it been harder or easier to get health care?
They treat you different if you have a place. Then they find out you’re homeless. “OK, give him what he needs, and then get him out of here.” Rush you out.

Are you treated differently?
Yeah, I think so. They try to push you out the door faster. If you don’t have a home, they admit you, but they think you’re trying to get a free ride or something.

How do they know you are homeless?
It’s on my card or something. On my file. Fixed address or something. I tried before, but it’s all on their computer. “What’s your postal code?” Then they find out. I don’t know postal codes. Numbers I’m good at.

Do you ever use a computer?
Facebook, email - no, none of that. But I know how to work a computer. It’s free at drop-in centres.

Robert

How long have you been staying with Open Access?
Almost 14 months. Next week I have to go look at the Salvation Army. Because this is almost finished now. I will go to the Salvation Army. I go to work for construction. I lose my union. I no pay every month. Every month I have to pay $20, and I no pay for a year. Without being a member of the union, I can’t go to work. I go apply for welfare. Now my supervisor for the contractor say I need to pay $300 or $400 dollar now. I don’t know. If I pay, I can go back to work.

Do you have an OHIP card?
Yes, and I have my passport, and my social insurance with my friend. I can lose it here. Not here, people can steal it.

Have you lost it before?
Yeah, I had to pay $100.

You had to pay to get all your ID back?
Yeah, I had to get my social insurance first. I paid $10. And then I got my OHIP card.

How do you feel – your health?
Nothing. I feel OK, but I have no family doctor here. I live in America for 14 years. I nearly quit [drinking]. I lose my family, my wife, my daughter for drinking. I never do jail in my life. Just the drinking.

*So, that’s really good – you’ve quit.*

No, nearly quit.

*You don’t seem like you’re drinking right now.*

No, I haven’t for 25 days. Lots of people give me a drink, but I quit.

*Are people helping you?*

Oh, I don’t know.

*What do you do in day?*

Yeah, sometimes I am working, sometimes yes, sometimes no. I go with my friend looking for a room. And I have to go apply for welfare. I am old – 63 years old. I don’t have a trouble for work. I like to work. I need to go to welfare. Then I need to pay the union. I have an appointment for traffic control. I used to do that for 6 months, but then I lose my job – for drinking.

*In the past few years, has it been harder or easier to get health care?*

I don’t know. I need to go apply – and pay $10.

*What do you have to pay $10 for?*

My social insurance number.

---

**Peter**

*How long have you been staying with Open Access?*

12 years. I also couch surf. I visit different cities, like Hamilton, New York. I also sleep outside. I like the water. I sleep in tents.

*Do you have a health card?*

I’m waiting for PAID [Partners for Access and Identification]. You can call 211 from any phone and they’ll tell you when the ID clinics are set up. They can tell I’m a Canadian citizen. I’ve had it [a health card] lost or stolen four times. I have it mailed to a shelter. I have no address.

*Have you ever had any problems getting health care?*

Have I been denied? Yes. It depends on the conditions. There are very surly receptionists. If you’re not kissing ass, you don’t get anywhere. You need to keep it simple – don’t give away too many details or say too much. Yes, I get denied if I don’t have a card with me. 40% of the time they say they don’t take new patients, or I’m not on file. 20% I get in. The other 20% I just give
up. Appearance matters. If you smell, of if you’re sweaty like you haven’t had a shower, it hurts your chances of getting help. If you dress better you have a better chance.

*In the past few years, has it been harder or easier to get health care?*

It’s harder now. There is way more rejection, way more. It takes me 15 minutes to clean myself so I can go into a clinic to be presentable. But there are no showers at this shelter. The clinics are not as accessible. I used to have a truck, but now I have no license and no car. I am disrespected when I go to a doctor. They have dissed me. I know it.

*Do you ever use a computer?*

I left home when I was 15. I used to be a general contractor and a foreman. I specialized in stucco. I had 17 employees for 31 years. I used to know how to use AutoCAD. But I don’t use the computer anymore. I don’t use email.

---

**Dennis**

*How long have you been staying with Open Access?*

Off and on for 4 years. Every time I break up with a woman I seem to end up on the street, right? I just broke up with a woman a year ago.

*Do you have an OHIP health card?*

It was lost. And I was sleeping on the Green Mile, and I had a little pink jar with $180 saved up to put down on an apartment. And they stole that. Right? And they stole my good track shoes.

*Where’s the Green Mile?*

It’s a stretch of land over to the highway. And it’s where we camp out, and there are tents and all that stuff.

*So, do you carry your ID and stuff in there? [Pointing to a bag.]*

Yeah, and a change of clothes. I don’t have ID.

*So, how long have you been without a card?*

About a year and a half.

*What do you do if you get sick?*

I get care. I go to a drop-in clinic or the hospital. And there’s nurses and doctors we see on the street. I don’t know who they work for. There’s one lady who is retired who works there every Friday. I met her in a drop-in. I saw a sign that said the doctor is in. So I spoke to a guy who knows me from many years ago. And I said, “Do I have to have a health card?” And they says, “No.” So, I told her my problem, and she gives me some cough candies.

*So, is there any incentive for you to ever have an OHIP card?*
Well, you see the thing is, if you go to the Sally Anne [Salvation Army], they want a health card number, but it’s illegal for anyone except for a doctor to take that number, and I won’t give it.

*Have you ever had any problems getting health care?*

Well, only if your health card is expired. I didn’t know that it had expired, so I couldn’t get treatment at that moment. And the nurse says: “No, you can’t, because you’d have to pay for it.” So, they says: “Go to this place.” And they gave me the address, so I went there. They paid for my health card. And I went to the health card place with my little slip of paper, and they said, “OK, that’s the temporary number. You’re covered. You’re paid for.” You see it’s all about the money. I was kind of mad.

*In the past few years, has it been harder or easier to get health care?*

If you know the ropes, you can get health care any time. If it’s an emergency, you can go to the hospital. If you don’t have a health card, they can’t refuse you under Canadian law.

*Do you ever use a computer?*

If I go to the library or to an Internet café, yes.

**Ray**

*How long have you been staying with Open Access?*

This is our second time in the Open Access in the past year. So, I don’t know.

*Do you have a health card?*

I’ve got my health card. I’ve even been a couple times when my card is expired. They still took me into a hospital.

*What happens if you don’t have a health card?*

I’ve even been to Rosewood Clinic\(^{42}\) without a health card. It’s a psychiatric facility, drug rehab facility, hospital facility. It’s privately owned.

*Do you have to pay?*

It depends if you have insurance or not. Like if you’re working full time, some companies won’t cover it, or cover only a percentage of it. Like if you’re there for a drug program or something. Some companies who are unionized will cover it. Some places won’t, and then you pay for it out of your own pocket. You can show up there without a health card. As long as they have you on file, they’ll take you in.

*What if you have no card on file?*

---

\(^{42}\) A pseudonym is employed in order to protect the identity of the interviewee.
Well, if it’s the police or something, they are gonna take you in. They will have no other choice but to take you.

In the past few years, has it been harder or easier to get health care?

Harder. Housing situations, doctor situations. The getting actual help, and people actually sitting there saying: “These are your plans, this is where you need to be. And here’s the help.” You don’t get it through anybody or anywhere. For everything… It’s a women’s world out there. If you’re a women, and you’re stranded, boom, all the help in there that you need. If you’re a man, you’re a man. Man, go out and get a job. You’re a man, go out and get some money. Do what you need to do to get some money. Anything.

Do you ever use a computer?

Yeah. It’s on my phone. Built in Internet, built in MP3, built in GPS stem, touch screen, everything, camera, video, recording, and we paid $153 dollars for it. It’s $45 per month for unlimited calls in North America and unlimited Internet. And you get $50 back.

Ben

How long have you been staying with Open Access?

I’ve only been here around eight [years]. I told you – I’m not a fake. [Laughs.]

You’re real.

I’m gonna have a little drink. I won’t do it. [Drinks vodka from a bottle tucked underneath clothes.] Then I’m gonna be good.

So in the summer, you like to sleep outside?

I like sleeping outside… is my face a little flushed?

You look hot. Are you hot?

Yeah, I do feel hot. I’m old!

Do you have a family doctor?

Yeah right – all the time. [Laughs.] You took that the right way, too.

So, do you have an OHIP health card?

I had one but I lost it.

How did you lose it?

Do you have to be so tricky? [Laughs.] I did have one, but you know anything I have that…You know what I have to do with my disability cheque? There’s a lovely old man, there’s two of them actually. They’re brothers. They run a convenience store. You know what? As soon as I get
my cheque, I’m so fucking irresponsible, I have to give him my money, because I trust him. You know what? Sometimes he says, “No, no, you wait until tomorrow.”

_Do you have to give him your money?_

No, I want him to. I beg him to. Plus all through the month I can run up a tab, nothing too big. You know that liquor store [muffles tape recorder with hands]. I can walk into it with…

_Have you ever lost your health card?_

Many times, at least three times.

_How would you get another one right now?_

I don’t have a clue.

_So, where did you get your last card?_

In jail. Yeah, in jail.

_And they got it for you?_

Yeah, I just did it for something to do.

_How healthy do you feel?_

Well, I’m 52 this year, and guess what… should I take it [clothing] off? [Laughs.]

_What if you have a really bad flu? Where would you go to get your liver dealt with?_

That’s a really good question, cause I’ve been out of jail for a couple of years now.

_Did you get help in jail?_

Yeah. I used to be a bad guy. I’m not a bad guy no more.

_Where can you get a check-up?_

You know what, I would just plunk myself down in a hospital and say, “Daddy’s home. And he’s not too happy.”

_Can’t you go see a family doctor?_

I lost my health card.

_If you had a health card, do you think you would use it?_

I’m not sure. I haven’t got to that. Honestly, I would wait until the last second. And that’s not a good thing. You know what I think of in my brain? You know what I’m really proud of? I don’t have any illegitimate children depending on me. Does that make sense?

_So, if you had a health card, you could go anywhere – a clinic or a family doctor._

So there’s a reason you mention it. You know what? I’m doing this more for you than for me.

_OK, so it’s important to me, but it’s not important to you?_
You know what? I do take my health for granted for what I put myself through. It’s like what I said, the common cockroach and Keith Richards. [Laughs.] Do you know Keith Richards? He was my hero. He’s doing OK now.

_Have you ever had any problems getting health care?_

Do I look like a guy who has ever had a problem?

_Have you ever had a problem without an OHIP card?_

It’s funny you mention that. One time I don’t know why – I don’t usually stick my nose in it – a big huge guy give her [indicates a friend] a punch. I gave him a couple of punches, anyways. His girlfriend – stupid situation. Anyway, I went to St. Mike’s. They did not want to serve me. I didn’t know my health card number.

_Where you still bleeding at this point?_

Oh, yeah, yeah. You know, I take that back, I can’t complain.

_What happened eventually?_

I had a girl with me. She said, “Don’t drink any alcohol with a head injury.” You know what? I had a hot lingering bubble bath [at the girl’s home], and then I went to sleep.

_With a head injury?_

The next day they stitched it up. I can’t believe I even remember that.

_In the past few years, has it been harder or easier to get health care?_

As long as you give your real name, they will take you in in the emergency room.

_Do you ever use a computer?_

Now I feel guilty. I’ve never used the computer. I’ve never drove the car. Quite frankly, it wouldn’t be fair to society. Would you like to see me driving down Highway 69?

_Lynn_

_How long have you been staying with Open Access?_

Off and on for three quarters of my life. It’s like, people become your family. Out here, as rough as it is, and as much as you hate it when you’re here – ’cause it is treacherous. It’s very draining, but you miss it, you miss the people.

_Are you all by yourself?_

No, I know certain people that I associate with at the Open Accesss. But the Open Accesss are not always available. I hate shelters.

_Yeah, is it dangerous by yourself?_
It can be, but you have to know who to be around, and how long to stay if somebody’s around. And learn to recognize the signs. Because I have been raped. I have been attacked. I have been stabbed - on the streets, in the stairwell. And robbed - they steal from you. They go through your pockets and take everything you have.

*How many times has this happened to you?*

Four times. But it happens on a daily basis that guys are hitting on you. Trying to pick you up. Asking if you want to do dates. ’Cause you’re a lowly homeless person they think you’re a hooker. And they offer you money for sexual favours – for like $10 bucks, $20 bucks, $40 bucks, whatever. Dirt cheap kinda crap, don’t want to use condoms. You know, it’s disgusting.

*You don’t see a lot of women here.*

You don’t find a lot of women who can handle this. I mean, I’ve watched myself age overnight. The elements alone, and never mind the stress. It’s like, wow.

*Have you had housing off and on?*

Yeah, I’ve had housing, but I gave it up. I can’t stand it. They put you in some area that you’re not familiar with, and it’s not good. Not in the city – like Wilson or something. I used to go there to pick up my cheque once in a blue moon, but you know, it’s so far. No friends. I don’t know where my resources are. Like downtown, I know where to eat. I know how to survive downtown. But I know in some of these other places their food bank system in different. But to get to the doctor, my doctor is downtown. The AIDS services are downtown. Everything I need is downtown.

*Do you have access to medication?*

I also lose my drug cards, my dental cards, my cheque stubs, everything, so it’s a real fiasco to pull all that shit together to try to get housing. You sit on the phone, on a phone where there is a 10-minute limit, and you’re on the phone with ODSP on hold.

*Are you taking your medication?*

Yeah, I have been taking my medication regularly, but this is the problem. I was at a women’s shelter, and it’s probably a great place for some people, but I couldn’t handle it. They packed my stuff into seven bags. I brought it in in two. They don’t know how to pack obviously. I had to fight with them for a token. They didn’t want to release my medication without me taking all of my belongings. They don’t have the storage space. But that’s wrong, so I had a doctor – from a clinic at the Health Centre. It’s all women, and they do what they can. The doctors are female. So the doctor called the shelter and said it’s a matter of life and death. Maybe not death, but it’s crucial that she has her medication, so can she pick up just her medication and leave her belongings?

*So, they wanted you to take away your seven bags, but where would you put them?*

They didn’t care. Out of their shelter is all they care. I will never, ever go back there.
So where do you keep your stuff now?

My stuff is in the truck of my friend’s car, another lady who volunteers at another organization where I go to a drop-in. She offered to keep it in her house, but I’m hoping this housing comes up at the end of the month. I really hate housing.

Do you have an OHIP card?

Yeah, but not with me. It’s in the trunk of my friend’s car. I could get it Wednesday. Not before that.

Is it safe?

I hope so, unless someone breaks into her car.

Have you ever lost your card?

Oh, God, a million times. I have more version codes than… it’s just crazy.

What do you do when you lose your ID?

With the OHIP, because I have a photo OHIP, you can phone or you can go there and they’ll give you your health card number on a piece of paper, and that’s good enough to use until your card comes - only the photo one, not the red and white one. They give you that piece of paper, and then they’ll mail it to you, but the other problem is you need a mailing address also.

So what do you do?

I send mine to a drop-in centre. When I’ve been really sick, sometimes my only option is to go to St. Mike’s [Hospital].

Have you ever had any problems getting health care?

I see a doctor at a drop-in clinic who never shows up. The clinic is good, but it’s only open Wednesday and Thursday, so the doc is sometime there on Wednesday, or sometimes Thursday. There is also a psychiatrist. I mean, it’s a great organization, but it’s very difficult for myself and the GP to hook up. They have great nurses that can do other things if you need other medications. They can sometimes call the doctor somehow and get an OK from him.

So, can you go to any clinic?

But I don’t understand why you shouldn’t. I’ve signed a paper at St. Mike’s to say they can access my number and version code.

St. Mike’s can look you up, but no one else can?

Yeah, isn’t that weird?

What about that drop-in clinic? Do you need one there?

No, but they did get my health card number, and I did have to sign that form. Yeah, and they did get it from the travelling bus, so it is connected, like all of that is connected.
Would you ever go to a regular family doctor?

Yeah, if you could just drop-in that would be great. I have a hard time keeping my appointments. ’Cause I have enough shit to remember everyday. Then you forget what day it is sometimes, so you lose track. Like I had four tickets to go to the hockey games and didn’t realize until that day at 8:30 at night. So that’s four tickets I blew, just because I forgot.

If you could change something about the system, what would it be?

I like the paper idea. When you’re sick and you need to see a doctor, why isn’t the doctor there to help you? Why don’t they see the person, and then deal with the health stuff later? It must be in the system somewhere. A database system, or can’t they just pick up a phone, and phone? I think OHIP is kind of stupid, the carrying around the card thing. You can’t use it for ID.

In the past few years, has it been harder or easier to get health care?

Harder. I think it’s just the bureaucracy. Follow the paper trail. You need this to get that. You used to be able to open a bank account with just one piece of ID. You can’t even do that anymore. The OHIP card – the only place that will take you without the OHIP card is St. Mike’s, and I think that drop-in clinic, I’m not sure. But pretty much other than that you’re SOL [shit outta luck] if you don’t have a health card.

Do you ever use a computer?

Yup. Yup. I was on Facebook, and I tried to get off it. It’s just a barrage of emails, and I’m like holy crap, who are these people? [Laughing.]

Lee

How long have you been homeless?

I’m been homeless for 10 years, but I had a home once for 2 years.

Do you have an OHIP card?

Yeah. I got a letter saying they’re going to send me one.

How did you get that letter?

I went into the office on College. That was two months ago. But they haven’t mailed me my card yet.

So, where would it be mailed to? Do you have a place to send it to?

I get my mail from a church.

So, was your card expired?

Yeah, I got it renewed. But they never sent me the card yet.

So it’s been two months?
Yeah, I should call them up and ask them: “Where’s my card?”

*Have you ever had any problems getting health care?*

I have a doctor who gives me the antibiotics I need. He comes every Thursday to the drop-in shelter.

*What happens if you need to see a doctor, and you don’t have a card?*

That hasn’t happened to me yet. I haven’t needed to see a doctor. Well, I had heart surgery a few years ago, a triple bypass. That was 10 years ago. I’ve had a couple heart attacks since then. I just drop dead, and they pick me up and revive me.

*On the street, you’ve had a heart attack?*

Just down there – Queen and Jarvis. I was going to take an elevator, but I don’t remember getting into the elevator. I just fell in the door. A guy inside there just pulled me in. He said: “You were dead. But you’re coming back to life.” You know, when he got off on his floor, I was coming back downstairs. The same time I was coming back to life, he robbed me.

*He robbed you?*

[Laughs.]

*It must be hard to keep identification with you when you’re on the street.*

I was sleeping up a street down here. And I wake up around 1:00 or 2:00 in the morning, and people are going through your pocket, you know?

*So you lose a lot stuff that way?*

Well, there are people who run around and do that to you. And they come around and say, “Are you OK? Are you OK?” But they are really looking for money [that] people are laying out on the street for you, like a dollar laying beside you. They’ll take that you know.

*Do things get stolen inside shelters?*

No, in there it’s pretty OK. It’s just when you get out into the streets. They’ll take anything from you and go through your pockets and everything. They’ll take your bag, and they’re gone, you know? They don’t mind stealing everything you got.

*It’s amazing that you’ve kept your ID safe with you for so long.*

Yeah, I hope I got it with me somewhere here [checks pockets].

*In the past few years, has it been harder or easier to get health care?*

About the same. But my last card was all broken up. Expired and all broken up.

*Have you ever used a computer?*

I have no feeling in one of my hands. So I have not enough feeling in this hand, and I’m too stupid to learn to type. Do you know what I mean?
Maria

How long have you been with Open Access?

Seven years. And I was at Nathan Phillips Square for a while - just outside.

How do you stay warm in the winter?

Boxes. Boxes and just blankets.

So, do you have an OHIP card?

I just got it back. I went through PAID ID [Partners for Access and Identification]. They filled out the appropriate forms. My picture and everything is still on file at the OHIP office. It’s still a month’s wait. It’s so stupid. It’s so hard to go around and make these appointments and keep them, because you’re busy during the hours they are available, so… You gotta find out where the ID clinics are and stuff like that.

So they [OHIP-approved agencies] move?

They move all over the place. Sometimes they will be at this drop-in or this drop-in on a certain day, so you just have to figure out… walking, and if it’s raining or snowing you’re screwed.

How many times have you done that?

About four times.

So you lose your ID a lot?

Or it gets stolen. Circumstances are just Murphy’s law.

Have you ever had any problems getting health care?

I’ve been billed.

Where does the bill go to?

Your house. Like I was in Brampton. I was renting a room at that point, and I got a bill for 360 bucks.

Did you pay it?

No, I didn’t pay it.

In the past few years, has it been harder or easier to get health care?

It’s funny, when I wasn’t homeless I was in good shape, so I didn’t need to go that often. Since I’ve been homeless, it’s been an ongoing circle of feet pain or tooth pain or eczema, or some stupid thing. So, the times I had to go in… like anytime I lose my ID, I try to get the hop on it and stuff. Basically the only thing is tooth pain, when it’s really, really bad. The thing with dentists, if we get a $200 emergency fund, that’s only for extractions, and it’s only for one time.
Like one time in your whole life?
Yeah, as of right now.

How do you get that?
It’s usually through the shelter you’re living in, or like welfare.

Who does the extraction?
They have a list of dentists who will do it. It’s just a $200 dentist card from OW [Ontario Works].

Do you ever use a computer?
I don’t do any of that. I look up YouTube stuff – entertainment purposes, not for information.

Mac

How long have you been homeless?
Well, this stretch here, about 8 months.

Can you go down to the OHIP office with what you have now and get one?
No, I need the kiosk. You just wait until you find out where the next kiosk is. At the Meeting Place, they have them once a year, because they have them all over the city. There may be one next month, but it may be in Scarborough or Mississauga.

Even though you have a physical card now that just expired?
They want you to be able to prove your address. They actually want you to have stuff to prove your address, because they mail it to your address. So if you go in there and say: “Hey, I’m a homeless guy.” “Well,” they say… “We don’t do pick-ups. We mail it to your address. So… next!” [Laughs.] Right, so that’s why everyone deals with the kiosk. So, whatever shelter it’s in, they do all the paperwork. They’ll deal with all that, and then it’s mailed right to there, so there’s actually an address to mail it to.

I see… so you’ve tried?
So, that’s like any kind of driver’s license, they say: “OK, we’re going to mail it to your address, no big deal.” But what if you don’t have an address? Where do they mail it? Right? And they won’t let you come in and pick it up. Their system is designed where they process it, blah, blah, blah, and it automatically goes in the envelope, your address, and it’s automatically mailed to you. So they don’t even want to even think about dealing with…

So, you’ve tried? You’ve actually been down there [OHIP offices]?
Yeah, yeah, that’s why I actually made the joke. They’re like: “Well, you’ve got to have an address for us to mail it to you. I don’t know what to tell you, Buddy. Next!” [Laughs]. Right? You know, ’cause it’s just some lady. It’s not like, you know, she can change the rules or make
exceptions. She basically has to do what she has to do, and one of the things is that they mail them out to you. Yeah, most street people don’t bother with anything over there [OHIP office].

But can’t you give a shelter address?

Not really. It depends on the worker. Some of them may be willing to, but once again you have to have proof of your address. Proof of address in their mind is a bill, something that has an official capacity. People have tried before writing a letter and mailing to themselves, to say, “Here, look.” But they’re like, “No, that’s not official.” The only way you can get away with that is if you sent a letter to yourself through registered mail and actually have the mailman take the letter to your door where you actually sign for it. Yeah, it’s a weird system. But then we try to go and explain to them, and they say, “Everyone has a phone bill.”

Have you ever had any problems getting health care?

You basically go to other drop-ins. If it’s something minor, a lot of the drop-ins will have a street nurse that will basically help you out with the smaller things. Like there is a foot-care nurse, because basically a lot of homeless people walking around have foot-care issues. But if it’s a situation where you go see the nurse and you’re like, I have chest pains, my fingers are tingly, or whatever… she’s like, “Oh my God, you’re having a stroke or something. Wait here. I’m going to call somebody.” Like you know what I mean? She’ll kinda go, “OK, you don’t have ID, but you have a serious health issue.”

In the past few years, has it been harder or easier to get health care?

It’s become a little bit harder. I guess, back in the day, you could go in and basically if you knew your number you were good. But now they have the magnetic strip and everything’s on that. They’re into this new mentality. They have a set of rules that they have to follow. If you don’t have a card that they can swipe, sorry, we don’t have procedures for people without health cards. “Here’s where you can get one.” OK, yeah. Back to that place again, right?

Do you ever use a computer?

Computers are not that bad. You can go to libraries. It’s like with the health cards and those kiosks, they have everything ready to go. They have all that.

Stacey

How long have you been staying with Open Access?

It’s my second time.

Do you have a health care card?

Mine recently just got stolen. Someone came right into my room and went into my jacket when I was sleeping and helped herself to my pocket and took it with my bus pass and my health card.

Is there a door to lock?
Yeah, we can lock our doors, but staff is now telling us that we are not allowed to lock our doors. And they come in while we’re sleeping to do bed checks. It’s to make sure that we’re there before curfew. That’s what I don’t understand. If the door is locked, doesn’t that mean we’re both [she and her husband] inside sleeping?

*Maybe they want to make sure no one else is inside?*

That’s not the point. You should be able to lock your door, right? It gives us that little bit of security.

*Have you ever had any problems getting health care?*

My card recently just got stolen. I have to do the paperwork all over again.

*What will you do now that it’s stolen?*

I have to do the paperwork all over again. And then wait the four to six weeks all over again. Or six to 12 weeks, depending on how backed up they are for them to send you a new one.

*Where will they send it to?*

It’s [an OHIP-approved agency] down on the Danforth near the school. I can’t remember the exact address. Someone at the clinic already has my birth certificate stored for me. They are really nice there.

*What are some examples of your health care needs?*

Actually, it brings me down. It’s depressing. We’re actually going through a lot of other stuff too… We’re fighting a custody battle to get our baby back. Well, it’s hard. Living in a shelter, trying to get the baby back.

*How was your prenatal help?*

I did see a doctor outside of Toronto. For the last year in Toronto we have seen doctors in drop-ins or clinics. We just got a family doctor last month.

*Was the delivery doctor nice to you?*

Yes, but the other doctors and nurses were not nice to me at all. Because I kept telling them I was in labour, and they were not listening to me. It took them at a least half an hour to find out I was in labour… The doctor looked at me and says, you either give birth to this baby right now, or we’re putting you out. So I said, whatever’s best for the baby. I wasn’t thinking about me or anything. They had to cut me open. C-section. I woke up and there’s my baby. I was scared. Literally my whole hand would fit on his back.

*Were you helped with breastfeeding?*

I was pumping until CAS [Children’s Aid Society] took him.

*They wouldn’t let you to continue to pump?*

No.
Do you ever use a computer?
I’m on Facebook.

Tom

How long have you been staying with Open Access?
15 years.

How do you feel? How healthy are you?
I’ve had hep C for 20 years. I drink. I get stoned just to forget about it.

Do you get any drugs or any help for your hep C?
No.

How do you know you have hep C?
I got diagnosed when I was in jail.

Do you have a health care card?
No, not in my pocket, no.

Do you leave it somewhere?
The Community Spot.43

Have you ever lost your card?
Yes, many times.

Have you ever had any problems getting health care?
Yeah. North Bay. Last year. I didn’t have a health card.

But you have one - it’s just somewhere else. Did you tell them that?
Yeah, I tell them I don’t have the card with me. I was hurting.

So, how did you get help?
I had to buy my dope off the street.

Did you still need to see a doctor?
Anxiety. Anxiety.

In the past few years, has it been harder or easier to get health care?

43 A pseudonym is employed in order to protect the identity of the interviewee.
Tony

How long have you been staying with Open Access?
I’d say about 10 years, on and off going to shelters.

Do you have a physical health card?
It’s at St. Sebastian’s Church.\textsuperscript{44}

How did you get it?
I got it delivered to St. Sebastian’s Church. I got my birth certificate. I used a letter for my second piece of ID. I don’t drive. I got a letter like an affidavit stating who I was. St. Sebastian’s got it for me. They’ll help you do things. They don’t do it all for you. They give you the tools to do it yourself. You can’t just sit back. I mean I’m the youngest of three children. Everything was always done for me. I still get in my head that I can’t do things. My mom didn’t teach me a lot. I mean she loved me to death, but there’s a lot of coping skills she didn’t teach me.

So what happens if you get terribly sick with the flu?
If I get really sick I just go to the emergency at the hospital. I just say I’m NFA, no fixed address, and I’m on your system. I just don’t have a health card. [Coughs.]

Do you ever get to talk to anyone?
No.

Have you tried to go to a regular walk-in clinic?
No. I never do that. Pretty much I go just to an emergency room.

You would only go to the emergency room?
Yeah. But sometimes the drop-in centre [that] I go to will have a doctor there once a week. They have a hot shower, meals. You get to watch some TV. It’s open from 7:30 in the morning until 11:30 [am]. They give you showers and you can do your laundry.

Have you ever been turned away without a card?

\textsuperscript{44} A pseudonym is employed in order to protect the identity of the interviewee.
Without a card, yeah. That’s perfectly acceptable. Because there’s rules that are set in place. What if I could be a terrorist or something, and they’ve giving me the health care, and I’m not even a citizen of the country? That just wouldn’t be right.

*Have you ever had any problems getting health care?*

No. But I mean I’ve had some not very pleasant experiences with the health card because I’m an alcoholic. When it comes down to the emergency room and you’re drunk and stuff. Half the time you go to the emergency you’re drunk and you’re intoxicated, and you’re passed out in some snow bank or something. That’s not – I wouldn’t like that. I mean, I would try my best not to be prejudicial against me, but you can’t treat them really wrong… [Coughs]. I mean at some point when you’re in that position, you want to give someone the best care, and your heart’s there, ’cause you chose that profession for a reason, and you see someone who doesn’t give a shit about their life. Pardon my language. They know what they shouldn’t be doing, but they keep on doing it. I’m caught in that, and I’ve got to stop. If I don’t make it soon, I’m never going to make it. There’s a percentage after a certain amount of time, at a certain age, that’s it. It’s ingrained. It’s who you are, who you’ll always be, and that’s it. But you know, I don’t believe that. But it scares me sometimes. I hear it all the time. [Coughs].

*In the past few years, has it been harder or easier to get health care?*

I don’t think so. One thing I don’t believe is that they haven’t fully checked me out, ’cause a few times I totally blacked out. I passed out because I had a huge thing on my head. I looked like John Merrick [the Elephant Man].

*How many times have you done that?*

Twice. Then I went for follow-up – a CAT scan. And then they said everything is fine. But they didn’t show me anything. You know how on TV they show you, you know this is what’s wrong, and this is what it should look like? They didn’t do that at all.

*What did they say?*

They just said: “You’re fine.” And that was about 10 minutes later. I don’t know how long it takes for that kind of thing to come through, but 10 minutes later they said: “Fine, you can go.”

*Do you ever use a computer?*

Facebook. I like to talk to my family. In the state I’m in right now, I can’t see them. I want my ground not to be shaking. I want my ground to be as smooth as this floor.

**Eric**

*How long have you been Open Access?*

One year. I’m employed in the summer. I can pretty much stay with any friend doing roofing.

*You have a health card right now, but it’s with a friend?*
Yeah. I’ve lost all my ID about five times, just being drunk and stupid. There’s organizations out there, but because I’m normally employed I just go through all the bullshit again. I can use my cousin’s address to get it mailed. I have used an ID clinic on Secord and Barrington.

Did it work for you?

It worked better. It got sent there. You take your birth certificate up to Warden to get your health card. They make you get your own health card. You tell them that you’re NFA [no fixed address]. I went up to Warden and Lawrence, an OHIP office. The card got sent back to Barrington. I told them I was NFA.

Have you ever had any problems getting health care?

Dentists. OW [Ontario Works] will not do fillings or anything like that. They won’t do anything cosmetic. It’s only for emergencies. Probably the big thing would be dentists. They’re really hard. I got a toothache. It’s not inflamed yet. There’s a big waiting list for people with bad teeth.

What do you if you have a terrible toothache?

You have to get a Tylenol. I have to wait until the end of the month to get my pay stub, so I can go see a dentist for free. For people on OW and Social Assistance, for people on Street Allowance, same thing. They basically will pull it. But you need your OW statement and your health card. There’s a big list of dentists, but I’m still gonna have to wait a week and a half.

So they pull a tooth, but give you no false tooth?

Yeah, probably they leave a hole.

Can you go as much as you want?

I think you can only go for emergencies.

You didn’t keep your pay stub?

I made a mistake. I didn’t have foresight. I guess I could have requested a stub from my worker, but…

Who’s your worker?

My social worker.

Why don’t you go see your worker to get the paper, to bring to the dentist?

’Cause it’s time – bullshit. It would probably take a day, maybe two. My day – do you want to know how it is? I wake up at 7, and I go for coffee. I have coffee and breakfast here, and then I go to Timmie’s for another coffee. Then I walk to the next place I have to go – to another Open Access. I may not eat lunch. Sometimes I’ll go to another drop-in to eat lunch. Like today there is a place on Church where you can have a shower. Showers are big – like finding a place to have a shower. Then I make my way to the next Open Access and eat around 5:00. It takes up your day.
Trevor

How long have you been with Open Access?

A year and a half.

Do you have your OHIP card right now?

I lost my ID. Someone stole it. I’m getting it back slowly. ‘Cause I need landed immigrant status too. I’m not a Canadian citizen. Last time that almost took 12 weeks, and I can’t get a social insurance until I get that landed immigrant ID. They can take taxes when I’m working, but I can’t do other things, like open a bank account. They say that the Ontario OHIP card is no good for ID, but why is the government giving us ID that is no good? I tried to fly to Winnipeg with my health card, but because they wouldn’t accept that as ID, I lost my flight. I had to go all the way back home.

Will you get a new card?

No, I don’t have it. I have to get one. The card will get sent to PAID [Partners for Access and Identification] and I will go pick it up. PAID is going to give me a letter with a mailing address. It’s the same with the landed immigrant status. They’re going to help me too. I have a copy of it, but it has to have the seal or the stamp on it. They go to different churches, certain days at different places.

Have you ever had any problems getting health care?

I’m homeless, and I have a girlfriend, which makes it a lot more stressful. I met her three months ago. She’s over there sleeping. She’s been homeless about five months. She was living with a guy who was abusing her, so she took off. Somehow she got introduced to the system here. We’ve been looking out for each other ever since. I’ve been to the hospital with her eight times since I’ve known her. We were on St. Clair and she broke her ribs. She fell down and cracked her head. They found clots in her system. The thing is we went to about four different hospitals. Even though they did x-rays and MRI’s, they didn’t find these clots. If we hadn’t gone to a fifth hospital, she would have died. They took a CAT scan and an ultrasound. None of the other hospitals even mentioned it. Now she has a blood clot on the other side, and they want her to wait six months, so I started at them, freaking out at the doctor. “Why don’t you do it now, or next week? Why wait?” He said he wouldn’t do it, so we went somewhere else. We have to go back again next week.

In the past few years, has it been harder or easier to get health care?

This is the first time I’ve been in this situation. I lost my job and couldn’t pay rent. I had a room in a place, but I don’t do drugs and I don’t drink. People in this house were smoking crack 24 hours a day. Every five minutes there was a knock at the door. They’d be fighting… so I just ended up leaving. I paid a month’s rent, but left after a week because it was just too much. It was
near the subway. The traffic was unbelievable. There would be a hundred people in there every day, maybe more. I don’t know if the guy was selling, or what. When I came out, I just turned my head.

**Sean**

*How long have you been staying with Open Access?*

Eight months. I periodically drop in and out of this realm, I guess. For the past two years I’ve been more substantially in this community than in my own place.

*Do you have ID?*

I got an OHIP and a status card. The rest of it I don’t have. A lot of people acquainted to [sic] here, a lot of them are missing their ID’s. Health care is a very important thing. There are some organizations here that do run a van or something, and you can get a minimum amount of stuff, but you can’t get any of the heavier stuff like medications without a family doctor.

Most of these people don’t have the tolerance or capability to go through application after application. Even if you go to the doctor, you have to fill out some kind of application, some kind of medical form again, some kind of a history. Who has a history on a lot of these people? I think if there’s one thing they need to create is some kind of a process. Documentation is important for a lot of people. It shows their existence. But medically, I think one of things if they had a scan or something, or a print of something that would come up with their own file. ’Cause they’re always their ID. You know, they waste so much money on stupid things, the government. There’s a lot of hypocrisy in the government. But you know, anytime they want to spend money on the right places, they never do. Out of the people I know right now, and I’m saying a small group of just say 20, approximately 12 to 14 of them are missing their ID. The other percentage has one piece of an ID, or a part of an ID. So they’re still not in the system. They are more out of it.

*Do you physically keep your ID on you?*

Yes. But if I know I’m going to an idiot and not in control of my bodily functions, I’ll leave it with someone. There are a couple of people I truly trust. They own their own house. I’ll say: “I might be screwing up. Watch this for me.”

*Have you ever had any problems getting health care?*

I’ve walked away from a couple of these places you can just drop-in. I wasn’t really happy with them. I’m just a savage, that’s the perception in people’s eyes here. I walk out and shake my head. It’s not even worth getting upset or angry. There was this young girl who was going to be a doctor for me – she was graduating, and she checked me over one time. She got me over at St. Mike’s, and they did some ultrasounds on my legs and stuff. She said, “We may have to look into getting your ACL’s [anterior cruciate ligament] and MCL’s [medial collateral ligament]
fixed, you know?” But when I tried to call her after getting back to the city, and tried to call her, she’s gone out of the country, so there goes my one hope of getting someone I felt… ’Cause she listened to me. She actually listened to me. Now she’s gone. “Maybe I’ll catch you when I get back.” I don’t need someone looking at me like I’m savage or something. It’s just garbage. I’m not the only one who feels like that.

*Have you been talked down to before?*

Oh, yeah. But I look at them and kind of laugh. Most of the time I walk out. I’ve had dentists do it to me. I’ve had physicians do it to me. I’ve had interns do it to me. I want a doctor who understands how to talk to somebody, somebody I can relate to. Encouragement at this level is very important. The people here need to solidify themselves. Do you know all the bullshit they need to go through for the $213 street allowance? There’s got to be a better way – a fingerprint or a retina scan. You can’t go too high tech on it. They can do it for the dumb military. What’s the harm in keeping a better record for people on the street? Keeping track of ID, people deteriorate really fast. Drugs take away from the hurt and the suffering and the pain on a daily basis.

*Where do you get help for your health needs?*

I’ve started recently to go to the travelling bus. I’ve checked it out a couple of times. That was only for a mild painkiller and some vitamin B. It was a nurse. This one travels all over the city. They’ll just park out in the van. They don’t have anything substantial or any kind of heavy medication.

*Do they ask for an OHIP card?*

No. If you need it, they may say pick one of the hospitals, say St. Mike’s or St. Joe’s. But I know a lot of the people here, and I’ve talked to them. They don’t like going there because there’s a security presence in there that intimidates them. For some of these people, they fade in, fade out. Hygienically they aren’t smelling the best, or looking the best. People are putting them down. It’s a morale-type thing, so they don’t want to go there. The only thing they have to work with are the vans. They’ll do a cleaning or put a bandage on it. There are two levels of society, and unfortunately they’re not involved in the first one. The first one is always going to step on people, and it’s usually them. Treatments that they need, emotional, psychological, mental, it’s not available.

*In the past few years, has it been harder or easier to get health care?*

Again, they have so many regulations, so many procedures you have to go through. It gets frustrating when all you want is tell somebody, look I fell down and broke my arm, and they want a life history. The health profession says the government is cutting back. Why don’t the government make health care an essential service?

*Do you use a computer?*
I email, but very simple. I’m not computer literate. I’ll go to Neighborhood Link, or I have a Job Employment Centre card. So, I can go to those ones. Basically it’s like get onto the Internet and on the Yahoo, and then go into my email. Boom, that’s it. I don’t do anything computer-wise though. I used to tell my ex-girlfriend what was wrong with me, and she’d say to call me back in an hour. She’d give me the best out of three different alternatives.

Mick

*How long have you been staying with Open Access?*

Off and on for twenty years - about six years for the Open Access.

*What happens if you get sick?*

If I get sick, I just rest and make sure I’m warm. I only see a doctor if I’m bleeding or broken. Last time I went to the hospital was when I cut my hand open. I cut it on a porch [wheelchair] lift. I spent the whole day waiting in the emergency room.

*Do you have an OHIP health card?*

I just received it back a month ago. When I’m on the streets, I don’t carry my ID with me. At the time I went to the hospital I had my ID with me ’cause I was working. When I’m on the street, I keep my ID in a storage locker at a shelter. They supply the locks, so if they need to get into it when I’m not around, they have the combo.

*Why don’t more people do that?*

There’s only so many lockers to go around, and they’re highly coveted. It’s one of the few places that are truly safe. People don’t care about having ID, because if they don’t have ID, they can’t get “c-picked”.

*What’s c-picked?*

Checked out by the police. CPIC [Canadian Police Information Centre]. It’s an actual acronym. You can give any name you want. Since you don’t have anything with your name on it, they have to believe you, and if they don’t believe you, they know you by sight. Then you’re SOL [shit outta luck]. But if they don’t know you and you don’t have any ID, you can just say you’re Joe Blow. They don’t know. You could have warrants out. You could be a bad guy from the States. You could be anything. Usually people who give a false name are wanted for something.

*What about probable cause?*

Well, it happens [being c-picked] when you do something stupid like drinking or smoking a joint.

*So it’s advantageous not to carry ID?*

Yeah, that’s right.

*Do you ever see a doctor for anything?*
Yeah, when I broke my ribs. When I broke my ribs and got stabbed.

*Stabbed?*

Somebody broke a bottle and stabbed me. He threw a bottle at me.

*Did you have an OHIP health card at the time?*

No, I don’t think I did. They found me unconscious on the side of the street. I had bits of glass in my head. I just woke up in the hospital and walked out. They gave me some pills, and asked me to get an x-ray. I had the blue hospital card from St. Michael’s. I know my OHIP health card in my head. Because I don’t have it, I’ll memorize the number in my head. Because I don’t always have it. I try to remember as much as I can in my head.

*That’s really smart.*

I always forget the two numbers on the end. That always changes.

*The version code.*

Yeah, I always forget that.

*Have you ever had any problems getting health care?*

Usually it’s security who gives me a hard time if I’m just sitting there waiting, and waiting, and waiting with everyone else. I don’t like security guards.

*Why is that?*

They think I’m there to abuse the system. I say: “No, I hardly ever come in here.” Usually I’m just passing through to use the washroom or something.

*So, what does that look like? There’s a waiting room full of people, and someone will come up to you?*

Yeah. They say: “Why are you here?”

And I say: “My hand.”

“OK, well you’ve been here a long time.”

“Well, that’s because I’m still waiting.”

They don’t know how long I’ve been waiting, but they say: “You’re still waiting. You’re still waiting.” I’m not going to go outside bleeding, just to keep your little room cleaner.

*So are you saying they identify you, and nobody else in the room?*

Yeah. I don’t cause trouble. I can go three or four days without saying a word to anybody. And I can sit there for hours waiting patiently. But they think I’m sitting there taking up space, or breathing their valuable air, or whatever. I don’t know. I don’t know. I rebel against authority. And if they have a uniform on, that’s even worse.

*In the past few years, has it been harder or easier to get health care?*
About the same. Last time I had to spend overnight in the hospital about twenty years ago, it was a doctors’ strike. Still no service now – just a lot of waiting. 12 hours for stitches is quite a while. But I don’t go enough to say.

Do you use a computer?

Just to surf the web. I have an email address, but no Facebook.

Donald

How long have you been staying with Open Access?

20 years anyways. I work here in the kitchen in the morning. I’ve been doing that for about 10 years. And I was coming here about five years before that.

Do you have a health care card?

Yeah. I lose ’em, but I get new ones.

How do you do that?

I just go apply. I used to drink a lot. I used to lose my ID a lot. They have me on their computer. I got an agency letter. OHIP doesn’t want to see any ID if I have that letter.

That’s a good system.

I have a cardiologist over at St. Mike’s. I have a hep C program. It’s a full time job.

Have you ever had problems getting health care?

No, nothing. I got chronic liver disease, chronic lung disease, and chronic heart disease all at the same time. You know? I got hep C. I knew a dozen years ago I had that, but it didn’t mean anything. Then I found out that I had emphysema, and I’d had another heart attack. I was staying at another shelter, and they had me up and down three flights of stairs. There was no bed rest. They won’t let me stay there in the daytime. I got trapped there for six months. I can’t do anything for my hep C because of my heart. I can’t do anything for my lungs, because that will affect my heart. I have to wait until my heart settles down. They’re looking for housing for me, but we’ll see what happens. I will have to go to the hospital. It’s a matter of when. They’re going to have to do something for my emphysema ’cause my lungs are getting worse.

Is it harder or easier now to get health?

I know the system.

Do you use a computer?

No, I’m illiterate. I can read and write, but I don’t do anything with the computer. You know, cigarettes are killing me. I quit smoking crack, and I don’t drink.
Ida

How long have you been staying with Open Access?

16 years. All different places. I only go to the ones I know. I have a place. I come here for the food. I drink a lot, so sometimes I sleep outside.

How do you feel?

I’m not healthy a lot. For a lot of things.

Do you have a health care card?

No, I’m supposed to get one this week.

How will you get one?

I’m working these workers, my housing workers. They’re supposed to help me. But like I say, I drink so much. My nighttime is daytime, and my daytime is nighttime. So, it’s hard to get up.

I see. You’re up now, but no one is around to help you?

In the daytime I want to sleep. I can pull up [sleep on] a sidewalk. I can sleep anywhere.

What happens when you get sick, and you don’t have a card?

I would go to a hospital if I needed to. They know me very well. The majority are fine, but you sometimes get the odd asshole. Sometimes I don’t get what I need, or what I think I need. I can get very verbal when it comes to that. Like when it’s taking too long, and I am in tears crying, and they see me, and I can’t move, and they let me sit for six hours. They usually have me in and out of there pretty quick. I’m pretty verbal. Then I get kicked out by security.

Do you lose your card quite a bit?

Yeah.

Do you use the computer?

Email. My friend helps me.

Fred

How long have you been staying with Open Access?

About 10 years.

Do you have a health care card?

Yeah, I have everything but a SIN card.

Do you ever lose your cards?
I do, but I usually go to a clinic [ID clinic].

Do you have a family doctor?

I usually go to a drop-in clinic. You don’t need a health care card on Sherbourne. You can walk into any emergency hospital, and you can get help.

Have you ever had problems getting health care?

You can walk into any emergency hospital, and you can get help. If you don’t answer the questions, they can be pretty blunt. It comes across as a bad attitude.

Has it been harder or easier to get health care in recent years?

I prefer to go to the hospital than the drop-in. The hospital can give you help right away.

How do you feel?

Not very healthy.

Do you ever use a computer?

Yeah. I go to the library or a drop-in place. It’s free. I email and use Facebook. I look up stuff, but they always ask me for money, like Ask.com. It’s really stupid. They say, “Give me $10, and I’ll give you a response”. But you know that’s just wrong. [Laughs.] You also have to give them a valid Visa card. They just want the number.

Laura

How long have you been staying with Open Access?

9 years off and on. Like not straight every year. I’ve had my own place in between. But yeah, nine years. Tomorrow there’s two other sites. Tuesdays, it’s the hardest one, when Open Access doesn’t start until January 10. ’Cause Tuesday there’s only one site. So, you have to be there early or you you’re not going to get a bed.

How do you feel?

I’ve been using for like 10 years. My drug is crack cocaine. I’ve been using since I came to Toronto. I fell in love with crack right away. I’ve been using it ever since I came here. I’ve lost my kids because of the addiction… They took him away when I was sleeping. I knew what was going to happen. I figured they could have woken me up to say, “Bye.” Their point of view is that if we would have woken you up, you would have gotten attached to him, and you wouldn’t have wanted to let him go. I knew I would have to let him go, but I wanted to hold him. But I went to sleep. That’s when they took him away.

Could you fight for your [youngest] baby, or was there no hope?

There was no hope. Like, I already knew. I knew in my heart I was not ready to stop using drugs. I knew in my heart. The reason they took him is that they found traces of cocaine in his blood. So,
that’s why they took him away. For that reason, and because I already gave up my daughter to Children’s Aid. Once you’re involved with Children’s Aid, you’re red flagged. Like even if you go have another one and you have your stuff together, they will go get into your life, and see how they can take your kid away.

*How does that happen?*

The hospitals. Once the hospital knows you’re here to have a baby, they punch your name in the system. Involvement with Children’s Aid shows up on the computer. I’m glad the baby came out as healthy as he did. He was almost full term. The doctor came up to me in the room. I was still a bit groggy because they have me some drugs, but he said, “Listen, you have a beautiful 5-pound baby boy. Would you like to see him?” I said yes, but then I fell back asleep. When I woke up the next day, I thought about it, and I thought the only way I knew I could deal with it, is that I went up to the nurses’ station, and “Listen, I’m OK, I don’t want to see him.” Because I knew if I would have seen him… It would be very hurtful for me. I knew I wasn’t taking him back.

*Do you have a health care card?*

Yes, I do.

*Do you ever lose it?*

Yes, I do. I’ve lost it. I go to either 777 Bay Street and apply for another card, or if you don’t have ID, what you need is a letter from someone saying who you are. So I would go to an agency. They know who I am. They know my first and last name. So they write a note for me. I bring that to 777 Bay Street, and they say, “Good enough.” And they issue me a health card.

*Have you ever had problems getting health care?*

I have a family doctor at a drop-in centre. I get tested for all kinds of stuff. She will test me for diseases. I did a test three years ago. Here’s an example of how addiction can take over your life: they found something on my cervix. I’ve been letting it go for three years. I finally got another appointment in January. I had other appointments, but I kept letting them go, letting them go, ’cause I was too busy getting high.

*What else do you do during the day?*

I need to do laundry, I need to go to the food banks. It’s not easy. Everything else comes in the way, so I’m not able to make it.

*You’re busy.*

Having an addiction doesn’t help.

*Do you ever is the computer?*

Email, yup. Facebook, no.
Tanya

How long have you been staying with Open Access?

7 years.

Do you have a health care card?

No.

Do you want one?

I don’t really want one. When everything else gets settled, I will think about it. But day-to-day, when you are on the street, you can’t really think about that. Like a health card, what am I gonna do with that?

So, do ever want to see a doctor?

No, not really.

What if you are sick with the stomach flu?

Well, then it’s a hard thing. I go to the emergency.

Are they nice to you?

No, not at all. They make you wait longer, they are not as nice to you. You’re homeless, so they look at you like you’re a piece of virus.

How do they know you are homeless?

Of course they know.

Is it because you tell them, or they can see something on their computer?

They just know. They see homeless people 24 hours a day. They just know. You don’t get treated the same. You’ll get the odd one who treats you like normal, but other than that, not really. I was sick still, and they released me from the hospital, and I’m still sick.

Do you ever go to the travelling health bus or anything informal?

No, just the hospital.

Are you too busy do you think?

It’s not that I’m too busy. You just can’t trust too many people. You can’t trust too many people, doctors, dentists.

Have you ever had problems getting health care?

Until after 16 hours of waiting. And then having to do something, and them calling security. They were pushing everyone else through. They gave me a shot of Gravol and released me – for getting picked up in an ambulance. It was a stomach flu, something like that.

In the past few years, has it been harder or easier to get health?
Easier for me, ’cause I got a good man, and my clothes are always clean. Things for me are progressing. The more normal you look and the more active you are in the normal mainstream, the more people treat you better. I’m cleaner.

Appearance matters?
Absolutely. You gotta go with the normal. I feel better for myself, which makes me progress even more.

But you’re still here?
I still come here ’cause it’s a social club. These are my buddies. [Gets up to break-up a fight.] This is what I’m trying to tell you [about people in shelter]. This is what I’m trying to tell you.

Do you ever use a computer?
No, I do not. GPS high in the sky. I am not crazy. Absolutely. I could if I wanted to - I have the capability and knowledge.

Jake

How long have you been staying with Open Access?
About 10 years. I had a place for three years. Rats actually. I had it until the beginning of the summer. They were in the ceilings. It was just a matter of time until they came into the house. They were walking up and down our driveway. Normally they are skittish of people. These ones were huge. They were the size of lap dogs. Seriously. They were incredibly big. One of them I thought was the size of a raccoon.

Do you have a health care card?
Yes.

Do you ever lose it?
Yeah, I do.

How do you get a new one?
If you know the circuit, you don’t need a health card, like on Sherbourne. I don’t think I’ve shown my health card in three years. Years ago when I lost the red and white card, it was a pain in the ass. They have everything at Sherbourne. They even have an infirmary. They monitor people who are under-housed or homeless. They monitor you.

Have you ever had problems getting health care?
Sometimes a doctor can be pretty callous. So quick, like get you out of there. I try not to go in there. I try to go to Sherbourne. Your health is ongoing. You need a log. Like when I go in and they see all my tattoos. “Oh, look: he’s a drug addict. Here we go again.”
How do you feel?
I feel like shit right now. I got bit up at another shelter. The guy had AIDS. The infectious disease [centre] at St. Mike’s says they have a 99% success rate. But nothing is guaranteed. He only bit me. The [post-exposure prophylaxis] pills make you feel terrible.

Do you ever use a computer?
I email all the time. I lost my Facebook password. I look up stuff on the Internet – like the pills I’m on.

Lyle

How long have you been staying with Open Access?
I’m really homeless. Not like 70% of people here. They like the food and they like the breakfast. My throat is sore. I sleep outside.

Are people nice [here] – the guests?
For the most part. You know when you buy a bag of apples, and you get one bad apple? They need the money to get a fix. Me, I need the money to buy food and cigarettes. There’s all sorts of addictions.

I’m interested in all the stuff you have to go through in life to get stuff done – paperwork, forms, documents, identification.

ID’s, stolen ID’s?
Yes, ID’s, too.

Mine got stolen.

What happened?
I had my stuff over there [indicating his duffel bag across the room]. And all of a sudden my wallet and everything was gone. I’m going to apply for my ID’s on Wednesday.

How?
I go through a drop-in up north. They even stole my bankcard. I got a temporary one. I sleep on the streets. My ID’s are going to a drop-in centre. You should watch your stuff.

So, do you have a health card?
Everything got stolen. It happened to me before. I saw him [an agency worker] last Wednesday, but he was busy. Come early. Come at 9:30 or 10:00. Three weeks, a month, boom, boom, boom. He’s going to give me a letter to go to get a health card. I can get you a copy.

Have you ever had problems getting health care?
I go to the emergency. They can’t refuse you. You tell them what happened. They check you. They tell you to go back in when you got it. They have to help you. You’re Canadian, so they see that. I lost it one time. I lost four ribs, but I told them, I lost my card. I’m in the process of getting it. So they actually billed me, ’cause I waited too long. It cost me $3800, so I brought in my card. Then you call OHIP, and you tell them what happened.

*That sounds like a pain.*

It is, but the pain is the butt is the person who steals your ID’s. What are they going to do with it? There is nothing they can do with it.

*When did you lose it?*

5 weeks ago.

*Do you ever use the computer?*

No, not anymore. I got an addictive personality. And I went to school for computers. I’m actually incredibly good on it. I went for web page making and design from the codes. I don’t want to go near a computer, ’cause if I jump on it, I’ll never get off. I used to have an email address at Yahoo. I just quit it.

**Walt**

*How long have you been staying with Open Access?*

For the last month. I did it all year in 2000. I came back three weeks ago and now I’m looking for housing. I had subsidized housing, but it became a drug house, so I said I’m getting out of here. I very seldom drink. I smoke cigarettes. It would be a bad thing to stay at a drug house. People coming in and out all hours of the night.

*Do you have a health care card?*

Yup. I have all my ID. I train martial arts, and I do a lot of walking. I have lots of clothes.

*How do you manage to keep hold of your ID?*

I keep it on me. Now there are so many drugs around everywhere. The heavy stuff. You can’t trust anyone. I can trust maybe one person in here [Open Access]. I know Lyle.45 He always puts you in the right direction. He’d never do you wrong.

*Have you ever had problems getting health care?*

I go to St. Mike’s hospital. I keep pretty good. I went and got a flu shot the other day. When I’m working, you have to be up to par. My eyesight is good. I’m in good shape. I know my body. My

__________________________

45 A pseudonym is employed in order to protect the identity of the interviewee.
mother was a diabetic and she died at a young age. You have to watch what you eat. You have to take your vitamins.

*What about seeing a non-emergency doctor?*

The Meeting Place drop-in? I’m sure I could get something there. If I went into another drop-in clinic, they would give me a form.

*But you could go anywhere, 'cause you have a health card, right?*

Right. Maybe I should just go in for spite, and say: “I want to see a doctor.” Maybe I’ll do that tomorrow.

*Do you ever use a computer?*

Well, I do text messages. If I need something done, a friend who will do it for me. As for video games, I don’t have time for that. Like faxing resumes, I can do that from the job centre.
Appendix B: Letter to Participants

To: Name of Potential Participant
Subject: Letter of Consent to Participate in OISE/University of Toronto Study
Title of Project: Adult Literacy, Health Care, and the Homeless: An Institutional Ethnographic Study of the Social Organization of Health Care

You are invited to participate in a study that I am conducting at the Ontario Institute for Studies in Education at the University of Toronto. The purpose of this study is to explore and assess the challenges faced by homeless individuals when attempting to gain access to free health care services in Ontario. You are invited to participate because of your first-hand knowledge of the ways in which individuals without a permanent home access a variety of health services in Toronto. I am interested in your first-hand experiences of attempting to gain access to health care in Toronto.

You will be asked to participate in one interview that will take approximately 45 minutes to complete. With your permission, the interview will be recorded in audiotape format in order to aid in the transcription of the interview at a later date. The information you share will help identify some of the barriers that individuals may face in gaining access to health care services. All materials and results will be kept confidential, and, in particular, your names and/or identifying or identified information will not be associated with the data, unless you explicitly indicate otherwise, or where disclosure is required by law. (The researcher has a duty to report where there is reasonable suspicion of child, dependent, or elder abuse or neglect, and where a participant presents a danger to self.)

If you wish to participate in this study, please complete the consent form below. I have carefully read and understood the details of the study outlined in this letter. I understand that no information will be released or printed that would disclose my personal identity, and all such research data will be destroyed upon the completion of the project on January 1st, 2018. Any risks or benefits that might arise out of my participation have also been explained to my satisfaction.

I understand that my participation is completely voluntary, and that my decision either to participate or not to participate will be kept completely confidential. I further understand that I can withdraw from the study at any time without explanation and without negative consequences. Any questions I have asked about the study have been answered to my satisfaction.

Name of Participant (please print)  Participant’s Signature  Date

☐ Please contact me with results of this study once they are published (check √ the box).
Contact information (email or telephone):

230
Appendix C: Interview Questions

1. How long have you been with Open Access?

2. What are some examples of your health care needs?

3. What happens when you get sick? Where do you go?

4. Do you have a health card? If not, how do you get help without a card?

5. Have you ever lost your health card? How do you go about getting a new health card?

6. Do you have a family doctor? If not, why not?

7. Have you ever had any problems getting health care? If so, how?

8. Do you feel that it has been harder (or easier) to receive health care services in recent years? If so, in which specific ways?

9. Do you have access to a computer with an Internet connection? What kinds of things do you use the computer for?

10. If you could change something about the health care system, what would it be?

11. Is there any way I can contact you in the future (email, etc.)?