Diabetes Care and Serious Mental Illness: An Institutional Ethnography

by

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Bloomberg Faculty of Nursing
University of Toronto

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Abstract

People with serious mental illness are genetically predisposed to diabetes. Their risk is heightened with the use of atypical antipsychotic medications. Contextual conditions also influence diabetes care and outcomes. There is a lack of research on diabetes care for the mentally ill in residential care facilities. Therefore, there is little understanding of the social relations that contribute to this group’s health disparities. Institutional ethnography was chosen to explore this phenomenon in a group of 26 women in a rural for-profit group home in southern Ontario. Work activities of residents and providers were examined to map out the social organization of health inequities. Interviewees included residents with diabetes, care providers, field workers, and health professionals. Observations and analysis of coordinating texts were further methods used to reveal disjunctures between discourses embedded within diabetes care guidelines and the actualities of living within imposed constraints of group home care. The overarching State interest in cost containment creates rationing that limits the care afforded residents, resulting in poor dietary intake and lack of quality of life opportunities. Further, group home policies regulate systems of safety, reporting, and financial accountability, but do not promote health. The medical and psychiatric divide also contributes to health disparities.
Diabetes care provision supports ‘self-care,’ which is challenging for this group, and health providers lack understanding of contextual constraints. Combined, these social circumstances perpetuate disease development and make illness management difficult. These findings warrant the need for State financial support and policy changes that give primacy to illness prevention, health promotion, and medical management so the mentally ill can realize health and wellbeing. A linkage between mental and physical health care is also crucial. Further, health providers are urged to be critical of social ideologies that sustain health inequalities, and to deliver services that are sensitive to unique particularities.
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# Table of Contents

Diabetes Care and Serious Mental Illness: An Institutional Ethnography ....................... i

Acknowledgments ........................................................................................................ iv

Table of Contents ........................................................................................................ v

List of Figures ............................................................................................................... xii

List of Appendices ...................................................................................................... xiii

Prologue ....................................................................................................................... xiv

Anne’s Appointment ................................................................................................. xiv

Anne’s visit with the dietitian ................................................................................... xv

Anne’s visit with the nurse ......................................................................................... xix

Background ............................................................................................................... xxiii

Findings ...................................................................................................................... xxiv

Discussion .................................................................................................................. xxvi

Problematic for Further Inquiry: The thesis ............................................................ xxvii

Chapter 1 ................................................................................................................... 1

Problem Statement .................................................................................................. 1

Relevance and Scope of the Research Problem ......................................................... 1

Purpose Statement .................................................................................................... 2

Rationale for this Study ............................................................................................ 3

Researcher’s Background .......................................................................................... 3

Diabetes care knowledge from group home operator role. ...................................... 3

Diabetes care knowledge from the Quality of Life Coordinator role ..................... 4

Background knowledge from diabetes educator role. ............................................. 5

Research Strategy ...................................................................................................... 6
Chapter 2 Review of the Literature ................................................................. 9

Introduction ........................................................................................................ 9

Review of the Health Sciences Literature ......................................................... 10

  Second generation antipsychotic use and diabetes. ...................................... 11
  Lack of integration between medical and psychiatric care. ......................... 13
  Health behaviours and level of physical activity. ......................................... 15

Summary of Health Sciences Research ............................................................ 19

Critical Appraisal of the Health Sciences Literature ......................................... 19

Qualitative Literature Review: Diabetes Illness Experience ............................. 21

  Representative articles. ................................................................................. 21

    The diabetes illness experience. ................................................................. 23

    Gender-specific considerations. ................................................................. 26

    Reflections for health care providers. ......................................................... 27

Summary of Qualitative Literature Review ....................................................... 29

Critical Appraisal of the Qualitative Literature ............................................... 30

Institutional Ethnography: Review of Literature .............................................. 31

Institutional Ethnography as a Method of Inquiry ............................................. 36

Chapter 3 Methodology and Research Design ............................................... 38

Philosophical Assumptions of Institutional Ethnography ................................. 38

Principles of Methods Used in Institutional Ethnography ................................. 41

  Participant observation. .............................................................................. 41

  Interviewing. ............................................................................................... 42

  Textual coordination. .................................................................................. 42

Other Methodological Considerations ............................................................. 44

  Fieldnotes. .................................................................................................. 44
My utopian perspective. .................................................................................................................. 203
Implications for policy changes. .................................................................................................. 204
Implications for health care providers. ...................................................................................... 210
Implications for changes within the group home. ....................................................................... 212
Implications for future research. .............................................................................................. 213
Strengths and Limitations .......................................................................................................... 215
Strengths of this study. .................................................................................................................. 215
Limitations of this study. .............................................................................................................. 215
Concluding Remarks .................................................................................................................. 216
References ..................................................................................................................................... 219
Appendix B: Interview Discussion Topics Guide for Field and Social Workers ...................... 238
Appendix C: Observational Study Guide .................................................................................... 240
Appendix D: Government of Ontario Mental Health Reform Policy Documents .................. 241
Appendix E: Lodging Houses By-law ......................................................................................... 245
Appendix F: House Rules ............................................................................................................. 265
Appendix G: Homes for Special Care Cost Sheets ...................................................................... 266
Appendix H: Menu at Rolling Hills .............................................................................................. 268
Appendix I: Letter from Regional Government .......................................................................... 274
List of Figures

Figure 1: The Annual Inspection Process: A Visual Account .................................................... 105

Figure 2: The Medical/Psychiatric Disconnect: A Visual Account ............................................ 149
List of Appendices


Appendix B: Interview Discussion Topics Guide for Field and Social Workers ..................... 238

Appendix C: Observational Study Guide .................................................................................... 240

Appendix D: Government of Ontario Mental Health Reform Policy Documents ................... 241

Appendix E: Lodging Houses By-law ....................................................................................... 245

Appendix F: House Rules ......................................................................................................... 265

Appendix G: Homes for Special Care Cost Sheets .................................................................. 266

Appendix H: Menu at Rolling Hills ......................................................................................... 268

Appendix I: Letter from Regional Government ....................................................................... 274
Prologue

Anne’s Appointment

At 9 a.m. Anne\(^1\) enters the diabetes clinic using a cane for support, accompanied by the woman who has been hired by the group home to drive her and the other residents to their medical appointments. Anne is approximately 162 cm tall but slouches over and has a large curvature in her spine at the shoulder area. She’s pale with fragile, aging, wrinkled skin, and straight brown hair that is graying, pulled back into a ponytail with a red hair tie. She is wearing dark blue polyester pants and a worn looking green sweater.

Both Anne and the driver approach the front desk. The secretary says, “Hi” to the driver from behind the half wall and asks her, “Is this Anne?” The driver confirms this and instructs Anne to sign the ‘consent to treat’ form the secretary has handed her. The driver holds Anne’s patient profile sheet, which contains her personal information, including her medical and psychiatric diagnoses, health and social insurance numbers, family physician and psychiatrist, next of kin, and list of medications she is currently taking. This document represents Anne at this and other medical appointments she attends. The secretary takes this form, along with her blood glucose records, and puts them into Anne’s file that already contains the referral form. This chart will be used at subsequent visits to track biomedical progress. Anne stands silently behind the driver while she pulls out Anne’s health card from her purse to give to the secretary, who enters the pertinent information into the computer. The driver informs the secretary that she is going shopping and inquires as to what time she should be back. She says, “Goodbye,” and tells Anne to hang onto her health card until she gets back. Anne takes a seat in a chair in the far corner of the waiting room and I sit beside her.

These initial interactions, which happen over a matter of a few minutes, immediately make visible Anne’s “health work” (Mykhalovskiy & McCoy, 2002, p. 17) as a person living in a group home. The home staff organizes medical appointments and transportation, and the driver is responsible for carrying Anne’s health card and ensuring she arrives safely to her appointment.

\(^1\) Names of participants and locations have been changed to protect anonymity.
Upon arrival at this particular clinic, Anne is instructed to sign a consent form without explanation from the secretary, who never does speak directly to her. The secretary uses this form, the referral from the physician, her medical profile sheet, and blood glucose records to create a chart that becomes representative of Anne, providing information deemed important for her care provision. These processes also begin to show how documents are central in organizing this visit, which becomes clearer as Anne’s appointment proceeds.

Anne recently moved into the group home, coming directly from Halifax, Nova Scotia to be closer to her parents, who retired in Ontario. While we are waiting she starts conversation and before too long she asks me, “Can I get off insulin because pills are cheaper aren’t they?” She is worried about the cost of insulin and she states, “The nephrologist told me if insulin is under 12 units you don’t need it.” She also states, “I want my creatinine and hemoglobin results because those are important to keep watch of because of my kidney transplant.” We are only waiting for 10 minutes before Anne is called in by the dietitian. This is enough time for me to realize that Anne is an intelligent woman and very informed regarding her diabetes and her kidney transplant. However, as she moves through her assessment appointment it becomes apparent in her interactions with the clinicians that she is perceived first and foremost as a woman with mental illness who lives in a group home, a situation that controls the type and amount of diabetes care she receives.

Anne’s visit with the dietitian.

“So, you’ve been diagnosed with diabetes for four years?” the dietitian inquires while scanning the referral form. “You use your meter two times a day?” checking her blood glucose records provided by the home. She exclaims Anne’s numbers are “spectacular.” She asks, “What time do you eat?” while confirming glucose readings are taken before breakfast and dinner. Filling out a form while she talks, she asks Anne what a typical breakfast would look like.

Anne states, “We have porridge or cold cereal and toast and coffee.” When questioned if they have juice at all through the day, Anne answers, “The diabetics get diabetic juice at lunch, afternoon break and supper.” She states, “I would like real juice but the home can’t afford it.” The dietitian asks how many people are in the home and Anne responds, “26, and if they give me juice they have to give it to everyone.”
The dietitian goes back to the form and asks, “What do you put on your toast?”

Anne exclaims, “I would like honey but we don’t get that in the home. Honey is a natural antibiotic, so it is good for me.” Anne then notices the dietitian drinking her water, to which she remarks, “Perrier water: nothing but the best for the dietitian, eh? And I have nothing.”

Moving on, the dietitian asks, “Do you have a snack in the morning?”

Anne replies, “We have coffee at 10 a.m. but we don’t have food. Diabetics should have food all day, little portions all day. They give big portions at this home. I can’t finish the food they give me on my plate. I eat it most of the time though, because I feel bad wasting good food.”

The dietitian asks, “Have you said anything to them at the home that the portions are too big for you?”

Anne exclaims, “No, it’s not my place to say anything.” The dietitian asks Anne what time lunch is served and she answers, “11:45 and everything is HOT (with excitement in her voice) and that is good…grilled cheese, bacon, eggs, beef, HOT and that is good.”

The dietitian then asks, “What time is dinner and what do you have?”

Anne replies, “Well, we have vegetables, frozen, and we are allowed now to have regular Jello and pudding because diabetic pudding is expensive. At night I have a slice of toast instead of cookies.”

The dietitian responds, “Do you have peanut butter on your toast at night?”

Anne states, “No, you would have to recommend peanut butter so I could have it at any other time besides breakfast. Special requests in writing have to be followed at the home, like fruit. Fruit is expensive so they’re cutting back on fruit distribution.” Anne exclaims, “Carol’s cutting back because she tells us she can’t afford it, to feed us things like fruit. I’m lucky though, because my son brings in fruit for me…cherries. I’m special. There are no grapes or kiwi on the menu at Carol’s. I would like to have grapes and kiwi. I would really like to have crackers. Do you think you could get them to order a box of crackers for me? Unsalted.”
Throughout Anne’s requests the dietitian is silently filling out the ‘Dietary Intake Record,’ and then asks, “So for dinner, what would you normally have?”

Anne answers, “We have soup, like tomato, cream of potato, but sometimes it’s too salty so I can’t eat that when it’s too salty because I have the transplant.”

The dietitian questions, “Do you eat it even though you don’t like it?”

Anne replies, “Yes, I realize as a diabetic I can’t skip meals.” The dietitian then asks Anne where she had her kidney transplant and she replies in Halifax in the year 2000. Anne explains that her diabetes was caused by one of the drugs she used to take, ‘KFOG.’ She says that before she started taking KFOG she was on Cyclosporine but one of the side effects is facial hair and her father complained that she was growing a beard. She explains she was unaware that products to remove facial hair were available so she switched to KFOG and got diabetes.

The dietitian shows Anne a plate with partitions to show quantities of meat, vegetables, and starches that should be consumed. Anne states, “They serve a lot of potatoes and lots of other starch.”

“Do you put your own food on your plate, Anne?” asks the dietitian.

Anne answers, “No, it’s not buffet: they serve it.”

The dietitian asks, “Can you tell them you want less starch?”

“No,” says Anne.

“Could you ask for small portions?” the dietitian asks.

Anne replies, “It’s not my place.” She asks the dietitian, “Could you get me crackers?”

“Ok, I’ll request that. Are you having any lows?” asking the next question on the form she is filling out. She notes all of Anne’s morning glucose readings are perfect, but she has a few out-of-target readings before supper.
“Well,” Anne states, “Those times I cheated.” The dietitian asks her what food she has that she thinks is cheating and she replies, “Maybe I’m eating potato chips. I pick them up for a dollar at the…plaza when we go shopping. I eat them every day or so in the afternoon in my room. They had diabetic chocolate in Halifax.”

The dietitian explains, “Yes, you can have dark chocolate because it doesn’t have any more sugar than diabetic chocolate.”

Anne looks excited and says, “Write that down because they won’t believe me! Write it down because they won’t let me buy it. I’m going to buy a bag of oranges so I can have them whenever I want. They say we can only have fruit at mealtime, is that true?”

The dietitian responds, “No, diabetics can have fruit anytime but it may be a rule at the home.”

“Write that down please. I could buy plums and kiwis.” Anne pauses, “Well, I need to keep them in the fridge and the fridge won’t be open at snack time. Only two people have the key.” The dietitian bypasses this comment and asks, “Do you have milk and cheese?”

Anne replies, “I don’t like milk and we get cheese slices. I like cheddar cheese, mozzarella, lots of cheeses but we have to buy our own cheese with our pin money (Personal Needs Allowance) and we only get $119.00 a month.” Looking at the form the dietitian asks Anne if she has yogurt, to which she replies, “I have to buy my own. I could put the fruit in it that I buy, like a banana. I love fruit in yogurt. But if I had yogurt and fruit that would make me special. I can’t do that, no I can’t have that.”

The dietitian suggests that Anne buy fruit twice a week when she’s shopping so it doesn’t go soft. “I go shopping once a week. I can’t afford to go shopping any more than that. Halifax had transit and I used the bus. Here we don’t have a transit system where the home is located.” The home is in a rural location, which restricts access to local transit.

The dietitian asks, “Do you have a nephrologist?” Anne responds, “Yes but I only see him once a year and what good is that? I used to see the nephrologist every three months in Halifax.”
The dietitian asks, “Have you ever been told to avoid anything for your kidney?”

Anne replies, “Salt.” She then asks the dietitian a question she wants answered, “When do you change the insulin in the pen? Is it when you see the ‘r’ line in the window?”

The dietitian responds, “You can ask the nurse that question. You see her next.”

Anne states, “What I asked you to put in writing, you have to or they won’t take it for real. The extra soda crackers, the dark chocolate, fruit for snack. No, I will buy the fruit. Otherwise everyone will say they’re allowed to have it too.” The dietitian confirms that she will put it in writing and ends her part of the appointment by telling Anne to wait there while she finds the nurse, who will see her for the next hour.

The dietitian summarizes her visit with Anne in her verbal report to the nurse as follows: She states Anne has excellent readings, both fasting and 4 p.m. She tells her she takes NPH insulin 4 to 6 units and she is “pretty good.” She informs her that Anne has chips sometimes in the afternoon. She explains that meals are provided at the group home and Anne knows portion sizes and uses Crystal Light. She has little fruit in her diet and explains that she and Anne had discussed buying fruit. She tells the nurse that she also discussed canned fruit, which has reduced potassium for her kidney transplant that was done in 2000. The dietitian informs the nurse that Anne has diabetes knowledge and that she has a question about using the insulin pen.

While Anne is shuffled to the nurse’s office, the dietitian tells me that she felt her suggestions were limited due to Anne’s reduced access to fresh fruit and such things as high fibre foods. She also felt that portion sizes were a problem and this would be difficult to fix. Additionally, she had issues with the timing of glucose testing but did not feel it was something to mention to Anne because it was done this way in the home. The dietitian felt “…guarded with suggestions, as they may not be part of the home’s routine, and this may create trouble.”

**Anne’s visit with the nurse.**

The nurse enters the room and greets Anne by introducing herself. She starts by asking Anne if she tests her sugars before breakfast and dinner, and Anne says, “Yes.” Anne asks the nurse, “What is more expensive, pills or insulin? Is there a possibility that I can get off insulin?”
She explains as she did with the dietitian that the nephrologist in Halifax had told her if she was on less than 12 units there is no point in taking insulin and she is now on 6 units.

Seemingly ignoring her question, the nurse states, “There is no blood work here. Was it done in (name of town)?” Meanwhile she flips through the loose papers in the chart. She tells Anne that she is going to get the unit clerk to call for it.

Openly frustrated now Anne informs her, “This is the last time I am going to a diabetes centre. I’m a guinea pig with all my diabetes medications and having to cut back on my food. I had a goal to cure diabetes with all my stuff. I should have cured something by now!”

Again ignoring this comment, the nurse starts asking questions from the assessment form, inquiring about associated diabetes complications. The nurse finally receives the blood work and Anne sarcastically states, “Looks like the left hand doesn’t know what the right hand is doing here. My father says there are over 3 million people here and there are 300,000 in Halifax, so maybe it’s easier to keep track of everything there. I’m only interested in the creatinine and the hemoglobin in that blood work. I’m not interested in anything else.”

Instead of giving her the results, the nurse asks, “Did the dietitian weigh you?”

Anne responds, “Yeah, 150.”

The nurse asks, “Now, NPH, have you been on that since your transplant?”

Anne explains for a second time, “No, three years later. My diabetes is not from adult onset 2, it’s a side effect of KFOG. I was on Cyclosporine and got facial hair. My father complained that I was growing a moustache. I didn’t know there were products to remove facial hair so I switched medications and wound up with diabetes.”

The nurse asks, “Do other family members have diabetes?”

Noticeably upset, she responds, “NO, mine is from a side effect!”

The nurse continues, “Do you have a kidney specialist?”
“Yes, but I only see him once a year, isn’t that ridiculous? He is from St Mike’s and he came to see me but he did no exam. He didn’t have me lay on a table. He didn’t check my side. He didn’t do any examination on me at all!” as she shows the nurse the area he should have palpated.

Continuing to fill out the form the nurse asks, “What is your ophthalmologist’s name?”

Anne exclaims, “YOU’VE GOT TO BE KIDDING! I DON’T KNOW!”

The nurse questions, “What time do you take your insulin? Do you give it to yourself?”

Anne replies, “Yeah. I use the pen. When do I change it? I remember when I was at a diabetes clinic in Halifax they said to change it at the green line.”

The nurse replied, “Change it when it starts to get low. Where do you inject?”

Anne answers, “I inject in my legs,” as she shows her where on the top of the thighs. “I don’t like to inject in my stomach because I have scar tissue.” She shows her the scar on her abdomen. The nurse demonstrates how to change injection sites to reduce the chance of scar tissue forming and thereby reducing the ability for the insulin to absorb readily.

Again Anne states, “I would like to get off the insulin,” to which the nurse responds, “Your numbers are very nice,” as she shows her the blood glucose records from the home.

The nurse says, “You need to ask your doctor that. Who is the doctor that is responsible for your diabetes? You need to ask him.” She continues to fill out the form, “What type of meter do you have?” She looks at the meter, “Oh, a One Touch Ultra 2. Where do you test?” Anne shows her the one finger she uses, which is calloused from doing finger pricks. She asks, “How do you treat a low?”

Anne replies, “I take a nap. I don’t know if it is low and I’d rather not test it.” The nurse continues to tell Anne how to treat a low if the sugar is less than 4 mmol/L and instructs her not to take powdered juice to get her sugar level up.
Again openly upset Anne says, “Don’t make me test all the time! I am bipolar. I’m in my 50s! Give me a break! Can I get off the insulin? I wanted to talk with the dietitian about my nutritional intake and the supplements I’m on. I guess I should ask the doctor but he doesn’t have time and I only see him for 10 minutes.”

Continuing to fill out the form without acknowledging Anne’s concern the nurse asks, “And exercise, do you exercise? What amount? For how much time?”

Anne sighs, “I walk, but it’s hit and miss with my arthritis and my problem with my spine. I walk up and down the driveway but I don’t time it.” The nurse does not inquire about the use of a cane, which Anne has draped on her left arm at this point. The nurse fills the section in on the assessment form about exercise. She asks Anne about short term and long term goals and completes this section without Anne’s input.

The nurse quietly states, “I guess continue with monitoring…” as she writes. She asks Anne, “Do you have any other questions? You’re ok with your pen, your testing, numbers are good, with your injections make sure you’re moving around. No other questions?”

Anne answers, “Can you ask the doctor if it is possible I can go off insulin? The nephrologist said I could go off if I was under 12 units and insulin is more expensive than medication.” The nurse tells Anne she should ask the doctor this question and then tells her, “Ok, I’m going to take your blood pressure now.” While taking Anne’s blood pressure she asks how her feet are.

“Well I have orthotics in the shoes and a foot nurse comes in to do our toenails every six weeks,” says Anne.

The nurse confirms, “So your feet are doing well?”

“Yes. I’m doing well.” Anne declines a follow up visit and the nurse doesn’t offer her the usual group sessions. Anne is discharged from the clinic with no further offers for diabetes education. The nurse finishes filling out the form, stands up and says, “Goodbye,” while Anne stands and approaches the door. It is now 11 a.m. and her driver is in the waiting room. She asks
for Anne’s health card back, which Anne retrieves from her wallet after some searching and passes to her. They say goodbye and exit the clinic.

Afterwards, the nurse discusses her thoughts with me regarding Anne’s visit. She comments, “I don’t know about trying to give education to someone with a lot of constraints with mental illness. She had no worker, and with a worker I can go through everything easier. I didn’t want to rattle her so I stopped all the time. I got some things accomplished. I suggested the side of her finger. Her numbers are good, so she’ll have to follow up with her doctor, but with her numbers being so good why would he want to take her off the insulin? She’s feisty but likeable… I was guarded though, unsure of myself, you know? We call them ‘EUs’ in ER, Emotional Upsets. We keep them comfortable. Don’t want to set them off.”

Background

The above excerpts were observations I made during a pilot research inquiry I conducted as part of a methods course in preparation for my thesis research project. I used institutional ethnography (Smith, D., 1990, 2005, 2006) as the method of inquiry to discover the disconnect between the social organization of diabetes care provision and the actualities of mentally ill adults who live in group homes. Interviewing and participant observations were used as the methods to collect data, and analysis focused on the exploration of social relations that create and sustain inequities. This pilot study was an important backdrop to the thesis project because it stemmed from my initial concerns as a diabetes nurse educator that our service provision might not be overly effective for a particularly vulnerable group of people.

Anne, who was chosen from an all female group home, was 54 years old with a dual diagnosis of schizoaffective and bipolar disorders, insulin dependent type 2 diabetes and had a kidney transplant. Anne is one of many individuals who has both mental illness and diabetes and is trying to manage her condition while living within the constraints of a group home environment. Her struggles as a woman faced with such extreme barriers became evident in this participant observation.
Findings

I show in this section how the above situation was structured in such a way as to silence Anne and impede appropriate assessment of her circumstances. I also highlight how diabetes care provision is organized in a manner that is ill suited for her and others with unique particularities. Work at this community diabetes clinic in southern Ontario is organized by diabetes practice guidelines that promote ‘self-care,’ whereby responsibility for illness management is assigned to the person with the condition. Further, as part of everyday work activities, clinicians entered into “text-reader conversations” (Smith, D., 2005, p.104), and interpreted and enacted various texts in their patient encounters. These social relations played a large role in coordinating diabetes care. Diabetes care provision is also organized in a manner that enhances patient volumes, while reducing labour costs, based on the requirements of the Ministry of Health and Long-Term Care, the primary funding agency.

All participants suggested in their own way in both the interviews and the participant observation that ‘living with diabetes is overwhelming.’ Although clinicians echoed that they attempt not to overload the patients, many questions are asked in order to complete the forms that direct care at the initial assessment appointment. Anne struggled with the number of questions that the clinicians asked her. By midway through her appointment she was visibly fatigued, stating that she needed “…a bolster. I’m tired; lots of concentration.” She only came to the appointment with two questions; 1) could she get off her insulin and 2) were her creatinine and hemoglobin levels alright, as this indicated to her that her kidneys were functioning properly. Neither question was answered, despite her repeating them several times to both clinicians. Although it was reiterated in the interviews with the clinicians that education is tailored to the individual, it did not appear to unfold this way for Anne. Both clinicians followed the forms in a sequential manner, attempting to complete their paper work and required tasks, while seemingly ignoring Anne’s presence as a person living with constraints above and beyond that of the typical person with diabetes. Anne, for example, stated that she maybe should ask the doctor about her nutrition intake and the supplements she was on, but she remarked, “He doesn’t have time and I only see him for 10 minutes.” Seemingly oblivious to Anne’s concerns, while still looking at the form the nurse asked, “And exercise, do you exercise? What amount? For how much time?”
Diabetes is a difficult chronic disease to manage, and those afflicted are expected to monitor glucose levels, lose weight, exercise, maintain proper eating patterns, make healthy food choices, have routine laboratory tests, and make regularly scheduled appointments with their physicians for blood pressure, eye, and foot examinations. For those taking medications and/or insulin, added responsibilities include testing for and treating hypoglycemia, and ensuring medications are taken at specific times in conjunction with food intake. Some people, like Anne, are not able to carry out all of the required diabetes self-care activities due to circumstantial situations, like imposed budgetary restrictions.

Anne was well aware of her marginalized position as a person with mental illness who lives in a group home and that her situation influences her diabetes care practices. This was apparent in many of her comments, like her acknowledgement of restricted access to fruit and real juice, and her not wanting to be considered ‘special’ by getting extras. She also alluded to not having full agency in decision making regarding food choices and portion sizes, and to not having access to affordable local transit to go shopping. She was wearing a worn sweater and remarked on the dietitian enjoying an expensive beverage, while she had nothing.

Another finding was Anne’s knowledge of how to obtain a few of the things she desired that were usually inaccessible to her by using her patient status, and by enlisting the help of health providers in the clinic. She decided she wanted a box of unsalted crackers, peanut butter at different times of the day (peanut butter was offered at breakfast only), fruit for snack, and dark chocolate. Anne insisted the dietitian put her requests in writing because she was aware that special requests must be documented to be considered for approval by the funding agency under which the group home operates.

A further discovery was the amount of knowledge Anne had in relation to her diabetes and her kidney transplant. She stated that diabetics should a) have little portions of food all day, b) consume sugar free juice, and c) she should have food that is not too salty, in view of her transplant. She gave a detailed explanation as to the cause of her diabetes and how it was not related to the kidney transplant, rather was a result of a certain medication she was prescribed. She was injecting her own insulin, was very particular as to injection sites, and she was careful
not to let the insulin in the pen get too low before changing the cartridge. She also tested her own glucose every day before breakfast and dinner.

However, even though she noted that Anne had a high level of knowledge, the dietitian did not offer her any diabetes education in view of her perceived circumstantial constraints. The dietitian did not introduce a goal sheet and the nurse filled out the short and long term goals without Anne’s input. Anne chose not to return for further visits, and diabetes educational class options were not discussed. Based on these findings, attitudes and assumptions regarding people with mental illness may play a significant role in what type and amount of education is offered. In Anne’s case, timing of glucose testing was not corrected, exercise options were not discussed, and numerous food-related concerns were not addressed because the overall assumption was that changes could not easily be made. Additionally, the work of clinicians seemed to be more focused on filling out forms.

Work was also organized at the diabetes clinic to enhance patient volumes, both because of the growing numbers of people developing diabetes that must be seen in a timely fashion, and because the funding body uses statistical information, like numbers of patients seen, as a marker for future funding. In order to provide ‘effective’ and ‘efficient’ services, strategies like group sessions were implemented and this trend will continue in the future. As stated by a dietitian during her interview, “...definitely the classes are a good thing in terms of we’re seeing a group of people at a time. It’s more cost effective doing it that way.” The promotion of group sessions has been adopted by staff members as one of the best ways to provide education. However, some people, like those with mental illness, may not be able to learn in classroom situations, and other alternatives may not exist.

**Discussion**

By mapping out some of the work processes using the tenets of institutional ethnography, it became evident that there is a definite disconnect between how diabetes care is organized and the actualities of the people with both mental illness and diabetes who live in group homes. Diabetes care provision is organized to satisfy the Ministry of Health and Long-Term Care’s conditions for funding. Diabetes care is also organized by practice guidelines, in which diabetes self-management is supported. The person is taught to make recommended lifestyle behaviour
modifications and to monitor her or his own wellbeing, therefore taking responsibility for the majority of illness management. The focus for health care providers is on teaching self-care practices and monitoring physiologic outcomes based on set targets. The person with mental illness does not fit into this social organization of diabetes care, as was shown in the participant observation.

The usual educative interventions offered by health care providers to people with diabetes, such as self-monitoring of glucose levels, food intake, and physical activity, may not be extended to those with mental illness. As noted in the clinicians’ comments, dealing with people who have mental illness evokes a sense of trepidation where providing education is concerned. Thus, even though they show the capacity to learn and retain knowledge, they may not be given the necessary information or be invited to attend group sessions. Further, people with mental illness who live in group homes may not be able to take full responsibility for illness management, regardless of diverse and unique capabilities. They lack agency over food choices for diabetes management, such as fresh fruit and vegetable options, and proper portion sizes for weight loss and sugar control. Anne had knowledge of proper diabetes care practices but did not feel it was within her control to make changes. As expressed by Anne, “It’s not my place to say anything.” Residents of group homes are also viewed as having insurmountable constraints that cannot be fixed. Recommended lifestyle changes may not fit into the home’s routine or budget, and as indicated, suggestions may not be offered. It is noteworthy to add that the group home never received the written requests that Anne asked the dietitian to provide.

Problematic for Further Inquiry: The thesis

I made important discoveries by using institutional ethnographic methods to explore the social from Anne’s viewpoint. In this study I showed that diabetes care provision is organized in a manner that emphasizes the efficient provision of services to as many people as possible, in accordance with Ministry of Health and Long-Term Care requirements. It is the expectation of health care providers that the person with diabetes take responsibility for illness management. The role of the diabetes educator is to teach healthy lifestyle behaviour changes and to continuously monitor physiological progress to keep people on the right track. However, as observed during Anne’s visit, diabetes care organized in this fashion does not fit well with some populations, such as those with mental illness who reside in group home settings. Their
marginalized position, being burdened with both cognitive constraints and minimal contextual resources, affects the extent to which they can engage in self-care recommendations that essentially ignore these limitations. This disconnect both creates and sustains inequities because the residents, in not being able to effectively manage diabetes, inevitably will develop associated complications in addition to their already compromised states.

These pilot findings only began to unravel the complex interweaving of social relations that play out in diabetes care for this vulnerable population. It is imperative that new approaches to diabetes care be considered to address the diverse needs of those living in the margins so they too can realize healthy lifestyles that lead to improved diabetes outcomes. The obvious next step is to embark on research that utilizes the group home setting as the point of entry to investigate the actualities of the residents and their care providers. This will generate new knowledge to better inform decision making in this area of health care. The thesis project, outlined in the following chapters, is dedicated to such a research inquiry, one that focuses on the everyday activities within the group home in which Anne resides.

Note: Data collected during the pilot project on the forms used by clinicians to gather patient information is incorporated into the thesis project in Chapter 6.
Chapter 1

Problem Statement

People with mental illness are genetically predisposed to diabetes (Canadian Diabetes Association 2008 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada), and their risk is heightened with the widespread use of atypical antipsychotic medications (Daumit et al., 2011; Brown et al., 2010; Amiel, Mangurian, Ganguli, & Newcomer, 2008; Sokal et al., 2004; Dombrovski & Rosenstock, 2004; Henderson et al., 2000). The rate of diabetes in group home settings is as high as 50% (L. Voruganti, personal communication, October, 2007). Although contextual conditions influence diabetes care and outcomes, research that investigates this phenomenon within this context is lacking.

Relevance and Scope of the Research Problem

Diabetes is a serious chronic illness that has reached epidemic proportions in developed countries, such as Canada. Among the populations at greater risk for both developing diabetes and suffering its associated complications are those who are diagnosed with serious mental illness and who live in residential care facilities. While diabetes affects 6 to 8% of the general population in Canada (Canadian Diabetes Association [CDA], 2006), people who are diagnosed with mental illness, such as schizophrenia and mood disorders, are 2 to 4 times more likely to develop diabetes, due to their genetic predisposition (Dombrovski & Rosenstock, 2004; Canadian Diabetes Association 2008 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada [CDACPG]). The risks for this group are compounded by the widespread use of second generation, or atypical, antipsychotic medications (Daumit et al., 2011; Brown et al., 2010; Amiel et al., 2008; Sokal et al., 2004; Dombrovski & Rosenstock, 2004; Henderson et al., 2000). Although these medications control symptoms of psychosis, they are known to cause diabetes, make existing type 1 and type 2 diabetes worse, and to increase cholesterol (Haupt & Newcomer, 2002).

Diabetes is also reported to shorten the lifespan by 13 years (CDACPG, 2003), and up to 20 years for people with serious mental illness (Daumit et al., 2005). Diabetes doubles the risk of heart attack or stroke, and is the leading cause of kidney disease, adult blindness, and lower limb
amputations in North America (Ministry of Health and Long-Term Care [MOHLTC], 2006). Approximately 80% of people with diabetes die as a result of heart disease or stroke (CDACPG, 2003). The death rate is higher in those with mental illness than in the general population due to the increased number of heart-related deaths resulting from overweight and obesity (Daumit et al., 2005). There is an estimated cost of $13.2 billion per year on treatment related to diabetes in Canada (CDA, 2006), with an expected increase to $16.9 billion by the year 2020 (CDA, 2012). Diabetes affected 2.25 million Canadians and 177 million people worldwide in 2006 (CDA, 2006). Today, over 9 million Canadians have diabetes or prediabetes (CDA, 2012).

Increasing the relevancy of addressing this problem, type 2 diabetes, which accounts for 90% of the cases, is largely preventable with lifestyle modifications such as weight loss and physical activity (MOHLTC, 2006). Knowler et al. (2002), the Diabetes Prevention Program Research Group, examined placebo, metformin, and lifestyle interventions with 3234 participants with prediabetes, and they found that lifestyle intervention reduced the incidence of diabetes by 58% over the 2.8 year follow-up. Therefore, it is possible to prevent or control the progression of diabetes. Further, people with chronic serious mental illness who live in group homes already suffer circumstantial constraints, without adding a medical condition such as diabetes. In view of the personal costs to afflicted residents of group homes who suffer reduced quality of life and shortened lifespans, in addition to the associated treatment costs, it is imperative to begin untangling the web of social relations that contribute to the lack of diabetes prevention and control in mentally ill people who reside in these settings.

**Purpose Statement**

People with mental illness are at particularly high risk for developing diabetes. For those who live in group home settings, I contend their risk is heightened as the product of a complex, multiple intertwining of social relations that shape their everyday lives. I further argue that the social relations that condition their diabetes experiences are not static and immutable. Rather, they are an integral part of an ongoing social process, linking local diabetes care practices to larger social and political forces. Diabetes care provision is structured around and contingent upon various social relations that create and sustain inequities for those who are positioned in the societal margins. The purpose of this study was to explore these social relations that are involved in the coordination of diabetes care in the context of mental illness and within the constraints of
group home care. By revealing the social relations that are responsible for not only impeding diabetes care and outcomes, but for creating and sustaining social and health inequities in this group, important social change can ensue.

**Rationale for this Study**

There is a plethora of health science research investigating diabetes and mental illness, making the link between atypical antipsychotic medications and metabolic conditions, reporting on this group’s poor health behaviours, and on the medical/psychiatric disconnect that leads to poor health outcomes. There is also a large body of qualitative literature on the diabetes illness experience that offers insight into the complexities of living with this chronic condition. However, research that explores the social organization of diabetes care within the context of serious mental illness and living in a group home setting was lacking. Therefore this research inquiry was groundbreaking because it was the first to offer insight into the complexity of social relations that create circumstances whereby disease development is perpetuated and illness management is made difficult.

**Researcher's Background**

I came to this research with multiple insights and perspectives on this phenomenon, having been a group home operator for adults with mental illness, a regional Quality of Life and Social Night Program Coordinator for people in group homes, and a community diabetes nurse educator. As a group home operator I developed an understanding of the complexities surrounding care provision afforded these people from an intrinsic perspective. Through the Quality of Life role, with access to the group homes in my region, I gained further insight into the expanse of circumstantial constraints. My knowledge in mental health was then carried on in my role as a diabetes nurse educator, wherein questions and concerns began surfacing regarding the increasing numbers of people with mental illness from the group homes that were attending the clinic with new diagnoses of diabetes.

**Diabetes care knowledge from group home operator role.**

The Homes for Special Care (HSC) for-profit residential home I owned and operated in the early 1990s was funded by the Ontario Ministry of Health and Long-Term Care. This particular home was licensed for 15 people and had an additional private bed. Adults with
varying psychiatric diagnoses, such as schizophrenia, schizoaffective disorder and manic depression, came under my care. As is the case with many of the HSC homes, I lived in the same facility, and therefore my hours of work were 24 hours per day, 7 days a week. Essentially all mental, physical, and health and safety needs of the residents were my responsibility, including providing food and lodging, scheduling, arranging transportation for, and attending all medical, psychiatric, and social support appointments. Grocery shopping, cooking, bathing, medication administration, caring for the ill, and meeting recreational and vocational needs, were included in the list of required duties of the homeowner. In exchange for all of these services I received payment from the Ministry of Health and Long-Term Care of $32.00 a day or $976.00 per resident each month.

Comprehensive care was extremely difficult to provide on such limited income. Strategies for economical food purchasing included buying in bulk quantities, using powdered milk, obtaining cheaper cuts and processed meats, and buying day old breads and pastries. I also had to limit the purchasing of fresh fruits and vegetables because these items were expensive, especially if not in season. One meal was prepared for everyone, and many meals were starchy, consisting of potatoes and pasta, which satisfied both the food budget and large appetites. I hired unregulated health care providers at $7.00 per hour, most of whom had little or no mental or medical health experience. The daily work that took priority included cleaning of the home, food preparation, and ensuring residents were bathed, laundry was done, and medications were given. Residents received an allowance of $112.00 each month, which was primarily used to purchase cigarettes. It was also common practice among the home operators to give cigarettes as incentive, which, upon reflection, went against any concept of modern health promotion activities. This reflexive knowledge of group home care was pivotal in my questioning the relevancy of the current diabetes education we offer at the diabetes clinic for this particular population.

**Diabetes care knowledge from the Quality of Life Coordinator role.**

Further to the group home experience, within the Quality of Life and Social Night Coordinator roles, I worked with over 400 residents from various homes in the region, enhancing life skills such as shopping, baking, and cooking. The differences in cleanliness, quality of care, and the general operations of each group home was enlightening, with homes ranging from both ends of the spectrum. It was apparent from the outset when I visited the homes that most
residents were sedentary, found either sleeping or sitting in the common areas, often while
smoking, or watching television. Most home operators appreciated the Quality of Life Program
because the Ministry of Health and Long-Term Care paid for my time, the supplies for in-home
projects, and the transportation costs for outings such as shopping trips and movies. Home
operators did not have the financial resources or the extra time required to provide these
opportunities.

Diabetes-related reflexive knowledge gained through this experience included an
understanding that residents obtained little physical activity and home operators did not have the
financial resources or time to dedicate to exercise programs or to facilitate resident involvement
in the community. Also, in teaching life skills, I knew each resident had their own unique
abilities and were in many cases capable of learning new skills. Residents also appreciated the
attention they received during craft, baking, and cooking sessions. They heartily expressed their
excitement and pride in having created something they could eat, or display in their rooms, or
give to someone as a gift.

**Background knowledge from diabetes educator role.**

As a diabetes nurse educator at our community hospital, I noticed an increasing number
of people from group homes were referred to our clinic with a diagnosis of diabetes. I also
recognized that the other clinicians at the clinic were seeing residents but were sometimes
unaware that they were from group homes. There were no indicators on the referral forms and
residents did not readily divulge this information, possibly due to the attached stigma with
mental illness. Many residents attended the clinic unaccompanied so I became concerned that
perhaps the information they were receiving was not being retained or shared with the care
providers. Our diabetes clinic promotes self-management, and in view of cognitive constraints, I
was worried that diabetes self-care activities may be difficult to carry out. Also, from my
experience as a group home owner, I understood the budget constraints and how this limited food
choices, so I wondered if the nutritional recommendations could be feasibly utilized. Finally, I
understood the issues surrounding exercise and questioned if the residents would be able to
engage in the prescribed 30 minutes of moderate-to-vigorous physical activity five days a week.

My concerns were corroborated when I noted that the group home residents that I was
seeing at the diabetes clinic of reference had poor outcome data. Their weights were climbing,
glucose levels were above normal, and increasing dosages and types of oral diabetes medications were required by the entire constellation. In some cases, insulin was being added to the medication regimen if glucose levels were too high and the maximum dosage of oral agents had been reached. Having insight into group home operations, my concerns centered on what this escalating problem meant for care provision for this population. Given what I knew about their contextual constraints, I wondered if the type of diabetes care the mentally ill were being offered at our clinic was overly useful, and how this would affect their health outcomes. My experiences as a group home operator and Quality of Life Coordinator also indicated to me that there were major social forces, over which they had no control, that were contributing to the development of diabetes, not merely lifestyle choices. This experiential knowledge and my desire to better assist this group led me to this investigation.

**Research Strategy**

Diabetes care for people with mental illness who reside in group home settings is a new area of study. Therefore a qualitative approach to inquiry was required in order to gain in-depth understanding. However, to address this particular research problem, an analytic approach was needed that went beyond the local experiences of group home residents. The approach had to generate knowledge that could answer the question, “How do things happen as they do in the lives of group home residents who have diabetes?” With understandings of how everyday experiences are socially organized, important sociopolitical changes can be proposed and implemented. This approach to inquiry, with its analytic commitment to exploring the social organization of knowledge, was institutional ethnography (Smith, D., 1990, 2005, 2006). In institutional ethnography, the individual experience is not the focus; rather translocal social relations are the objects of investigation (Smith, D., 2005). As noted by D. Smith, translocal relations are those that connect the local practices to the extra-local ruling relations, those that control and coordinate the everyday activities across time and place.

In institutional ethnography, the problematic is formulated by starting with the everyday experience to locate the point of entry, and then moving beyond this local problem or concern to explore and bring under scrutiny the social relations in which the experience is rooted (Smith, D., 2005). In this particular research inquiry, institutional ethnography enabled the exploration of the ‘social’ at the point of disjuncture between the actualities of those living with diabetes and
mental illness, and the way in which diabetes care is organized. The everyday practices within the group home were the ‘point of entry.’ Starting from the viewpoint of the people living with diabetes in the group home, the research problematic examined how the “health work” (Mykhalovskiy & McCoy, 2002, p. 17) of people who are labeled with a diagnosis of diabetes and mental illness was articulated to the work organization of the group home providing care for the mentally ill. The work organization of the group home and circumstances, rather than facilitating, create difficulties for people who attempt to carry out diabetes self-care activities.

The overall aim was to map out the institutional complexes that the people at the local site were participating in, often unknowingly, to make visible the organizing social relations (Smith, D., 2005). As reported by D. Smith, institutions are not particular entities, but are conceptualized as ‘functional complexes,’ or observable complexes of discourses and organizations. These functional complexes were not the objects of investigation, rather intersections or interconnections of sometimes multiple functional complexes were explored from the viewpoint of the people who were involved (Smith, D., 2005). Using this approach it was determined how diabetes care provision is organized, and how this is incongruent with the everyday actualities of people trying to manage the condition in the group home. I highlight these disjunctures in both the prologue and in the remaining chapters of this thesis project.

I review in Chapter 2 the health sciences literature on diabetes in the population of seriously mentally ill adults. I also examine the qualitative literature on the diabetes illness experience, as described by people living with this condition. This review of the literature points to the gap in research that investigates the phenomenon of interest, diabetes care for seriously mentally ill adults who reside in group homes. I conclude Chapter 2 with a review of the body of health-related research that uses institutional ethnography, the method of inquiry that informed this study. I present the research design in Chapter 3, which outlines the guiding principles of institutional ethnography, the taking of fieldnotes, reflexive journal keeping, and ethical considerations. I then describe the research setting, participant involvement, and methods of data collection, management, and analysis. Chapter 4 is the first findings chapter, in which I describe the residential care facility and begin to show how work activities at the local site are organized by group home regulations that do not focus on resident health. I show in Chapter 5, through an historical account of Ontario’s mental health system, how group home care has come to be
socially organized in such a manner that cost containment takes primacy over resident health and wellbeing. I discuss the social organization of diabetes care provision in Chapter 6, which highlights how the promotion of ‘self-care’ creates health disparities and inequities for some people, including the mentally ill. I also explore diabetes care practices in the group home, which points to the disjuncture between best practice treatment recommendations and the actualities of group home life. I then look at dietary intake and exercise, as integral components of diabetes care, within this social location in Chapter 7. I conclude in Chapter 8 with a discussion of the findings, which I position with other related literature. I offer recommendations for policy changes, considerations for health care providers, and suggestions for future research in this area. I follow with the strengths and limitations of this study and concluding remarks.
Chapter 2
Review of the Literature

Introduction

The literature review is the foundation for critiquing and examining what is already known in relation to the phenomenon of interest (Campbell & Gregor, 2002). In institutional ethnography the researcher reviews the literature to discover both the scope of related knowledge and to decide how the generated knowledge relates to her or his positioning within the research (Campbell & Gregor, 2002). According to Campbell and Gregor, the research stance of the institutional ethnographer is located in the everyday world and maintains a focus on the social organization of the phenomenon. The institutional ethnographer is interested in making the world understandable for those with whom the researcher stands, the people living the experience in the everyday world (Campbell & Gregor, 2002). These researchers note that the literature, usually perceived by scholars as the authoritative account, often serves interests other than those of the people experiencing the phenomenon. In keeping with these tenets while reviewing the literature, the institutional ethnographer must delineate and preserve her or his stance in relation to dominant knowledge, discourses, and viewpoints other than those grounded in the everyday world (Campbell & Gregor, 2002). “Her sociology, rather than re-enacting the objectifying break, explores and explicates the actual determinations and organization of the actualities of people’s experienced worlds…such a sociology speaks of the same world as that in which it is written and read” (Smith, D., 1990, p. 3).

In this review of the literature I present the current health sciences research on diabetes and mental illness and also the qualitative literature on the diabetes illness experience to gain understanding as to the existing knowledge and the research gaps. In congruence with the above principles of institutional ethnography, I also critically examined the literature to determine how this knowledge informs my research, which addresses the social organization of diabetes care for those with mental illness. Additionally, as outlined by Campbell and Gregor (2002), I explored the ways in which the knowledge was produced through reflecting on the research and asking particular questions such as, “How is the researcher-writer located?” “For what purposes was the account written?” “What activities does the account support?” and “What activities does the account make invisible?” After reviewing the existing literature I determined that it did not
effectively address the phenomenon of interest and a new approach to producing knowledge was required. This chapter concludes with a discussion of relevant health-related institutional ethnographic research to show how this method of inquiry was best suited to inform my work and to demonstrate how my research contributes to this body of literature.

**Review of the Health Sciences Literature**

Initially an extensive review of the literature was undertaken to determine what knowledge has been generated on diabetes and mental illness. The University of Toronto Gerstein Library was first entered using Ovid to access Cumulative Index to Nursing and Allied Health Literature (CINAHL) database to search as far back as 1982. Keywords and relevant subheadings for ‘diabet$’ were entered, which yielded 30383 articles. Next, the keyword ‘mental illness’ and appropriate subheadings were entered, which resulted in 6309 articles. Next, the term ‘residential care facilities’ was entered, which provided 11498 articles. These searches were then combined to provide only two studies, of which neither was relevant to this search. Other keywords such as chronic illness, chronic disease, medical comorbidities, medical conditions, serious mental illness, psychiatric illness, schizophrenia, affective disorders, group homes, psychiatric outpatient care, community mental health care, residential homes, board and care homes, and residential care facilities were also used in different combinations.

Next, Scholar’s Portal Searches were performed separately using the Sociology, Psychology: A Sage Full Text Collection, and Social Sciences Abstracts databases and entering the same keywords and including all relevant subheadings from the ‘auto explode,’ which resulted in no articles. Phrases such as ‘mental illness and care provision in community group home settings,’ ‘care provision for people with diabetes and mental illness,’ and ‘serious mental illness and medical care provision in residential homes’ were also entered with no results being found. The University of Toronto Libraries Ovid was also used to access the Medical Literature On-Line (MEDLINE) database, whereby literature from as far back as 1966 was searched, again with no studies being found on diabetes care for those with mental disorders living in residential care facilities.

A further review of the literature was undertaken using additional keywords, without limiting the search to adults residing in group homes, in order to ensure the inclusion of all relevant articles. Using the University of Toronto Libraries Ovid to access CINAHL and
MEDLINE databases, keywords including psychiatric patients, mood disorders, bipolar disorder, schizoaffective, physical activity, exercise, diet, weight loss, health behaviour, primary health care, and preventative services were entered. These keywords were also entered in The Scholars Portal Search, PsycInfo, and Sociological Abstracts. These searches were first limited to English language, and adults only, and then further limited to qualitative studies. An additional three studies related to health behaviours in those with serious mental illness were deemed appropriate, and thus were included with those from the original search of the literature. Throughout the length of this thesis project I continuously reviewed and incorporated the relevant literature in this area of health.

Research that links ‘mental illness,’ ‘diabetes,’ and ‘residential homes’ does not appear to be in the literature. There is, however, a plethora of health sciences research on diabetes and mental illness, which was compiled and is presented as follows under the subheadings ‘second generation antipsychotic use and diabetes,’ ‘lack of integration between medical and psychiatric care,’ and ‘health behaviours and level of physical activity.’ My critique, which follows the review, problematizes the health sciences research for generating knowledge that lacks utility in addressing important social and contextual factors, which I assert, are inherent for people who are living in group homes and positioned in the social margins.

**Second generation antipsychotic use and diabetes.**

There is an abundance of literature on the positive relationship between the use of second generation antipsychotic medications and the increasing incidence and prevalence of diabetes, heart disease, overweight and obesity, hypertension, and lipid abnormalities (Amiel et al., 2008; Woo, Harris, & Houlden, 2005; Goldberg et al., 2007; Brown et al., 2010; Henderson et al., 2000; Citrome, Jaffe, Levine, Allingham, & Robinson, 2004; Citrome, Blonde, & Damatarca, 2005; Miller, Leslie, & Rosenheck, 2005; Miller & Molla, 2005; Leslie & Rosenheck, 2004; Newcomer, 2004; Sussman, 2003; Haupt & Newcomer, 2002). Atypical antipsychotic medications include clozapine, risperidone, olanzapine, quetiapine, and more recent additions, aripiprazole and ziprasidone (American Diabetes Association [ADA], 2004), and paliperidone. In Canada, paliperidone became available and covered under the Ontario Health Insurance Plan in 2009, ziprasidone in 2010, and aripiprazole in 2011. However, the warnings remain on the product monographs that paliperidone (Janssen-Ortho Inc., 2011) and aripiprazole (Bristol-
Myers Squibb Canada, 2011) still increase the risk for elevated glucose levels. Although causal effects are not known for ziprasidone, screening for metabolic risk factors is recommended (Pfizer Canada, 2011). Second generation antipsychotic medications are widely used in view of their ability to alleviate psychiatric symptoms with less risk of extrapyramidal symptoms (Sussman, 2003; Newcomer, 2004; Henderson et al., 2000; ADA, 2004). Extrapyramidal side effects, such as tardive dyskinesia or involuntary tremor, were commonly experienced with the use of conventional, typical antipsychotic agents that were introduced approximately 50 years ago (Sussman, 2003; Newcomer, 2004). Although atypical antipsychotic medications are used primarily for various forms of schizophrenia and bipolar disorder, other conditions, such as post-traumatic stress syndrome, dementia, autism, personality disorders, psychotic depression, and aggressive behaviour are treated using this class of drugs (ADA, 2004).

The association of type 2 diabetes and schizophrenia has been recognized for many years. As reported by Krosnick and Wilson (2005), Sir Henry Maudsley wrote in 1879 that, “Diabetes is a disease which often shows in families in which insanity prevails” (p.320). Diabetes has been documented as occurring in 18% to 30% of individuals with schizophrenia, making those with schizophrenia 2 to 4 times more likely to develop this disease compared to the general population (Krosnick & Wilson, 2005). The rate of type 2 diabetes in the general population is much lower being 1.3% in people 18 to 44 years, 6.2% in people age 45 to 64 years, and 10.4% in people 65 years and older (Henderson et al., 2000). Schizophrenia and bipolar disorder are independent risk factors for the development of diabetes (Citrome et al., 2005). Schizophrenia was added to the list of risk factors in the 2003 Canadian Diabetes Association practice guidelines, and further highlighted as increasing the incidence of type 2 diabetes by at least three fold in the 2008 practice guidelines (CDACPG, 2008).

Although atypical antipsychotics are effective in treating psychiatric disorders, their use in a group that already has a 2 to 4 times greater risk for diabetes than the general population has serious implications. Atypical antipsychotic agents are associated with dramatic weight gain, the onset and worsening of diabetes (including acute metabolic complications such as diabetic ketoacidosis), and lipid abnormalities such as noticeably increased low-density lipoprotein and triglycerides, as well as decreased high-density lipoprotein (ADA, 2004).
Lack of integration between medical and psychiatric care.

People with serious mental illness have elevated rates of mortality and medical comorbidity (Brown et al., 2010; Sokal et al., 2004; Newcomer, 2004; Cradock-O’Leary, Young, Yano, Wang, & Lee, 2002; Dickey, Normand, Weiss, Drake, & Azeni, 2002; Dixon et al., 2004), and are at greater risk of receiving inadequate or inappropriate health care (Goldberg et al., 2007; Vreeland, 2007; Dombrovski & Rosenstock, 2004; Bartels, 2004). Life expectancy is reduced by 20% among people with schizophrenia (Bartels, 2004; Marder et al., 2004), with cardiovascular disease being the most common cause of death (Newcomer, 2007; Dombrovski & Rosenstock, 2004; Folsom et al., 2002).

There is a substantial amount of health sciences research on the lack of integration between medical and psychiatric health care for those with mental illness, which leads to poor patient outcomes where diabetes is concerned (Voruganti et al., 2007; Vreeland, 2007; Dembling, Chen, & Vachon, 1999; Dixon et al., 2004; Chafetz, White, Collins-Bride, Nickens, & Cooper, 2006; Dickey et al., 2002). Perceived barriers to medical care include the inability to afford prescriptions or services such as dental work, and lack of transportation (Dickerson et al., 2003). Those with mental illness receive less primary and preventative health care, and have high rates of undiagnosed or untreated medical illnesses (Cradock-O’Leary et al., 2002; Folsom et al., 2002; Bartels, 2004). A possible explanation, according to Folsom et al., is the person’s inability to describe medical symptoms to health providers due to cognitive impairment. Family physicians may also be uncomfortable or unskilled at treating people with mental illness, and psychiatrists might not feel comfortable or be proficient at providing primary and preventative health care (Dombrovski & Rosenstock, 2004; Folsom et al., 2002; Dickey et al., 2002). As reported by Voruganti et al. (2007), psychiatric care providers may also lack role clarity in the monitoring of physical health, and the necessary infrastructure and resources. People with psychiatric illness may receive different treatments than the general population, and are often not offered state-of-the-art interventions (Dombrovski & Rosenstock, 2004; Bartels, 2004; Folsom et al., 2002). Galassi, Reynolds, and He (2006), in their Canadian study on access to ideal treatment for cardiac conditions, found that psychiatric patients were significantly less likely to undergo revascularization or specialized procedures like angioplasty and cardiac catheterization.
People with mental illness who are prescribed atypical antipsychotic medications and subsequently develop elevated blood glucose levels may not be screened or treated. Ganguli and Strassnig (2011), based on their meta-analysis of randomized controlled trials on metabolic syndrome in serious mental illness, reported that despite recommendations, the rate of monitoring for metabolic changes with the use of atypical antipsychotic medications remains low in practice settings. Vreeland (2007) echoed the need for medical monitoring by health professionals for people on atypical antipsychotic agents. In their five year study of new-onset diabetes in those taking clozapine, Henderson et al. (2000) reported that out of 82 participants, 15 patients with one abnormal fasting blood glucose result, and five people with two or more abnormal values received no treatment or medical attention prior to data collection for the study, but were subsequently referred, diagnosed and treated for diabetes during the study. They noted that treating psychiatrists often ignored abnormal blood glucose results, wondering if this was a recurrent pattern in other mental health centres. One implication drawn from these findings was that psychiatrists should be more actively involved in their patients’ medical care by monitoring and responding to regular laboratory screening, and by routinely recording weights and blood pressures.

Cohn and Sernyak (2006) compared the major global consensus guidelines on the metabolic monitoring of patients treated with antipsychotic medications. The joint consensus report copublished by the American Psychiatric Association and the American Diabetes Association in 2003, which was recommended by Cohn and Sernyak, is as follows; screening of fasting plasma glucose and blood pressure at baseline, three months and annually, recording of weight at each clinical visit, and measuring of lipid profile at baseline, three months, and then every five years. Cohn and Sernyak argued that lipids should be measured every year. Also, as reported by Cohn and Sernyak, there should be monitoring of those with a positive family and/or medical history of metabolic disorders. Healthy lifestyle behaviour education was recommended for all patients, family members, and care providers of those starting atypical antipsychotic medications who are overweight or obese (Newcomer, 2004; Henderson et al., 2000; Citrome et al., 2005). Woo, Harris, and Houlden (2005) also recommended screening for risk factors prior to and during the use of atypical antipsychotic agents, education for families and care providers on the risk of weight gain and diabetes, and nutrition and exercise counseling for those who are overweight or obese and are prescribed these medications. Further, integration of psychiatric and
medical health care was strongly recommended in view of the increased prevalence of comorbid conditions in the seriously mentally ill population (Vreeland, 2007).

Voruganti and Parker (2008) reiterated that Canada’s current health care system is fragmented and unequipped to deal with this dual comorbidity, which due to its magnitude and nature, requires a novel strategy. These researchers noted that mental health and diabetes clinics are geographically distinct: Mental health clinicians are not familiar with diabetes care, nor do they feel it is their mandate to refer for diabetes, and diabetes clinicians find psychiatric patients puzzling and frustrating. Voruganti and Parker called for a comprehensive, coordinated management strategy that combines mental health care and diabetes care. Although it was not part of the health sciences literature, in the report titled, “Diabetes and Serious Mental Illness: Future Directions for Ontario, A Think Tank Report” (April 30, 2009), the Canadian Mental Health Association highlighted the growing awareness that chronic illnesses in this population require special attention, and that our current health care system does not address its particularities, including added risks, barriers to care, and complexities. Recommended strategies included recognizing this as a high risk group in policy documents and diabetes prevention messaging, developing standards and benchmarks for comorbid diabetes and mental health prevention and management, and forming collaborative partnerships between mental health programs, public health, diabetes education, and other community-based programs, among others (Canadian Mental Health Association, 2009).

**Health behaviours and level of physical activity.**

Some authors have suggested that people with serious mental illness have increased risk for medical illness due to poor health behaviours including smoking, alcoholism, unsatisfactory diets, and lack of exercise (Daumit et al., 2011; Knol, Pritchett, & Dunkin, 2010; Goldberg et al., 2007; Bartels, 2004; Sokal et al., 2004; Daumit et al., 2005; Holmberg & Kane, 1999). Bartels reported tobacco use is the most common form of substance abuse in this group, with between 60% and 80% being nicotine dependent. In addition to contributing to increased rates of asthma, emphysema, and other chronic respiratory diseases, high rates of smoking contribute to the increased risk of hypertension and heart disease, which is further compounded by lack of physical activity (Bartels, 2004; Sokal et al., 2004). According to Bartels, rates of drug and alcohol abuse disorders range between 15% and 60% and are associated with serious medical
problems, such as HIV and hepatitis. This population also tends to have a lower consumption of fruits and vegetables, and greater consumption of foods high in fat and lower in fibre than people of equivalent socioeconomic status without mental illness (Bartels, 2004; Holmberg & Kane, 1999). Obesity affects a higher proportion of individuals with mental illness than the general population, likely due to poorer diets and sedentary lifestyles (Jerome et al., 2009; McDevitt, Snyder, Miller, & Wilbur, 2006; Richardson, Avripas, Neal, & Marcus, 2005; Daumit et al., 2005; Sokal et al., 2004; Ohlsen, Peacock, & Smith, 2005).

Strassnig, Brar, and Ganguli (2005) examined the dietary habits of 146 adult community-dwelling outpatients with schizophrenia, most of whom were considered overweight or obese. They found that participants consumed more calories than the general population but made similar food choices, eating foods high in saturated fats and sugar (Strassnig et al., 2005). They reported that in general, people with schizophrenia consume low amounts of fruits and vegetables, and have sedentary lifestyles, which in combination increases the risk for a further reduction in an already shortened life expectancy. Xiong, Ziegahn, Schuyler, Rowlett, and Cassady (2010) used focus groups that involved five group home operators and 11 residents with serious mental illness, 10 of whom were overweight or obese, to examine factors that affect motivations to improve diet and physical activity. These researchers found there were differing opinions between operators and residents regarding ‘healthy’ foods. The home operators perceived the barriers to improved health as negative resident attitudes, poor interaction with health care providers, and dysfunctional relationships with the licensing body that values individual rights over healthy lifestyle choices (Xiong et al., 2010). Residents’ perceived barriers, as reported by Xiong et al., included their own negative attitudes, limited menu options and organized activities, side effects of medications, and existing health problems. Xiong et al. echoed the need for better coordination of medical and psychiatric care, and identified the need for training programs for group home operators on what constitutes a healthy diet and an effective physical activity plan.

Teachout, Kaiser, Wilkniss, and Moore’s (2011) intervention study with 13 participants with diabetes and mental illness in a psychiatric rehabilitation centre consisted of diabetes education classes, nutrition counseling, exercise instruction and onsite programming by nurse practitioners, and group psychosocial support plus intensive individual case management. These
researchers found that 100% of the sample lost weight, and fasting glucose measurements improved over a six month period. Teachout et al. noted that they were able to affect change in a very small number of participants with intensive intervention, but suggested that further work is required to determine how or if this can feasibly or economically be accomplished in community settings. In Ohlsen et al.’s (2005) ‘healthy lifestyle’ intervention study with 134 participants who had a serious mental illness, at baseline 116 were overweight (body mass index [BMI] >25 kg/m2), and of those 84 were obese (BMI >30 kg/m2). Out of all participants in Ohlsen et al.’s study, 60% had unhealthy diets, 11% used illicit drugs, 10% had pre-existing diabetes, and a further 2% were diagnosed during the program. Interventions included dietary counseling sessions, and weight management and physical activity programs (bowling, badminton, walking, swimming, and boating). Fifty-four percent of overweight participants lost weight, only 25% had unhealthy diets after the second consultation, and self-esteem improved significantly (Ohlsen et al., 2005).

Worldwide obesity has more than doubled since 1980, and in 2008 more than 1.5 billion adults ages 20 years and older were reported to be overweight with a BMI greater than 25 kg/m2 (World Health Organization, 2012). Canadian data is similar, with approximately 25% of Canadian adults considered obese with a BMI greater than 30 kg/m2 (Statistics Canada, 2012). BMI, calculated by dividing body weight in kilograms by height squared in meters, provides the most useful population-based measure of overweight and obesity because it is the same for both sexes and for those over the age of 20 years (World Health Organization, 2012). However, it should only be used as a rough guide because it may not correspond to the degree of different people’s fat versus muscle mass and overall distribution of body fat (World Health Organization, 2012). BMI-related health risks are well established, with a high risk being associated with a BMI of 30 to 34.9 kg/m2, a very high risk with a BMI of 35 to 39.9 kg/m2, and an extremely high risk with a BMI over 40 kg/m2 (Citrome et al., 2005).

Obesity is one of the most common problems among people with severe mental illness (Citrome & Vreeland, 2009), and has recently reached epidemic proportions (Daumit et al., 2011). McDevitt, Wilber, Kogan, and Briller (2005) introduced a walking program of moderate intensity, and screening prior to the intervention showed of the 15 outpatients with schizophrenia, bipolar disorder or major depression, 67% had hypercholesterolemia, 47% had
hyperglycemia, 87% were obese (with 46% of these having a BMI ≥ 40 kg/m²), and 40% were currently smoking. Of the 15 participants, 13 completed the walking program with an average attendance of 76% of the 30 sessions held over a 12 week period (McDevitt et al., 2005). However, mental and physical health changes were insignificant, and by the end of the study participants were reaching moderate intensity levels of walking only 22% of the time. The researchers noted that cognitive limitations may have made it difficult to use the heart monitors.

Although exercise is a cornerstone of diabetes care, little is known about the prevalence and types of physical activity in this population, because very few published reports exist (Daumit et al., 2005; Richardson et al., 2005; Ohlsen et al., 2005). Most studies are based on the use of self-report questionnaires that inquired about current levels of physical activity, health promoting behaviours, and medical comorbidities (Daumit et al., 2005; Holmberg & Kane, 1999). There are also intervention studies that tested short-term structured physical activity programs (Ohlsen et al., 2005; Richardson et al., 2005; McDevitt et al., 2005). In Daumit et al.’s (2005) study, 185 participants with either schizophrenia or schizoaffective disorder, self-reported on sociodemographic characteristics, levels of physical activity, and medical comorbidity. Approximately half (46%) of the 185 participants in Daumit et al.’s (2005) study were obese (BMI ≥ 30 kg/m²), and 49% reported that their health limited their physical activity. Of these participants, 26% had no exercise in the past month, and another 36% had physical activity levels lower than those recommended for the general population. Daumit et al.’s (2011) six month intervention study with 63 participants with serious mental illness who were overweight or obese (recruited from a psychiatric day program) consisted of weight management and physical activity classes. The researchers reported an average weight loss of 1.9% of body weight, and the participants increased their distance on a six minute walk by 8%.

Jerome and colleagues (2009) measured physical activity levels in 66 adults with severe mental illness, all of whom were overweight and 73% were obese (BMI ≥ 30 kg/m²). Participants wore accelerometers, or activity monitors, for a period of four days during usual activities in their home environments. Details of participants’ living arrangements were not described, although they were recruited from two psychiatric rehabilitation centres, one of which was located in an urban area and the other in a suburban area (Jerome et al., 2009). Participants engaged in regular activity but the majority fell short of meeting physical activity guidelines of
moderate-to-vigorous bouts of activity of at least 10 minutes in length for a total of 30 minutes per day most days of the week. Only 4% of participants accumulated at least 150 minutes per week of moderate-to-vigorous activity in a minimum of 10 minute intervals (Jerome et al., 2009).

**Summary of Health Sciences Research**

The health sciences literature delineates the linkage between atypical antipsychotic medications, weight gain, and the development of diabetes. People with schizophrenia and mood disorders are already at higher risk for diabetes due to genetic predisposition. However, atypical antipsychotic medications are widely used in this population and many people subsequently develop diabetes. Furthermore, studies indicate that structures are not in place to monitor for disease progression once treatment is initiated. There is also an apparent lack of communication between medical and psychiatric health service providers. This poses serious concerns for those living with mental disorders and comorbid medical conditions like diabetes. Access to medical practitioners is also an issue, which contributes to poor diabetes care and outcomes. Finally, where diabetes-related health behaviours are concerned, the mentally ill are reported to be less physically active, have poorer nutritional habits, and higher rates of overweight and obesity than the general population. Reportedly there is also a much higher prevalence of smoking and alcohol consumption in this group.

**Critical Appraisal of the Health Sciences Literature**

The above knowledge generated from health sciences research is produced by and for medical professionals to give direction for dealing with the burden of disease. This discourse, which may be foreign to many, is meant to be read by those who understand the technical language and terms that are embedded throughout the texts. Knowledge from the expert medical viewpoint is considered dominant, whereby objective information on the patient, the object of study, is produced, along with guidelines for treating the disease.
This discourse only enables us to see the problem from a medical perspective in which diabetes as a disease entity is individuated. Diabetes is portrayed as a consequence of genetic predisposition, the use of typical antipsychotics, and at-risk health behaviours. This knowledge, although useful for medical professionals in establishing standards for patient care, and of benefit to all patients when equitably applied, is limited to a physiological focus on the patient. Objectification of patients silences their reflexive knowledge and experiences. Thus, their unique social and contextual conditions that may be influencing illness management are overlooked. It may be impossible for the person with mental illness, for a variety of reasons, to adopt different lifestyle behaviour patterns. Additionally, in the few studies that dealt with physical activity, researchers tended to remove people from their social contexts to participate in prescribed short-term exercise programs. This may not be useful in understanding the levels and types of physical activity in which people with mental illness routinely engage on a daily basis, and how these activities are socially organized as part of diabetes care. In the one study that measured the amount of routine physical activity in the natural setting, the researchers neglected to gather data about what types of activities were being performed and under what conditions. However, the researchers that used focus groups to explore motivational factors for improving dietary intake and physical activity in residents of group homes, although centered on resident lack of motivation and negative attitudes, were able to generate knowledge of important circumstantial constraints, including group home operators’ poor working relationships with licensing bodies, lack of medical knowledge, and resident lack of money and agency over food.

Finally, in this body of literature, the onus is placed on health care professionals to implement research-based guidelines in their care of a unique population, whose challenges are poorly understood. No studies offer suggestions to facilitate health behavior change in people with both mental illness and diabetes. The recommended screening processes for the use of

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2 Individuate: I use this term to denote how diabetes, as a problem, is viewed as being the outcome of at-risk health behaviours and genetic predisposition, rather than one that is multifactorial and connected to larger social forces. In the treatment of diabetes as a personal problem, sociopolitical, economic and cultural circumstances are not brought under scrutiny because the gaze is narrowly focused on the individual. Socially structuring the illness in this manner creates inequities in health care and outcomes. Anderson, Blue, and Lau (1991) described the individualizing of the problem and how this process created further marginalization in a group of Chinese women with diabetes. Their study is highlighted in both the review of the qualitative literature on the diabetes illness experience, and also in the institutional ethnographic literature that informs this thesis project.
atypical antipsychotic agents and for diabetes monitoring may be difficult and time-consuming to implement in everyday practice, particularly with the reported fragmented medical and psychiatric care provision.

Taken together, the information gathered from this literature review suggests that an at-risk population is put at greater risk for developing diabetes without having built-in structures for monitoring or strategies for prevention. More importantly, the literature points to gaps in the research in the area of diabetes care for the mentally ill who reside in group home settings. This research problem has yet to be understood from their viewpoints, and research findings must be interpreted and written for the people from within this same social situation in order to make changes.

**Qualitative Literature Review: Diabetes Illness Experience**

Qualitative research that investigates diabetes care in mentally ill adults who reside in group homes is lacking. Therefore the qualitative literature on the diabetes illness experience in the general population of adults was reviewed to glean an understanding of knowledge generated in this related area of research.

**Representative articles.**

The qualitative research on the diabetes illness experience adds to the health sciences research by providing insight into the actualities of living with a chronic illness and the difficulties encountered by people trying to manage the disease in the absence of mental illness. In this literature the social and contextual factors that shape the illness experience are discussed, along with lay perspectives on health care services. Issues like underlying patient-provider power imbalances and conflicting treatment adherence expectations are explored. Finally, the ‘self-care ideology’ embedded within the health care system that underpins self-management is also highlighted because of its influence on those who are socially disadvantaged.

The representative articles within this body of literature used various philosophical frameworks including Participatory Action Research (Koch, Kralik, & Taylor, 2000; Koch, Kralik, & Sonnack, 1999), phenomenology (Mitchell & Lawton, 2000), ethnography (Schoenberg, Amey, & Coward, 1998; Mercado-Martinez & Ramos-Herrera, 2002), feminist critical social theory (Anderson, Blue, & Lau, 1991), interpretive descriptive (Rayman & Ellison,
2004), exploratory (Hornsten, Sandstrom, & Lundman, 2004; Samuel-Hodge et al., 2000), critical interpretive (Tang & Anderson, 1999), and grounded theory (Thorne, Harris, Mahoney, Con, & McGinness, 2003; Burke, Earley, Dixon Wilke, & Puczynski, 2006) to inform the research inquiries. Methods used to collect data were in-depth interviews (Thorne et al., 2003; Hornsten et al., 2004; Rayman & Ellison, 2004; Anderson et al., 1991; Tang & Anderson, 1999; Mercado-Martinez & Ramos-Herrera, 2002; Mitchell & Lawton, 2000; Schoenberg et al., 1998) and focus groups (Koch et al., 2000; Koch et al., 1999; Samuel-Hodge et al., 2000; Burke et al., 2006).

One study was carried out in Mexico, one in Sweden, two in Australia, four in Canada, and four in the USA. Women from rural and remote areas were involved in two studies (Samuel-Hodge et al., 2000; Schoenberg et al., 1998), and socio-economically disadvantaged adults were included in three studies (Mercado-Martinez & Ramos-Herrera, 2002; Anderson et al., 1991; Tang & Anderson, 1999). In all but one of the studies participants had been living with diabetes for a minimum of one year. Rayman and Ellison (2004) examined the experiences of women who were new to intensive diabetes therapy within the last six months. Participants were on diet management alone, or taking oral hypoglycemic agents and/or insulin to assist with glycemic control.

The research inquiries explored lay perspectives on the origin and management of type 2 diabetes (Mercado-Martinez & Ramos-Herrera, 2002; Schoenberg et al., 1998), and the influence of contextual factors such as spirituality, and the multi-caregiver role (Samuel-Hodge et al., 2000). The experience of living and coping with diabetes in various social contexts, and how individuals develop meanings and make sense of their illness experience was also explored (Mitchell & Lawton, 2000; Tang & Anderson, 1999; Koch et al., 1999; Hornsten et al., 2004; Rayman & Ellison, 2004; Anderson et al., 1991). Additionally, self-care practices and influencing factors on self-management decisions and personal life choices were examined (Burke et al., 2006; Hornsten et al., 2004; Mitchell & Lawton, 2000; Rayman & Ellison, 2004).

Health care professionals’ understandings of the illness experience and their perceptions of proper self-management were compared to the understandings of those living with diabetes (Hornsten et al., 2004; Rayman & Ellison, 2004). Lay attitudes towards health care professionals’ diabetes expertise were also investigated (Burke et al., 2006; Thorne et al., 2003;
Tang & Anderson, 1999; Mitchell & Lawton, 2000), along with potential power imbalances in the patient-practitioner relationship that may impact diabetes care and outcomes (Tang & Anderson, 1999; Anderson et al., 1991). The ‘self-care movement’ in healthcare systems and its impact on those who are socially disadvantaged was included in this review as an important argument that health care professionals’ perception of noncompliance to treatment adherence may be related to inability to access resources (Anderson et al., 1991). I further examined this body of literature for gender-related differences and similarities, and to see if males and females were equally represented. The major concepts are presented under three main categories as follows; ‘the diabetes illness experience,’ ‘gender-specific considerations,’ and ‘reflections for health care providers.’ The diabetes illness experience was further divided into subheadings; ‘restructuring your life,’ ‘stress,’ ‘fatigue,’ ‘self-blame,’ and ‘finding freedom.’

**The diabetes illness experience.**

The first line treatment strategy for people with type 2 diabetes is to initiate a restrictive diet that includes low fat, controlled carbohydrate, and high fibre food choices, to incorporate exercise into daily routines, and to lose weight. These are lifestyle behaviour modifications that can be extremely difficult to initiate and continue on a long term basis. “Non-compliance with suggested therapeutic regimes is cited in the health literature as the most important problem in the management of diabetes” (Koch et al., 1999, p. 713). Although health professionals widely promote self-management to deal with chronic disease by focusing on empowering the person with diabetes to take control, the complexities involved in providing this support are not well understood (Thorne et al., 2003). Assumptions underlying the priorities of support for self-care practices, as reported by Thorne et al., tend to be derived from formal understandings of physiologic blood glucose control and management of disease progression, rather than developing a more comprehensive appreciation of what it is like to incorporate a chronic illness into the complexity of one’s life. Various perspectives of these complexities are reiterated through this analysis of the literature.

**Restructuring your life.**

The most consistent theme across the studies was that the diagnosis of diabetes is a starting point of an altered life, whereby immediate restructuring is necessary to incorporate and adapt to living with this chronic illness (Tang & Anderson, 1999; Anderson et al., 1991; Koch et
al., 1999; Samuel-Hodge et al., 2000; Hornsten et al., 2004; Rayman & Ellison, 2004). This means a new definition of ‘self’ as someone who is ill or unhealthy (Hornsten et al., 2004; Rayman & Ellison, 2004; Koch et al., 1999; Tang & Anderson, 1999), socially different (Rayman & Ellison, 2004; Koch et al., 1999), with a body that needs constant monitoring and management (Anderson et al., 1991; Rayman & Ellison, 2004). The majority of responsibility for challenging day-to-day management is swiftly delegated to the individual, who must follow the complex treatment regimens for a lifetime (Rayman & Ellison, 2004; Schoenberg et al., 1998; Burke et al, 2006).

**Stress.**

Stress figured prominently across all of the studies, and was related to concern about the demands involved with obtaining and maintaining proper glycemic control, and worrying about developing possible life-threatening complications or dying (Samuel-Hodge et al., 2000; Koch et al., 1999; Koch et al., 2000; Hornsten et al., 2004; Mitchell & Lawton, 2000; Burke et al, 2006). Diabetes-related stressors included worrying about traveling, dining out, and holidays (Rayman & Ellison, 2004), inability to afford treatment supplies (Anderson et al., 1991), having hypoglycemic reactions (Rayman & Ellison, 2004), taking insulin or ‘the needle’ (Koch et al., 2000; Mitchell & Lawton, 2000), and fear of suffering loss of limbs, kidney disease, blindness, or death (Mitchell & Lawton, 2000; Anderson et al., 1991; Samuel-Hodge et al., 2000; Rayman & Ellison, 2004; Koch et al., 1999; Koch et al., 2000; Burke et al., 2006). Further, Anderson et al. (1991) and Samuel-Hodge et al. (2000) found that stress also stems from carrying multiple career and caregiver responsibilities while trying to fit in the demands of diabetes management.

**Fatigue.**

Fatigue was a recurring theme within this research (Samuel-Hodge et al., 2000; Koch et al., 1999). Feelings of tiredness interfered with routine daily activities, negatively affecting quality of life (Koch et al., 1999). Koch et al. found that women’s perceptions of themselves changed after they developed diabetes because they had a reduced level of independence and had to rely on family members (1999). Some participants described being overwhelmingly exhausted most of the time, and all of the women at some point experienced symptoms of depression (Koch et al., 1999). Although, biologically, fatigue is a symptom of both ‘above’ and ‘below’ target blood glucose levels, some studies pointed to fatigue being related to other factors, which may be
overlooked (Koch et al., 1999; Samuel-Hodge et al., 2000). Participants in Samuel-Hodge et al.’s study described their fatigue as stemming from three sources: being overworked, feeling worn out from the responsibility of self-care, and stress-related fatigue from worrying constantly about the illness.

*Self-blame.*

It was reported that many people living with diabetes carry a sense of shame, blaming themselves or feeling like others hold them responsible for developing the illness (Thorne et al., 2003; Rayman & Ellison, 2004; Mitchell & Lawton, 2000). If they are overweight, health providers or close others speculate they do not exercise, or eat too many sweets, showing no restraint (Hornsten et al., 2004). The diagnosis of diabetes is accompanied by social stigma (Rayman & Ellison, 2004; Hornsten et al., 2004). In Rayman and Ellison’s study, participants described a societal belief that those with diabetes have no willpower, which left a sense of being victimized, and an unwillingness to let others know of their diagnosis. Further, some people do not divulge that they have diabetes in the workplace for fear of losing their job or being socially rejected (Anderson et al., 1991; Rayman & Ellison, 2004).

*Finding freedom.*

Diabetes is always central to thoughts and daily decisions (Koch et al., 1999; Burke et al., 2006). In particular, the dietary restrictions placed on people impact their lives significantly (Koch et al., 1999; Samuel-Hodge et al., 2000; Koch et al., 2000; Thorne et al., 2003). Adherence to the prescribed diet demands knowledge of the correct and appropriate amount of food choices, and the consumption of meals and snacks at regular, preset times. Many develop feelings of anger because they have a disease that demands a considerable amount of time and energy (Rayman & Ellison, 2004).

A repetitive theme was ‘taking time out,’ denying the presence of diabetes for short periods by deliberately choosing foods not included in the diabetic diet (Koch et al., 1999; Mitchell & Lawton, 2000). In Koch et al.’s (1999) study, freedom from monitoring food intake on special occasions was considered by participants to be joyous, even if feelings of guilt surfaced. Women in the same study felt rebellious at times towards the diabetes-related demands placed on them, and would have “that bit of chocolate” (Koch et al., 1999, p.716), or would
occasionally eat whatever they liked. Rayman and Ellison (2004) noted that some people just stopped self-care activities for varying periods of time in search of relief.

Mitchell and Lawton (2000) explored the experience of living with the consequences of personal choices, and found that the participants indulged in moderation as severe restriction and rigid guidelines were seen as unreasonable. Participants in Mitchell and Lawton’s study stopped managing their diabetes for periods of time for various reasons, for example, to seek temporary freedom from pressures of diabetes, ‘they did not care’ at particular moments, or they experienced feelings of futility. In the same study individuals unanimously spoke of taking into consideration the consequences of their choices, because they wanted to avoid negative or harmful outcomes. Taking time out was ‘finding the balance’ by being committed to living with diabetes while still being able to enjoy life (Mitchell & Lawton, 2000).

**Gender-specific considerations.**

Women’s illness experiences appeared to be well represented in this body of literature, but there was underrepresentation of men’s perspectives. Of the 12 articles reviewed, six recruited women alone and five included both men and women, but findings were grouped together and comparative accounts were not offered. Koch et al. (2000) were the only researchers who explored the diabetes illness experience exclusively from a male perspective. The men in Koch et al.’s (2000) study reported that diabetes had made a positive impact on their lifestyles. For these men, personal meanings of diabetes were interwoven with health and wellbeing. They did not perceive themselves as being ill and a surprising degree of acceptance among the participants was noted (Koch et al., 2000). Rather than restricting food intake, they ate outside their diet with a sense of control and did not experience feelings of guilt (Koch et al., 2000). All of the men expressed concerns regarding complications but initiated steps to reduce their risks. For example, all had routine eye exams and made positive changes in lifestyle behaviours, such as reducing alcohol consumption, losing weight, and quitting smoking (Koch et al., 2000). Spouses were prominent supports by actively gaining knowledge and taking over the responsibility for meal planning and preparation to ensure that the men consumed healthy food (Koch et al., 2000).

In studies exploring women’s perspectives (Rayman & Ellison, 2004; Koch et al., 1999; Samuel-Hodge et al., 2000; Tang & Anderson, 1999; Anderson et al., 1991), participants
generally felt unsupported and overwhelmed, as diabetes self-management was added to existing responsibilities and family care giving commitments. Women tend to be care providers for their children and their immediate and extended family members, and often have the responsibility of meal preparation and housekeeping (Anderson et al., 1991; Rayman & Ellison, 2004). Many women also maintain paid employment outside the home. In contrast to Koch et al.’s (2000) study where the men felt supported, Rayman and Ellison’s female participants described preparing two separate meals so as not to impose their dietary needs on the family. Relationship strains with both family and friends, and emotional struggles were noted, along with feelings of betrayal and distrust (Rayman & Ellison, 2004). As reported by Samuel-Hodge et al., the main sources of support for women participants were daughters, who reminded them to take medication, helped with housework when required, and provided transportation to appointments. Religion was a major emotional support for participants because it provided a sense of strength to enable coping (Samuel-Hodge et al., 2000).

Reflections for health care providers.

The meaning of proper self-management differs significantly between health care providers and those living with diabetes (Rayman & Ellison, 2004; Hornsten et al., 2004). Medical professionals tend to be disease focused, while people living with diabetes view management from an illness perspective, with the disease being heavily influenced by contextual factors (Rayman & Ellison, 2004; Burke et al., 2006). Based on accounts by lay participants, when glycemic control is attained, health care professionals tend to be supportive and if it is not obtained, they may be punitive, judgmental, and critical (Thorne et al., 2003; Tang & Anderson, 1999). Some authors found that lay expertise regarding personal health and wellbeing is generally disregarded by health care providers (Anderson et al., 1991; Tang & Anderson, 1999; Koch et al., 1999; Mitchell & Lawton, 2000). Their experiences are not perceived as being regarded as legitimate knowledge, and self-understandings, personal goals, evaluations, and strategies are often not heard (Tang & Anderson, 1999; Koch et al., 1999).

Communication with health care providers can become strained as individuals fail in their attempts to manage successfully. Compliance with medical recommendations may become a matter of scrutiny. Study participants spoke of hierarchical social relations involved in their interactions with providers (Mitchell & Lawton, 2000). In Koch et al.’s (1999) study,
participants reported that health care providers attempted to coerce them into compliance by using such tactics as threatening initiation of insulin if glucose control was not obtained. Those who do not meet biomedical expectations are labeled as noncompliant, without inquiring about social and contextual circumstances, which are generally multilayered and numerous (Anderson et al., 1991; Tang & Anderson, 1999; Koch et al., 1999; Mitchell & Lawton, 2000; Thorne et al., 2003; Hornsten et al., 2004).

According to Tang and Anderson (1999), the issue is that while health professionals know that life circumstances play a role in how people manage diabetes, they expect people will restructure their lives to accommodate the illness. This expectation is beyond the reach of many, particularly those of lower socioeconomic status. This was exemplified in Anderson et al.’s (1991) study with immigrant Chinese and Anglo-Canadian women. A Chinese informant described being unable to afford a glucose meter to monitor her glucose levels. She was not fluent in the English language, so she was unable to further her education or find higher paid employment. She feared her diagnosis would jeopardize her job and could not ask for time off for appointments. She worked six days each week, plus was responsible for housework and caring for her small children, which left little time for self-care activities (Anderson et al., 1991).

Although the structuring of illness management is the product of circumstantial and social situations, health professionals often view ethnicity as a determinate of behaviour (Anderson et al., 1991). The researchers argued that cultural and ethnic categories are embedded in a set of social relations that are constructed in ongoing interactions among people, including those with health care professionals. In the treating of ethnicity as a static, objective fact that determines illness management, health care providers contribute not only to the social structuring of ethnic categories, but also to the person’s experiencing of illness (Anderson et al., 1991). Anderson et al. pointed out that in order to deliver culturally sensitive care, health providers must maintain reflexive awareness of texts and discourses that organize their practices.

Furthermore, embedded in the concept of ‘self-care’ is the idea that individual effort alone is responsible for success, and failure is a result of personal weakness of the individual who does not respond to opportunities (Anderson et al., 1991). Within the self-care ideology it is assumed that health and wellbeing is the afflicted person’s responsibility, but in many cases they are powerless (Tang & Anderson, 1999; Anderson et al., 1991). According to Anderson et al.,
the trend toward individualizing social problems obscures the socioeconomic and political barriers to adequate health care for those who are socially disadvantaged. In not questioning the dominant societal ideologies, such as ‘self-care,’ health professionals sustain these barriers and their position of dominance in relation to patients (Anderson et al., 1991).

**Summary of Qualitative Literature Review**

In summary, the qualitative literature highlights that diabetes carries with it profound consequences for the physical, psychological, and emotional wellbeing of those afflicted. Stress is prominent and related to various aspects of the illness experience, from self-care management worries to fear of dying. Both physical and mental fatigue related to stress and overwork is so great for some people that it leads to overwhelming exhaustion. ‘Finding freedom’ is a pragmatic coping strategy used as a way to obtain release from the exhaustive demands of the illness. Self-blame also accompanies this disease because people believe diabetes is self-inflicted from poor lifestyle habits, namely laziness and overeating. Due to the attached stigma, the diagnosis is often not shared with friends or employers for fear of rejection or loss of employment. A negative self-identity develops as the strongly held societal beliefs are internalized and often depression ensues.

Diabetes management involves engagement with restrictive, time-consuming, and expensive self-care regimens that are difficult to incorporate into life situations. Decisions regarding illness management are multi-factorial and based on life’s experiences and current circumstances, and on important values and priorities. However, health professionals often overlook people’s experiential knowledge about their health and wellbeing, as well as the social and contextual factors that influence illness management. Health care providers, being focused on disease, tend to evaluate health status merely on biomedical markers and intensify their scrutiny of those who cannot reach these targets. Contrary to health providers’ opinions, as was discovered, study participants were very concerned about their health and wellbeing. In fact, diabetes appeared to be in the forefront of their thoughts. Participants reported a sense of responsibility for disease management, as noted in their worry about the influence of day-to-day decisions on their diabetes. From the individual’s perspective, medical advice, when sought, may be ineffective in dealing with struggles because issues are not being heard or addressed.
Finally, the ideology of self-care, which underpins service delivery in health care today, is framed in a manner that overemphasizes individual self-management and de-emphasizes the extensive resources that are required to support such activities. Illness management is reduced to individual capabilities, removing the personal from the sociopolitical, cultural, and economic context. This paradoxically increases barriers to adequate health care, particularly for the socially disadvantaged, which places them further into the margins of society.

**Critical Appraisal of the Qualitative Literature**

Researchers who contributed to this body of qualitative literature sought to understand from the individual’s perspective the day-to-day experience of living with diabetes. The participants were actively involved in producing the knowledge from their viewpoint, as they were considered the experts in their own lives, and in their illness management. Their voices were not silenced, as in the health sciences research. Rather, the participants’ actualities were preserved and shared through such strategies as the use of quotes and narratives. By privileging experiential knowledge over medical knowledge important insights were gained. From the individual’s perspective, illness management was not disease focused, which created tension in the process of receiving medical treatment when biomedical markers were not reached. The notion of ‘resistance’ to restrictive regimes of care was also highlighted, along with other strategies people adopted in the process of illness management. Their personal, social, and contextual constraints to illness management were made known, along with their physical and emotional responses to these barriers.

Also, within this body of literature the researcher-writers took philosophical positions, which were maintained in the written accounts by advocating for their informants. They recommended more sensitive, nonjudgmental, and client-focused health care and they emphasized the need in some cases for financial support to manage diabetes. The authors challenged the subordinate positioning of people with diabetes in relation to their health providers, and they questioned the lack of acknowledgement of local knowledge. They also drew attention to social and contextual constraints that condition self-care.

Anderson et al. (1991) generated knowledge beyond that of the individual experience by using tenets of institutional ethnography to understand the existential meaning of illness. Dominant discourses and ideologies such as the notion of self-care and ethnicity as a determinant
of health behaviour were brought into question. The State was problematized for placing the responsibility of illness management on the individual without taking into account sociopolitical, cultural, and economic contexts that make it impossible to realize health and wellbeing. Health care professionals were also brought under scrutiny for their part in not questioning the basis of the ideology, thereby sustaining it in practice.

However, in general, within this body of qualitative literature, the inquiry did not go beyond the individual experience. Conceptual understandings often took primacy over the actualities grounded in the everyday world. In order to create social change, exploration must go beyond theoretical understandings of personal experience to include concrete understandings of ‘how it is that things are the way they are,’ and ‘how they happen as they do.’ The social relations that shape people’s lives must be revealed to show how health inequities are sustained in our world. Understanding how social institutions coordinate local experiences brings us closer to being able to make the necessary social changes. This type of knowledge is generated through institutional ethnographic research because its analytic focus is on the ‘social.’ Additionally, some research informed by institutional ethnography discusses the “health work” (Mykhalovskiy & McCoy, 2002, p. 17) in which people engage in order to care for themselves, which is relevant to my research problematic.

Institutional Ethnography: Review of Literature

There is a growing body of literature that uses institutional ethnography to discover how things are put together in society, how people living in different circumstances are actively drawn into a common set of organizational processes. This type of research has taken root in such areas as sociology, nursing, social work, occupational therapy, community health, education, and law. In these studies, institutional ethnography as a method of inquiry is used to investigate work and textually mediated practices to show how ideological processes of ruling are at play. This review presents relevant health-related institutional ethnographic research, along with methodological strategies used to gain insight into the researchers’ topics of interest. Their ability to inform my work in the area of diabetes care in residential homes is also discussed.

In the area of community health care, institutional ethnography has been used as a method of inquiry for investigating the Canadian AIDS movement (Smith, G., 1990; Kinsman, 1996; Mykhalovskiy & Smith, G., 1994) and the social organization of “health work” in the
context of living with HIV/AIDS (Mykhalovskiy & McCoy, 2002, p. 17). Outpatient services for HIV-positive people have also been examined using institutional ethnography (McCoy, 2005). George Smith’s (1990) activist work on AIDS management employed institutional ethnography, as a reflexive-materialist method, to provide a scientific basis from which to socially organize communities. McCoy’s study drew on both interviewing and focus group discussions to explore physician-based health care for socially marginalized people who were HIV positive. The aim in McCoy’s study was to contribute to reflexive health promotion practices in AIDS service organizations and sites of AIDS health care delivery by learning about the health-related work experiences of people from various social and economic circumstances. McCoy discovered that, in turning the gaze from the individual to the institutional work processes within which he or she engages, it was possible to explore the social relations that are consequentially shaping his or her life in ways that make change possible. Accounts that were presented in this study direct attention to institutional practices that shape what doctors can do for their patients and what strategies can be adopted to enhance access to health care (McCoy, 2005).

Within the long term care system, Diamond’s (1986) institutional ethnographic account of nursing homes in the United States revealed the linkages between social policies and their consequences for those who live in these environments. Diamond worked as a nursing assistant and used participant observation to explore how the operation of these facilities as businesses shaped a range of processes, such as nursing assistant wages, the patients’ economic status, the patient pacification process, and the invisibility of caring work. Diamond brought under scrutiny the social policies that shape the lives of people who both work and live in long term care settings. Issues raised by Diamond concerned the underlying assumptions about nursing assistant work that result in minimum wage remuneration, conceptions of patients as passive rather than active in their everyday experiences, the embodiment of a hospital environment in what is supposed to be ‘home,’ the social relations of caring work, and the task oriented focus of business-centered organizational models (Diamond, 1986). Diamond reported that a vital and empowering voice for patients and care providers is required in both future research and in political action related to nursing home care.

Institutional ethnography has also contributed to research in Canadian health care reform. Contemporary health care reform, undertaken to reduce government costs, has been criticized for
its emphasis on ‘official knowledge,’ mediated through texts, which focuses on productivity and accountability (Rankin, 2001). Its influence on both patient care and the work practices of nurses and physicians was investigated through textual analysis of certain documents (Rankin, 2001; Rankin, 2003). Rankin (2003) investigated the ‘Patient Satisfaction Survey’ for its active role within the dominant hospital management discourse that subordinates actual experiences of nurses and patients, thereby seriously jeopardizing quality of care. Rankin’s (2003) account drew on her own experience as a family member of someone who was hospitalized. From this background, she elucidated patient satisfaction technologies as the constituents of a textually organized relation that supports corporate interests. She discovered that in building an objectified account to validate quality, as is the case with patient satisfaction surveys, the experiencing individuals (the patient, family, and care providers) become invisible, along with their local knowledges of what actually happened during their hospital stay (Rankin, 2003). In another study, Rankin (2001) used textual analysis to examine how the ‘Alternate Level of Care,’ as a categorization of a patient, organized and influenced nurses’ and doctors’ actions and thinking, and how it connected these health care professionals into health care reform’s managerial agenda. Rankin (2001) demonstrated how texts link frontline caring practices into such standardizing acts as hospital bed utilization management and fiscal efficiency.

Health services research has also been critiqued for its active role in the organizing of hospital restructuring (Mykhalovskiy, 2001). In his study, Mykhalovskiy explored how health services research, in its socially active character, coordinates medical and managerial practices and rationalities into extra-local ‘medico-administrative’ relations. Mykhalovskiy used text analysis, participant observation, and interviews to investigate the interpretive processes and social relations involved in the activating of the health services research report for the purposes of hospital restructuring (Mykhalovskiy, 2001). Health services research was critiqued for its representation as being a neutral, technical fix for costly health care service provision (Mykhalovskiy, 2001). Mykhalovskiy revealed that health services research operates as a social practice, whereby it plays an active integral role in standardizing and reducing the amount of hospital time allotted to patients who have suffered heart attacks.

In studies of Canadian health care, especially within the field of nursing, institutional ethnography has been used to explore such aspects as nursing knowledge-based action
(Campbell, 2001), the social organization of nurses’ stress (McGibbon, 2004), the social construction of ‘competence’ in nursing work (Jamieson, 2004), and the social organization of nursing practice in northern outpost settings (Vukic & Keddy, 2002). Campbell’s inquiry of home care services for people with disabilities investigated the textually mediated, organized relations of nursing. Through observing how a case manager activated an assessment form during an interview with a home care applicant, Campbell discovered that specific textually mediated ruling interests organize nurses’ decisions about applicants’ service eligibility.

Nurses have used institutional ethnography in different patient populations, for example, to look at the woman’s preterm labor experience by exploring their activities in response to the threat of premature labor (MacKinnon, 2006). The everyday home experiences of women who have had heart surgery have also been investigated using this approach (Angus, 2001). Angus used open ended interviews to critically examine the social relations, such as gender, age, class, immigration, and social and material circumstances, that shape women’s recovery experiences during the first month home from hospital. Finally, Anderson et al. (1991) used this approach to examine immigrant Chinese and Anglo-Canadian women’s existential responses to chronic illness in the context of socioeconomic barriers. Anderson et al.’s inquiry explored the diabetes experience in both Chinese and Anglo-Canadian groups. The women’s diabetes care activities were investigated to show important differences in illness management in light of material circumstances, and to show how the ideology of self-care structures health care delivery (Anderson et al., 1991).

Collectively, these institutional ethnographic studies explored life experiences and institutional processes from the viewpoint of certain groups of people, many of whom were positioned at societal margins. Included in these investigations were people living with chronic disease (Smith, G., 1990; Mykhalovskiy & Smith, G., 1994; Mykhalovskiy & McCoy, 2002; McCoy, 2005; Anderson et al., 1991), people with disabilities (Campbell, 2001), women (Angus, 2001; MacKinnon, 2006), elderly people (Diamond, 1986), health care providers (Diamond, 1986; McGibbon, 2004; Jamieson, 2004; Vukic & Keddy, 2002; Rankin, 2001; Rankin, 2003), and hospital inpatients (Rankin, 2001; Rankin, 2003). Analyzed were institutional processes of acute health care (Smith, G., 1990; McCoy, 2005; Mykhalovskiy & Smith, G., 1994; Mykhalovskiy & McCoy, 2002; Campbell, 2001; Angus, 2001; Rankin, 2001; Rankin, 2003;
Anderson et al., 1991), long term care (Diamond, 1986), and health services research (Mykhalovskiy, 2001). Important connections were made between the organizing forces and the lives of those who are shaped by them.

Methodological strategies used to analyze and present the data in these research inquiries are also noteworthy. Texts are integral to the coordinating of activities (Smith, D., 2006), and textually mediated social relations were exemplified throughout this body of literature (Smith, G., 1990; Mykhalovskiy & Smith, G., 1994; Campbell, 2001; Mykhalovskiy, 2001; Rankin, 2001; Rankin, 2003). “Text-reader conversations” (Smith, D., 2005, p. 104) were eloquently represented in Rankin’s (2003) study through a detailed written account of her and her aunt’s actual experience of attempting to complete a patient satisfaction form. Participant observation was also used as a methodological strategy (Diamond, 1986; Mykhalovskiy & Smith, G., 1994; Mykhalovskiy, 2001; McGibbon, 2004; Jamieson, 2004; Vukic & Keddy, 2002; Smith, G., 1990). Diamond worked as a nursing assistant in nursing homes while he did covert research to explore the social organization of long term care systems from his own and his coworkers situated experiences. In taking a standpoint in the embodied actualities, where people were in fact situated in the local setting, Diamond preserved the “…corporeal, incarnate base,” which he considered pivotal to the project (Smith, D., 2006, p. 59).

Interviewing and focus groups were also used as methodological strategies and in order to maintain informants’ voices, excerpts from discussions were included in the final written accounts (Angus, 2001; MacKinnon, 2006; Mykhalovskiy, 2001; McCoy, 2005; Mykhalovskiy & McCoy, 2002; Diamond, 1986; McGibbon, 2004; Jamieson, 2004; Vukic & Keddy, 2002; Mykhalovskiy & Smith, G., 1994; Anderson et al., 1991). Anderson et al.’s use of sequential interviewing with participants over two years promoted understanding of life with chronic disease and changes in illness management over time. Finally, as a political activist, George Smith (1990) studied AIDS management in Ontario using a different approach to interviewing, whereby he attended meetings, did presentations, and had conversations with government officials who were knowledgeable on the topic of interest. His work, using institutional ethnography, enabled transformation in AIDS treatments. George Smith helped create AIDS ACTION NOW! and the Community AIDS Treatment Information Exchange, better known as CATIE (CATIE@20, 2010).
The overall aim in any institutional ethnographic project is to explicate institutional processes that shape people’s lives in consequential ways to create knowledge that can effect positive change. These inquiries started with the people outside the ruling regimes and then extended extra-locally to show how the ideological processes of ruling were at work. Important discoveries were made that may have otherwise remained elusive by turning the gaze from the individual to that of the institution and its work processes. Knowledge produced through this form of research facilitates a focus on how local situations are textually and discursively coordinated so that we can understand where change is required to eliminate health disparities.

**Institutional Ethnography as a Method of Inquiry**

Although limited, the use of institutional ethnography in health care research has potential to generate knowledge on the social organization of contemporary society. The inquiries start from the actual lives of people in local settings, and their reflexive knowledge about their social world is privileged. Researcher-writers in these studies are committed to understanding the social organization of the world by starting from the social location of the people whose interests are being served, those standing outside the ruling regimes. Viewpoints from positions other than in the everyday world, as from within the dominant medical institution, cannot generate the required knowledge of the social organization of health disparities. However, the local perspective is the point of departure, not the sole location of the research analysis. As shown in these studies, in taking a stance with the people in their social location, both within the research and in the written representations, and in mapping out and analyzing the extra-local coordinating social relations, institutional ethnographers are able to critically articulate the workings of overarching social institutions.

In reviewing the literature, I found no research that provides insights into the actualities of the people living with both mental illness and diabetes in group home settings. Therefore a qualitative approach was required to gain in-depth insight into the phenomenon. However, it was not enough to merely understand their lived experiences. It was important to understand the social organization of diabetes care for group home residents before changes could be made. Thus, institutional ethnography as the method of inquiry was best suited to guide my research. The above body of literature that embodies this “sociology for people” (Smith, D., 2005, p.10) was extremely useful in its ability to inform my work. Finally, since this is a new area of
research, my inquiry on this particular phenomenon adds to the growing body of institutional ethnographic literature within the area of health care in the field of nursing. The philosophical assumptions of institutional ethnography and the design of my thesis project are described in detail in the following chapter.
Chapter 3
Methodology and Research Design

Philosophical Assumptions of Institutional Ethnography

Institutional ethnography, as a method of inquiry, was proposed as a sociology to investigate social life in terms of how it is actually organized (Campbell & Manicom, 1995) by beginning from the lens of everyday experience to examine social relations and social institutions (Smith, D., 2005). The basic framework for the design of institutional ethnography is in the epistemological character of the problematic, the fact that it arises in the everyday world as a problem about knowing (Campbell & Manicom, 1995). The everyday world is conceptualized as a problematic, being continually shaped, created, and known by people within it and its organization (Denzin & Lincoln, 2000). The notion of the problematic aids the researcher in identifying his or her stance in relation to the inquiry because delineating the problematic requires that the institutional ethnographer be conscious of the relations, which are not readily visible, in the research setting being investigated (Campbell & Gregor, 2002). The researcher is not methodologically removed from the research, rather is directly involved in the entire process (Campbell & Gregor, 2002) and his or her perspective becomes an integral part of the research (D. Smith, personal communication, June 5, 2007).

As an ontology or theory of how the social exists, institutional ethnography provides a framework for giving selective attention to the aspects of actual ongoing social processes in both time and place to map out the social in its institutional forms (Smith, D., 2005). The mapping of the social relations starts from and always includes the local site of origin, and the larger organization that shapes the problematic is exposed. The ontological shift of this research is in the movement away from idealist theorizing to the empirical investigation of the everyday world as a research problematic (Campbell & Manicom, 1995). Although Smith drew on the work of such scholars as Karl Marx, George Herbert Mead, and Mikhail Bakhtin, her inquiry rejects the dominance of theory in its use (Smith, D., 2005). Thus, the understanding of social organization as it is coordinated and concerted reflexively and recursively across space and time is centered in the concrete world of people’s actual practices and activities, not in generalized theoretical explanations (Campbell & Manicom, 1995).
Foundational to the institutional ethnographic project are four criteria as follows; “…individuals are there; they are in their bodies; they are active; and what they’re doing is coordinated with the doings of others” (Smith, D., 2005, p. 59). The focus of the research is not on the individual: however, they are always present and their practices are taken up relationally (Smith, D., 2005). According to D. Smith, “Relations operate independently of particular individuals and they stand over and against us and yet they enter into our local actualities of our bodily being and we are active in them” (personal communication, August 14, 2009). The social, which is the object of investigation, is not a distinct phenomenon in itself but is an aspect of what people are doing. According to D. Smith (2005), the social, as the main focus, is reflected in people’s activities as they are coordinated with activities of others. D. Smith (2005) refers to George Herbert Mead’s (1962) ideas of symbolic interactionism that coordinate people’s actions, Marx’s conception of the economy and relations of exchange, and ideas from ethnomethodology’s conversational analysis to build her conceptual interpretation of coordination in institutional ethnography.

In institutional ethnography people remain the expert subject knowers and the researcher extends their knowledge and does not displace them in written representations (Smith, D., 2005). Originating in feminism and feminist standpoint theory, D. Smith has adopted Sandra Harding’s conceptual understanding of standpoint to socially position the subject of knowledge as the creator and expert. D. Smith’s use of the term standpoint differs in that it does not identify a socially determined position, class, gender, or race in society, but rather establishes a subject position as a site and point of departure for the institutional ethnographical inquiry (Smith, D., 2005). More recently, D. Smith has moved away from the use of the term standpoint, preferring to no longer use this as a theoretical concept due to the propensity towards misinterpretation (D. Smith, personal communication, August 16, 2009).

Institutional ethnography does not claim universality, rather it is assumed that each individual possesses a unique biography, experience, and position, within which are situated her or his own perspectives, feelings, beliefs, needs, desires, and interests (Smith, D., 2005). Differences in perspectives and experiences are central to discovering how people are active in producing coordinated institutional forms (Smith, D., 2005). Instead of displacing varying viewpoints through interpretation, the institutional ethnographer relies on each diverse account to
assemble the process as it is known by the people experiencing it (Smith, D., 2005). Thus, according to D. Smith, experiential knowledge is not positioned subordinately to an overriding interpretation.

Language is important, because it is through language that thoughts and ideas flow back and forth between the individual and the sociological realm, often in textually mediated form (Smith, D., 2005). “Institutional ethnography attends to those phenomena of consciousness, thought, culture, and the like as they have become objectified in the translocal organization of people’s work and as a product of that work” (Smith, D., 2005, p. 69). Therefore, language is fundamental to these forms of organization. D. Smith (2005) takes up Bakhtin’s literary theory model (1981, 1986) that conceptualizes dialogue as a form of social coordination. D. Smith uses this notion of ‘dialogic’ to describe social structure, not as generating particular patterns of action, but an ongoing historical process in which people’s activities are caught up and responsive to what others are doing. A process is thereby created that is historically committed, and also projects forward into the future (Smith, D., 2005).

By adopting Bakhtin’s dialogic conception of an ongoing historical process in which each moment of interchange, of people’s doings, of our use of language, and of our work, is embedded in and contributes to the movement of the present from the past into the future, institutional ethnography avoids extracting the particularities of people’s everyday lives and doings to construct abstractions that isolate them conceptually. (Smith, D., 2005, p. 68)

Institutional ethnography is emergent, with both ‘exploration’ and ‘discovery’ being key to its project (Smith, D., 2005). As reported by D. Smith, each step in the research process builds upon the discoveries and then moves systematically through extended dimensions of the institutional regime. This form of research is thought of as dialogue, whereby the researcher is engaged reflexively, changing analyses and interpretations throughout the course of the research (Smith, D., 2005). The project exposes important concepts that are embedded within and are connected to the actualities the researcher is investigating (Smith, D., 2005). The researcher engages with these actualities in a reflective manner, consistently checking conceptual understandings with what is being learned through actualities as they are experienced by those
involved (Smith, D., 2005). Research findings, according to D. Smith, are the products of the diverse accounts of the people experiencing the phenomenon.

**Principles of Methods Used in Institutional Ethnography**

In an institutional ethnographic inquiry various methodological strategies like participant observation, interviewing, and investigation of ‘texts as coordinators’ (Smith, D., 2005) are used to gain important insight. The principles of each method are outlined as follows:

**Participant observation.**

According to Diamond (2006), participant observation allows for the incorporation of physicality of the author and others, providing a “corporeal incarnate base” (p. 59) to ground bodies in action and coordination. Participant observation enables the exploration of “the ‘social’ in motion” (Diamond, 2006, p. 60), as the primary narratives happen in an actual time and place, and are ongoing rather than static. Participant observation also provides a ‘place’ that is the starting point, as it begins in a specific setting. As Diamond highlights, this method captures stories over time, rather than as a snapshot or a reconstruction of a story in a specific time, like in interviews. It also offers “…a way to start in the local particularities to establish a problematic with a focus on how actualities of people’s lives come to be hooked up with institutional relations” (Diamond, 2006, p. 60).

Spradley (1980) recommends that the researcher gain an understanding of the social situation by initially making descriptive observations, whereby “…the activity in process is approached without any particular questions in mind, but only the general question, ‘What is going on here?’” (p. 73). Observations can be divided into one of two types, grand tour and minitour observations (Spradley, 1980). Grand tour observations provide an overview by describing the major aspects or general features of the social situation, including the spacial location (Spradley, 1980). Three major features of all social situations are space, actor, and activities, each of which provides grand tour descriptions. Spradley notes that other dimensions of social situations include object, act, event, time, goal, and feeling. Mini-tour observations use these same questions, but deal with more specific, detailed aspects of the social situation the researcher is observing (Spradley, 1980).
Interviewing.

Institutional ethnography is an emergent method of inquiry that is subject to revision as the researcher takes a step by step approach to unraveling the complexities of social relations at play (DeVault & McCoy, 2002). In institutional ethnography, interviews are meant to map out and reveal organizational and institutional processes that coordinate and control local activities, rather than discover individual experience (DeVault & McCoy, 2002). DeVault and McCoy highlight that interviewing in institutional ethnography is performed in order to build an understanding of ‘how things work,’ and to learn how activities are coordinated in multiple sites over time and place. As such, DeVault and McCoy report interviews do not need to follow a set of standardized questions, because the researcher is building a picture of the ‘extended relational chain.’ The term ‘talking with people’ is used to describe interviewing in its aim to dialogue in formats other than the usual interview style (DeVault & McCoy, 2002). Mykhalovskiy stated, “Describing interviews as a set of questions doesn’t get to the actual work involved…analytic thinking begins in the interview. It’s like an analytic rehearsal,” whereby understanding, as it develops during the interview, is checked by confirming with the informant (as cited in DeVault & McCoy, 2002, p. 757).

Interviews are organized around the notion of work, or more specifically the participant’s activities that are connected to others’ activities (DeVault & McCoy, 2002). Rather than selecting informants from the outset, people are chosen as the research progresses to gather more information about the social relations in question (DeVault & McCoy, 2002). According to DeVault and McCoy, the aim is to find the social that resides in people’s actual doings, those activities that sustain particular ruling regimes, by investigating everyday work practices. Work practices may be paid or unpaid and include everyday experiences, frontline organizational work, or governing work, such as management and administration (DeVault & McCoy, 2002). Interviews are generally audiotaped and transcribed to maintain details that can be reflected upon (DeVault & McCoy, 2002). The transcriptions are important texts that enable research participants to have voices in the published accounts, as reported by DeVault and McCoy.

Textual coordination.

“Advanced contemporary industrialized societies are pervasively organized by textually mediated forms of ruling” (Smith, D., 1990, p. 212). Although texts are often viewed as ordinary
inertia, not recognized as being located within our temporal and local world, they are extremely active in coordinating one’s activities with others (Smith, D., 2006).

The investigation of textual practices makes visible many phases of the organizational and discursive processes that are otherwise inaccessible. In particular, the formality, the designed, planned, and organized character of formal organization depends heavily on textual practices, which coordinate, order, provide continuity, monitor, and organize relations between different segments and phases of organizational courses of action, etc. (Smith, D., 1990, p. 217)

Institutional ethnography is used to illuminate how such textually mediated relationships occur and are sustained within institutions, creating important links between local and extra-local settings (Olesen, 2000).

Texts, such as print, film, television, audio, and computer, can be crystallized and preserved, and detached from their local historicity, and in so doing, are able to standardize and objectify knowledge as people take them up and mobilize them in certain ways (D. Smith, personal communication June 5, 2007). Although media differ they are still forms of writing, speaking, or imaging that are replicable, and thus can be read, heard, and watched by more than one person in different places at different times (Smith, D., 2005). Replicable and replicated texts are essential to standardizing of work activities across time and translocally (Smith, D., 2005).

Texts speak in the absence of speakers; meaning is detached from local contexts of interpretation; the same meaning can occur simultaneously in a multiplicity of socially and temporally disjointed settings (Smith, D., 1990). In the distinctive formation of social organization mediated by texts, their capacity to transcend the essentially transitory character of social processes and to remain uniform across separate and diverse local settings is key to their peculiar force (Smith, D., 1990). This is only accomplished, however, by individuals in everyday local settings who enter into and participate in objectified forms through “text-reader conversations” (Smith, D., 2005, p. 104), constituting organizational and discursive relations beyond themselves (Smith, D., 1990). D. Smith introduces the notion of text-reader conversation, which a) enables us to recognize the reading of a particular text in a certain local setting by a
specific person, b) proposes that the reader, who is engaged in a text-reader conversation, firstly activates the text and in activating it becomes the text’s agent and responds to it in a manner that is relevant to his or her work, and finally c) makes visible the text, activated by a reader, as participating and playing a role in organizing sequences of action (2005).

_The key to incorporating texts into the ethnographic mode is to be able to recognize that their reading is situated in an actual time and place; that it is an integral part of a course of action; and that there’s a text-reader conversation going on that involves an actual person (maybe more than one). (Smith, D., 2005, p.168)_

The researcher must find the particular texts in the sequences of action that are coordinating the work activities being carried out by different people, not only in that setting but in other settings (Smith, D., 2005). The researcher must also recognize text as a material presence in local situations in which it is activated by a reader to understand what it is the text commits the reader to, which is central to the text’s coordinative work (Smith, D., 2005). Texts are not the focus in and of themselves, rather attention is paid as to how they enter into and coordinate people’s work activities within institutional settings.

The above principles guided the observational studies and the interviews in both the pilot study and the thesis project. The outlined principles related to textual coordination also directed the investigation of relevant texts in the thesis project that were found to be organizing people’s everyday work activities related to both group home care and diabetes care provision.

**Other Methodological Considerations**

**Fieldnotes.**

According to Emerson, Fretz, and Shaw (1995), fieldnotes are inscriptions and as such are products of and reflect conventions for transforming events, people, and places into words on paper. In the transformation process the ethnographer inevitably selects and leaves out certain things, and presents or frames objects in particular ways (Emerson et al., 1995). These presentations reflect and incorporate various understandings, meanings, and sensitivities that the researcher has gained by participating in the described events (Emerson et al., 1995). According to Emerson et al., fieldnotes are distinctively a method for capturing and preserving the insights
and understandings stimulated by the deep immersion in the everyday social life of the research participants, which enables thick description. Fieldnotes are written in such a way that they are not predetermined or prespecified and their character is reflected in changes in their content and concerns over time (Emerson et al., 1995). Written notes are intuitive, reflecting the ethnographer’s changing sense of what may be interesting or important to future readers, and empathetic, reflecting their sense of what is interesting and meaningful to the participants (Emerson et al., 1995). According to Emerson et al., there are four implications for writing fieldnotes as follows:

1) What is observed and treated as data or findings is inseparable from the observations process. The methods to determine what the researcher sees, experiences, and learns are inherently connected to the findings. It is therefore critical for the researcher to document her or his own activities, circumstances, and emotional responses because these factors shape the process of observing and recording of others’ lives (Emerson et al., 1995).

2) In writing fieldnotes, the researcher should give special attention to the indigenous meanings and concerns of the research participants. The object of participating in the field is to gain understanding of what experiences and activities mean to the people being studied and these understandings should be reflected in the fieldnotes (Emerson et al., 1995).

3) Contemporaneously written fieldnotes are an essential grounding and resource for writing broader, more coherent accounts of the participants’ lives. Fieldnotes provide subtle and complex understandings of others’ lives, routines, events, and meanings. It is imperative to document these emergent experiences as they occur, in a constant, continuing process. This makes visible in the written representations the researcher’s changing insight over time in the field, as he or she gains local knowledge. Keeping a record of events as close to their occurrence as possible both preserves their idiosyncratic, contingent characters and elicits distinctive vivid memories and images when reread during analysis (Emerson et al., 1995).

4) Finally, fieldnotes should detail the social and interactional processes that make up people’s everyday lives and activities. Since the researcher discovers things by interacting with participants, it is important to observe and record detailed accounts of sequences and conditions
marking such interactions. In detailing interactions the researcher is also able to identify and follow social processes during witnessed events (Emerson et al., 1995).

Emerson et al.’s (1995) outline for fieldnotes guided my written accounts. Following Emerson et al.’s strategies, written documentations were entered on a daily basis in a notebook, detailing social and interactional experiences occurring within the group home setting as they took place. I also kept record of my own participatory activities, the surrounding circumstances, and my emotional responses to various events and discussions through stringent reflexivity. Particular attention was paid to sequences of interactions, as this is extremely important in institutional ethnography to discover interconnections between local activities and translocal ruling relations.

**Reflexivity.**

Institutional ethnographers are embodied knowers and as such cannot remove themselves from what they know and learn about the world, as they, in concert with other people, enact the world they inhabit according to the social organization of knowledge (Campbell & Gregor, 2002). By virtue of what the researcher knows and how they take up their exploration locates him or her vis a vis other people (Campbell & Gregor, 2002). Therefore, according to Campbell and Gregor, rather than treating the knower’s location as a bias, it becomes integral in the discovery of how one’s knowing is organized.

According to Guillemin and Gillam (2004), the researcher also brings personal values, beliefs, backgrounds, and biases, which influence the planning, conduct, and writing of qualitative research. These factors must be accounted for because they affect both representation and interpretation of research findings (Koch & Harrington, 1998). This requires critical, ongoing reflexivity on the researcher’s part (Guillemin & Gillam, 2004). As noted by Guillemin and Gillam, reflexivity also brings to view the researcher’s philosophical position and draws attention to conduct throughout the entire course of inquiry.

Cutcliffe (2003) suggests the use of reflexive journals to enable transparency where researcher position, mind processes, and bases for decision making are concerned. Key components in reflexive journals are as follows; a) a daily schedule of the logistics of the study, b) a personal diary for reflection and catharsis, and c) a methodological log for decision making
and accompanying rationales (Lincoln & Guba, 1985, as cited in Cutcliffe, 2003). These guidelines for reflexive journal keeping were used in both the pilot study, and in the thesis project.

Reflexivity was key in this research project because I came into this investigation with experiential knowledge in both group home care and in diabetes care provision. My insight was pivotal in my being able to recognize the disjuncture between diabetes care provision and the imposed constraints of group home care. My experiential knowledge of the actualities of everyday group home life also enabled gathering of rich data that built on this knowledge. However, much reflexivity was required because as a registered nurse and a diabetes expert, I have an ingrained awareness of biomedical markers and prescribed treatment strategies. Therefore, I automatically paid attention to work practices in the group home that deviated from my understanding of diabetes care provision that leads to positive health outcomes. I was drawn, for example, to examine the timing of glucose testing and how it was performed in such a manner that useful diabetes-related information could not be extracted. Reflexivity facilitated a heightened awareness of this tendency to gravitate towards prescribed treatment modalities and assisted in maintaining a focus on the larger social forces responsible for creating inequities in health.

Ethics.

In the Tri-Council Policy Statement it is reported that we have an obligation to include vulnerable populations that are considered incompetent to consent for themselves into research because it is unjust to exclude them from studies that may be potentially beneficial to them as individuals, or to the group they represent (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada, Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans [Tri-Council Policy Statement], 2003). These people deserve equivalent justice, respect, and inclusiveness bestowed upon those deemed competent (Tri-Council Policy Statement, 2003). In addition, those who suffer cognitive impairment can still verbally assent to or dissent from participation (Tri-Council Policy Statement, 2003). Also highlighted in the Tri-Council Policy Statement, individuals who are not legally competent must only be invited into research when the phenomenon of interest can “…only be addressed using individuals within the
identified group(s), free and informed consent will be sought from their authorized representative(s), and the research does not expose them to more than minimal risk without the potential for direct benefits for them” (p. 2.9).

The broad ethical principles in the Tri-council Policy Statement (2003) that constitute the moral standards for research involving human subjects are respect for human dignity, beneficence, and justice (Denzin & Lincoln, 2000; Polit & Beck, 2006). These principles provide general guidelines but are not extremely useful for ethical issues that arise throughout the research period, particularly in qualitative studies where the time spent in the field can be quite lengthy (Ramcharan & Cutcliffe, 2001; Guillemin & Gillam, 2004). As reported by Ramcharan and Cutcliffe, research relationships are also sustained for extended periods, in this case with a vulnerable group, and must be managed with respect for the individuals’ emotional, social, and physical wellbeing. In this study, it was extremely important to use such strategies as establishing ongoing or ‘process’ informed consent, both individually and collectively develop and maintain boundaries, and outline terms and conditions of the researcher-participant relationships, in order to sustain an ethical research process (Ramcharan & Cutcliffe, 2001). Reflexivity, as a tool for ethical research practice, assisted with this process (Guillemin & Gillam, 2004).

In congruence with these criteria, the research design intentionally involved the residents, as understanding their life’s experiences was crucial and any potential social changes will affect them. Strict attention was paid to obtaining free and informed consent and it is delineated in the research design section how their best interests were protected, as outlined in the Tri-Council Policy Statement (2003).

Analyzing Data in an Institutional Ethnographic Inquiry

Formal analytic strategies, such as interpretive coding, do not tend to be used by institutional ethnographers to analyze the data (DeVault & McCoy, 2002). If grouping is done it is kept simple and connects topics of discussion to institutional processes and sites (DeVault & McCoy, 2002). According to DeVault and McCoy, different institutional ethnographic projects have varying analyses including the use of data to map out institutional ‘chains of action’, to describe text-based forms of knowledge, or to show how people’s lived experiences are shaped by ruling relations. The aim is to trace how the people living in certain circumstances are drawn,
often unknowingly, into a common set of organizational processes (DeVault & McCoy, 2002). Analysis is achieved by moving back and forth between the data that focuses on the work activities and the context in which it was produced (DeVault & McCoy, 2002). As reported by DeVault and McCoy, instead of focusing on experiences, attention is paid to processes and coordination. Not all interview data is used, as the analysis often follows a specific thread of social organization and the researcher is not interested in every aspect of the institutional process (D. Smith, personal communication, June 6, 2007). The project exposes important concepts embedded within and connected to the actualities the researcher is investigating (Smith, D., 2005). The researcher engages with these actualities in a reflective manner, consistently checking conceptual understandings with what is being learned through actualities as they are experienced by those involved (Smith, D., 2005).

Campbell and Gregor (2002) reported, “Generalizability in institutional ethnography relies on discovery and demonstration of how ruling relations exist in and across many local settings, organizing the experiences informants talked about” (p. 89). In contrast to theorizing individual experiences to make something generalizable of the data, as in grounded theory and symbolic interactionism, institutional ethnography’s aim in illuminating the social is materialist and empirical (Campbell & Gregor, 2002). According to D. Smith, the researcher must find the standardizing, generalizing, and universalizing processes within the ethnographic data (2005).

Interpretation, which is required to make sense of the data, is disciplined first by the analytic framework of social organization of knowledge and then by the materiality of the data (Campbell & Gregor, 2002). According to Campbell and Gregor, “…institutional ethnography relies on, explores, and explicates linkages that are lived, are brought into existence in time and space by actual people doing actual things” (p. 98). The researcher must avoid laying on a conceptual or theoretical framework as a method of understanding (Smith, G., 1990). Rather, according to G. Smith, the data collection and the ongoing analysis of the data both inform and contextualize the direction of the research, enabling the sketching or ‘mapping out’ of social relations that produce the ruling regime. The overall aim of data analysis is to understand how things happen as they do by seeing organization in people’s talk and in text of institutional documents (Smith, G., 1990). These principles outlined by Dr. Dorothy Smith, the founder of the
method of inquiry, and users of institutional ethnography, guided the analysis of this thesis project (discussed further in this chapter).

**Rigor: Ensuring trustworthiness of the research.**

Rigorous, or trustworthy research, is dependent upon both the methods used to collect the data and the researcher’s interpretation of the data (Denzin & Lincoln, 2000). The validity of research results is established when methodological procedures are logically consistent with an accepted and adequately described theory of knowing and are demonstrably carried out (Campbell & Gregor, 2002). Campbell and Gregor point out that the goal in institutional ethnography is not to use analytic strategies, such as triangulation, to test the accuracy of ‘what informants say,’ as in traditional ethnography, or to construct concepts, categories, and theories that account for the participants’ understandings of their experiences, as in grounded theory.

Methodologically, rigor in institutional ethnographic research is not attained through technique, such as sampling or thematic analysis, rather it comes from the coherence of the developing map of social relations (DeVault & McCoy, 2002). Thus, as noted by DeVault and McCoy, the researcher is not required to check recurring themes. She or he must instead check the new knowledge being generated in regards to ‘how’ something works, proceeding through the investigation while returning to informants as required when questions or inconsistencies arise (DeVault & McCoy, 2002). This kind of analysis utilizes what people know and what they are observed doing for the purpose of identifying, tracing, and describing the elements of translocal social organization (Campbell & Gregor, 2002).

**Mapping.**

Institutional ethnography inquiries make ‘power’ understandable in terms of relations between people and relations that rule (Campbell & Gregor, 2002). People and events are tied together in ways that make sense of such abstract concepts as power, knowledge, the economy, the State, and policy (Campbell & Gregor, 2002). These concepts are often treated as ‘black boxes’ precluding explanations of how the world works (Smith, G., 1990). In institutional ethnography, ‘mapping’ assembles different work knowledges that are also positioned differently and where relevant should include an account of the texts that are coordinating work processes in the institutional setting (Smith, D., 2005). The analytic procedure of mapping actual sequences
of work and texts extends ethnography from people’s experiences and accounts of their experiences into the work processes of institutions and institutional action (Turner, 2006).

Mapping requires the tracking of coordinated sequences of work that people do with reference to texts encountered and used in their routine daily activities (Turner, 2006). The researcher can begin with a particular text, such as a memo or report, and then observe what people do with the text (Turner, 2006). The focus of inquiry and analytic description, according to Turner, is on how the individuals take up the text in unique but standardized ways. As reported by Turner, the work is to see the textual practices as being temporally located in sequences of action that are taking place, so that the text is made present, is occurring, in a setting. The researcher must also see how the individuals produce their acts as standard, both located in and constituent of the sequence and accountable in its terms (Turner, 2006). Turner notes, the focus is always on how texts are taken up and how actions are coordinated so they produce the particular institution’s standard sequences, its decisions, policies, and outcomes.

To ensure rigor, the analytical process utilized the above steps for mapping out the coordinating work practices from the local site through the institutional regime, highlighting the connections and the points of disjuncture. The textually mediated social relations that coordinate group home care are exemplified in mapping figures within the findings chapters (see Figure 1: The Annual Inspection & Figure 2: The Medical/Psychiatric Disconnect). Texts that organize group home care were integral in this investigation because work processes are clearly tied to the regulations outlined by the governing bodies. Diabetes care guidelines were also fundamental in discovering the profound disconnect between what is promoted for diabetes care in Canada and the actualities of the mentally ill who reside in group home settings. I also verified my understandings of the data with research participants and when any questions or inconsistencies arose I sought clarification. All findings were also verified with my supervisor and committee members during group meetings.
Research Design

Research sample and setting.

The investigation took place at Rolling Hills Rest Home\(^3\) (hereafter referred to as Rolling Hills), a residential care facility for adults with mental illness. The home was licensed to provide services for 26 adults 18 years of age and over. All residents were female, although the majority of group homes accept both male and female occupants. Of the women residing in this particular home, 17 were funded through the HSC Program, eight were under the Domiciliary Program, and one resident’s family paid privately. All of the residents had a diagnosis of mental illness such as schizophrenia, schizoaffective disorder, bipolar disorder, or depression. In congruence with principles of institutional ethnography, this group home was the starting point and the main focus of inquiry, but the investigation extended to other sites, including the HSC Field Office located at The Centre for Addiction and Mental Health Services, and the Community and Health Services Department of the regional government.

Rolling Hills is located in Southern Ontario in a rural setting, which is geographically where many Ontario Homes for Special Care (HSC) group homes are situated. Rolling Hills is located approximately 10 kilometers from (name of nearby town), a town with a population of approximately 80,000 with all necessary amenities, including dentists, shopping facilities, hospital, and coffee shops. The property of Rolling Hills is comprised of 13 acres with approximately 8 acres of this land being rented out as cropland and the remaining 5 acres surrounding the house are grassland.

The home owner and her two adult children live in the 140 year old original farmhouse, which is a large, two-storey building. The residents live in an addition that was built onto the back of the farmhouse when the decision was made in the 1950s to start taking people in from Queen Street Mental Health Centre under the Approved Homes Program. This property was previously owned by the home owner’s grandparents, who originally housed men to help with chores on the then operating farm. Her grandparents sold the farm and parcelled out 10 acre lots, and this particular piece of land changed hands twice prior to being bought and reopened in the

\(^3\) The name of location was replaced with a pseudonym to protect anonymity.
1960s as an HSC residential care facility. The current owner’s mother purchased the home in 1971, which brought it back into the family, only to sell it again a few years later. The current owner purchased it back in January of 1986 and has maintained operations for the past 26 years.

**Justification for group home selection for the inquiry.**

This particular group home was chosen as the site for the inquiry because it is located in a rural setting, which is representative of some HSC group homes in Ontario. Many of the original home operators were farmers who housed psychiatric patients to work on the farm in exchange for room and board under the Approved Homes Program, prior to the deinstitutionalization movement. At the inception of the HSC Program, the people who were already keeping psychiatric patients were the first to become licensed. The evolution of the HSC group home and its operations can be explored by starting in a home that was originally a farm that opened its doors to psychiatric patients being let out into the community, as this home did. A few of the original residents remain in this home today, which was important for investigating the evolution of the residents’ daily work practices within the home. Additionally, as the home was located at a distance from the local town, it was possible to explore queries surrounding transportation accessibility for medically necessary appointments, and quality of life and recreational opportunities.

This group home also happened to be situated within the catchment area of our community diabetes clinic where some of the residents have attended assessment and follow up appointments. This connection was extremely important for exploring information sharing, and to discover if and what type of knowledge provided by the diabetes educators is actually utilized within the group home. I am familiar with the knowledge that is offered in the clinic of reference and what self-care practices are expected of the person diagnosed with diabetes. Noted previously, this experiential knowledge was the impetus for my research inquiry, as I had questions related to the utility of the current diabetes education that is provided for mentally ill adults who live in residential care facilities.

Finally, as reported, the rate of diabetes is higher in the mentally ill than in the general population. However, due to smaller number of residents per home, some group homes do not have a large number of residents with diabetes. In this particular home, out of the 26 residents, 10 had a diagnosis of diabetes. A further two residents had a diagnosis of prediabetes, a
condition that places the individual at high risk for the development of type 2 diabetes. All were on different diabetes medication regimens, including insulin, oral antihyperglycemic agents, or diet and exercise alone. This diversity within the group home enabled important information gathering on individual diabetes-related experiences and work practices related to diabetes care.

**Participant selection.**

Institutional ethnographers do not report descriptively on a population, and therefore informants are not considered a sample (DeVault & McCoy, 2006). Rather, informants are chosen who can report on different perspectives, circumstances, and situations, as well as those who can provide viewpoints that are missing (DeVault & McCoy, 2006). In this study, residents, care providers, the home owner, the regional social worker, and two HSC field workers affiliated with the home, were purposely selected to participate in interviewing and observational studies based on their varying perspectives, experiences, and knowledge related to the research phenomenon. Field workers within the HSC Program are social workers and their primary role is that of surveillance of both the residents who are placed in these settings and all home operations. The attending family physician was also asked to participate in an interview because he had knowledge regarding the organization of the residents’ medical care provision. The Social Night Coordinator, who is responsible for organizing and overseeing the structured weekly recreational event, was involved in an interview because her perspective was deemed relevant to diabetes care practices.

**Inclusion criteria.**

The inclusion criteria for the residents were as follows; 18 years of age or over, a diagnosis of schizophrenia, bipolar disorder, and/or schizoaffective disorder, or another form of mental illness, a diagnosis of diabetes, willingness to participate, ability to communicate in English, and currently living in the group home. The inclusion criteria for the home owner, care providers, Social Night Coordinator, physician, social worker, and field workers were as follows; experience working in or affiliation with the group home, knowledge of day to day processes of operating the group home, willingness to participate, and ability to communicate in English.

The home owner was well situated to provide information regarding the group home operations because she has owned this home for 26 years. She also has a wealth of knowledge
and experience because she was raised in this and another group home that her mother owned and operated from the time she was two years of age. She is actively involved in all aspects of the home operation, including administrative functions, resident physical and mental health care needs, and recreational outings. Additionally, she is a member of the Ontario Homes for Special Needs Association, a committee that was organized in 1998 to give a voice to the home owners and to provide a venue to network and build working relationships among the operators. She is also well informed where the overall process of group home operations is concerned.

*Exclusion criteria.*

Third party representation for signing free and informed consent was an option put forth at the outset of the study. If any residents were deemed not to have capacity to provide informed consent and if they were willing and able to participate, ongoing free and informed consent would have been sought from their authorized representative (Tri-Council Policy Statement, 2003). This was not an issue, however, because all residents were deemed competent. Residents who did not wish to be involved in interviewing or observational studies were excluded without fear of penalty. The interests of the residents were protected at all times during the inquiry, for example, by checking consistently that my presence in their home was not uncomfortable for them. In addition to written consent, ongoing process consent was obtained from each informant at the beginning of and throughout each observational study.

*Methods.*

Since the objective was to understand the social organization of diabetes care, the focus was not on the individual, but rather on how and by whom the work of diabetes care gets done, and how it is coordinated with other work activities. Diabetes-related work practices of those who are located outside the home were also explored. Within the group home, the exploration of the daily activities of the residents, care providers, and group home owner was the point of entry. The inquiry used participant observation and interviewing, and investigated textual coordination of relevant documents to discover how diabetes care practices are organized by forces that lie beyond the home itself (Smith, D., 2005), and how this influences care for the people living with diabetes at Rolling Hills.
My intention was to affect practice changes to improve diabetes care and outcomes for mentally ill adults, and as such I will be publishing findings from this thesis in journals within the medical field. Because certain factors are identified as increasing risk for the development of diabetes such as age and ethnicity, I gathered this information. The demographics of the entire group of women residing at Rolling Hills were as follows: Ages ranged from 22 to 74 years. Three women were between 18 to 29 years, one was between 30 to 39 years, three were between 40 to 49 years, 12 were between 50 to 64 years, and seven were 65 years and older. Self-identified ethnic backgrounds were as follows: 14 Caucasian women did not specify an ethnic background, a further two identified their ethnic background as Chinese, four Italian, one Native American, two French, one Irish, one Yugoslavian, and one woman was of Ukrainian descent. Most of the women had lived in Canada all of their lives, but one emigrated 39 years ago from Yugoslavia. Marital status included single, divorced, and widowed women, and there were varying levels of education from not completing secondary school to having obtained a university degree.

**Interviewing.**

All inclusion criteria were met by the entire group of residents who had diabetes, so all were asked to participate in an interview. All but two women agreed to be involved, and thus a total of eight interviews were conducted with the residents in the group home. One woman who decided not to participate in the interview did not wish to answer personal questions and felt diabetes was a personal concern. The other did not specify her rationale for not participating; just that she was not interested. The group home owner, three care providers, the family physician, the regional social worker, and the HSC field worker affiliated with the group home were asked to participate. Additionally, a retired field worker from the HSC office was asked to be involved in an interview because she had insight into the evolution of the HSC Program. Finally, the Social Night Coordinator was included, as she had knowledge of the operations of this weekly event. Written informed consent was obtained from all participants separately prior to conducting each of the interviews.

Prior to the interview, I asked each participant to consider and provide a pseudonym that would replace their real name for reasons of anonymity. I suggested that people sometimes use names that they associate with favourite or famous persons, or names that evoke fond memories.
The women residents tended to choose flowers and names of relatives to whom they had a bond, and a few asked me to help them choose names. In these instances, I prompted the women to choose any name they liked. One care provider chose the Phoenix, a mythical bird that symbolizes rebirth and immortality. Another chose to use a favourite cat’s name. Other providers used names of favourite people in their lives or just names they preferred. Carol, the home owner, chose her pseudonym and that of the residential home, ‘Rolling Hills Rest Home,’ because she felt it described the setting.

An interview guide (Appendix A) directed the interviews, which were semi-structured and lasted from approximately 20 minutes to 2 hours in length. All interviews were audio recorded and transcribed verbatim by myself. The concept of ‘work’ was kept central by asking questions throughout the interviews such as, “What is the work that you do?” “Why do you do this specific work activity?” “Can you describe this particular task?” “Why is this carried out in this manner?” and “Who and what is involved with the coordination of this particular activity?” The topics of discussion were somewhat different for the field workers and social worker, and the interview topic guides for these participants have also been included (Appendix B).

Central to the inquiry was discovering how the self-care activities of the residents living with both mental illness and diabetes connected or did not connect with that of the care providers and affiliated health professionals. It was also important to explore the type and amount of diabetes self-management activities the residents participated in, and if these practices were hindered or interfered with in any way by local or translocal processes and/or structures. Thus, the interviews with the residents explored their daily routines, activities, meal times and snacks, diabetes testing schedules, and outings. Passivity around diabetes self-care was also an area of interest because this too is recognized as work. Finally, a woman just moved into the group home one month prior to her interview and data was collected on her experience as a person who was living with diabetes and was also in the process of settling into the home.

Observational studies.

Prior to conducting participant observations an observational study guide was formulated to provide clarity on which experiences and events were to be observed, and my role as the researcher in the process (Appendix C). Written informed consents were obtained from all participants prior to initiating observations and ongoing verbal consent was obtained thereafter.
One woman resident declined involvement in participant observations. I took detailed notes while watching residents and care providers as they went about their daily routines, sometimes having discussions with them or participating when invited to join in. I observed different ‘glucose testing’ days, both before breakfast and supper. I also conducted observations on different days at numerous intervals, including an overnight stay, to capture a 24 hour period. In total, I conducted 15 participant observations with up to 25 women residents, along with two care providers and the home operator, ranging from one to eight hours in length. Specific activities of interest were those involving meal preparation and serving, eating patterns, and cleaning up afterwards. Snack times are also scheduled into the routine in the group home and were part of the observations. Other observations within the group home included the daily tasks that were carried out by the residents and care providers, those that enabled exercise, diabetes practices, and other activities that filled up their day. Participant observation was also used to gather data while residents were on recreational outings including shopping trips, dances, and bowling. For these outings I shadowed the residents, attending to their various activities while writing detailed observational notes. Throughout the process particular attention was also paid to sequencing and coordinating of activities.

In this particular research project participant observation was an important methodological approach to discovering the social from the residents’ subordinate position. This method also assisted in keeping in touch with the embodied activities of the care providers’ and home operator’s work practices, and also enabled me to capture an actual ‘day in the life’ of the group home. This approach facilitated the understanding, from varying perspectives, of the actualities of living within a group home setting.

**Textual coordination.**

As textually mediated forms of social organization are integral to the institutional ethnographic inquiry, due to their essential connection between local activities and translocal organizing ruling relations (Smith, D., 1990), I included an investigation of how texts enter into the overall process of care provision for people with mental illness. The analytic intent was meant to discover how institutional relations have historically helped to give rise to the current configuration of housing and care arrangements for people with mental illness in Ontario. I collated the Ministry of Health and Long-Term Care documents on mental health care reform in
Ontario and the various documents related specifically to housing programs for the mentally ill. I also examined the main text responsible for socially organizing diabetes care provision across Canada, the “Canadian Diabetes Association 2008 Clinical Practice Guidelines for the Management and Prevention of Diabetes in Canada.”

The various documents that are responsible for organizing work activities in the group home were also investigated. To do this, I developed working ‘maps’ of textual coordinations to show how texts are interpreted and enacted in a standardized way in sequences of action. As in Diamond’s (1986) study of nursing homes, I explored texts as they appeared in distinctive work sequences, whereby the embodied work was made accountable within an administrative process. I also investigated the organizing documents for their neglect of certain interests, while giving primacy to other interests, which are prioritized as such in work activities.

**Analysis**

To analyze the data, the interview transcripts and observational notes were read first to make sense of the data, and then read numerous times in detail to draw out all of the participants’ work experiences and daily activities within Rolling Hills. I went back and forth through the data using an iterative process. During data collection and analysis I always sought confirmation of my understandings from participants and additionally asked for clarification when questions or inconsistencies arose. The aim was to discover the work practices, and how they were coordinated, and how they were or were not connecting to others’ work activities. Also analyzed were the ways in which the work activities were ‘hooked into’ and shaped by pervasive ruling relations. Many work activities at the local site were connected directly to group home policies, which serve government interests. There is also a definite disconnect between what is recommended in the diabetes guidelines and how diabetes care was organized within the group home.

Mapping sequences of work activities at Rolling Hills that the people carried out through interpreting and enacting texts was integral to the analytic process. According to Campbell and Gregor (2002), recurring events or recurring use of words are also meaningful in making visible organized patterns of activities across time and place. Certain words and phrases were used consistently in describing diabetes care provision in the group home and these were teased out in the analysis of the data. Some of the data were grouped into themes accordingly, as participants
made reference to particular concepts, such as ‘food as pleasure,’ in which eating (especially snack food items) was viewed as both a pleasurable activity and ‘unhealthy’ at the same time. In order to preserve the expert knowledge of the participants, excerpts from the interviews and observational studies are included in my descriptive analysis of the institutional processes. Pertinent texts that organize diabetes care practices in the group home setting are discussed in the findings.

**Data Management**

All data, including interview transcripts, observational notes, and fieldnotes, were kept in a secure locked cabinet in my office. Participant identifiers were removed from transcripts and replaced with pseudonyms. A master list of study participants and their study pseudonyms were kept on file and stored in a secure computer file, on a computer that is password protected. Audiotapes of interviews were also kept in a locked cabinet and all data will be destroyed after 25 years in accordance with University of Toronto’s Ethical Review Board’s standards.

Findings from this study were verified by sharing them with the study participants. Additionally, my supervisor and committee members played an integral role in verifying the findings through their review of the data and analytical procedures. Finally, since knowledge sharing is imperative to initiate important changes, the findings from this study will be presented in publications, at various conferences including the Canadian Diabetes Association Annual Conference, and to the Ministry of Health and Long-Term Care through networking strategies.

**Researcher’s Location in the Research**

I entered into this research inquiry from my own actual location inside the social organization of health care as someone who owned a group home and had some knowledge of their operations, and as a diabetes nurse educator with an understanding of diabetes care provision. My philosophical position aligns with principles of institutional ethnography in that I believe social life arises in the locally situated practices of actual individuals, and these activities are socially organized by forces outside the local group home setting. I believe the circumstantial situations of people living in group homes have been conditioned by various social relations that need to be revealed in order to make required social and political change. My personal understandings of the difficulties surrounding diabetes care for people with mental illness have
been made explicit from the outset. The evolution of my understandings as the research process proceeded is reflected in my writing in reflexive journals and in the final thesis paper. This reflexivity ensured rigor and enhanced trustworthiness of my research findings by making explicit how knowledge was constructed, and ‘what was going on’ throughout the research process (Koch & Harrington, 1998).

An institutional ethnographer begins reflexively from the local historical setting of people’s experiences from inside the social organization of her or his own world, and the social world to be investigated (Smith, G., 1990). The researcher, rather than taking a neutral or disengaged position, extends her or his knowledge by actively participating as a social member of the local world, while raising consciousness of its extra-local forms of social organization (Campbell & Manicom, 1995). Unlike ethnomethodology’s objective use of members’ knowledge, institutional ethnography views participants as having “…knowledge as members of a setting” (Smith, G., 1990, p. 638). According to G. Smith, knowledge provided by these people in their everyday experiences determines the relevancies of the research in the extra-local realm.

With these elements of institutional ethnography in mind, I gained entry into the group home as a visitor, observing daily activities and learning about their life experiences. I have written myself into the journal notes and the final paper, thus enabling researcher presence in the interpretations of the data. I was also a participant at times. For example, when I attended Social Night, residents asked me to dance and I did join in. Interactions where I was present and participating in activities were included as such in the findings. I am presented in the findings in first person. I have treated my reflexive knowledge as one of the many perspectives shared within the study. Over the next four chapters I present the findings from the thesis project, followed by discussion of the findings, recommendations, and concluding remarks.
Chapter 4
Rolling Hills Rest Home

The chapter begins with a detailed description of Rolling Hills. This is followed by a scenario of a typical morning inside the group home, which is based on early observations I conducted, to gain an understanding of how the routines and daily practices are organized at this setting. This is followed by my analysis of the vignette, and findings of the subsequent three chapters build on this discussion. These findings serve to position my overall argument that group home care in Ontario is socially organized in such a manner that social inequities and health disparities are inevitable. The overarching State interest in cost containment creates rationing that limits the amount and type of care that can be afforded the residents, as will be shown. Further, group home policies regulate systems of safety, reporting, and financial accountability, but do not promote health and wellbeing. State imposed regulations with which the people at the local site attempt to align are contradictory and create unsafe situations in their manifestation, and others are impossible to carry out in view of budgetary restrictions.

Description of Rolling Hills

The trip to Rolling Hills is quiet and the sun is just coming up as I drive along the country road at 6:30 a.m. Both sides of the road are lined with various types of mature trees, and sections of forests that have been cleared in areas where farmland has been subdivided. Over the years, houses have been built on these properties. Each home is different, unlike in suburban areas, and each is situated on a well-maintained property with acreage. There are a few scattered farms, with some fields being used for cropland. Halfway down the road on the south is Rolling Hills, which blends in with the other homes except for its large, brown and green wooden sign at the end of the driveway that says ‘Rolling Hills Rest Home.’ There is a white three-board fence running along the front of the property, with two brown brick gateposts with lights on either side of the entrance. At the end of the driveway there is a small children’s wooden school bus shelter. The property has a mixture of mature evergreen and maple trees, lush gardens, and an old well on the front made of stone with a shingled rooftop.

The paved driveway leads to a parking area where a large industrial size garbage bin sits awkwardly in this country home setting. Also, there is a dark beige school portable to the left,
which houses the other business the home operator has, a First Aid company. At the far end of the driveway is ‘the barn,’ a large garage that has been renovated over the years to accommodate two apartments, both of which were originally added as a means of recruiting employees who are willing to work in exchange for rent. There is a large garage door in front, with entrances to both the upstairs and downstairs apartments on either side. A tall hedge surrounds the entrance to the one apartment that has a brick walkway and garden in front. Currently, a part time staff member and her partner live in the upstairs apartment, and the home owner’s retired mother resides in the ground level apartment.

Rolling Hills sits on the hill in the middle of the property and is a large two-storey home with cream coloured aluminum siding, brown trim, and matching shutters on the windows. The house has a wooden porch where the front door is located, but this entrance is not used. People enter the home owner’s residence, which is the main front section of the house, via the side door. This is a single steel door with a glass insert, decorated with brown aluminum trim. Leading up to the door is a brick walkway and a raised brick porch with gardens in both the front and down the side of the house. Along the walkway there are two very large mature maple trees with more gardens and stonework around them, a couple of decorative benches, and cast iron, vintage type street lights. There is no one outside and it is a quiet walk up the path as I approach the door.

The housekeeper answers the door and asks me to come in. She is a young, petite woman from the Philippines who was hired four years ago by the home owner for $500.00 per week to cook, clean, and provide some services related to resident care. She starts her workdays at 5 a.m., and thus is already cleaning the kitchen and preparing food when I arrive. The home owner, who is in the kitchen, says, “Come on in.” Inside is a small room, which has a big bay window, a large coat closet, and two big refrigerators. At one end there is a doorway that leads to a bedroom through which staff and the home owner access the women’s part of the home. At the other end is the doorway to the home owner’s ‘country’ kitchen, which is decorated in yellow and blue, with oak cupboards and matching trim, stainless steel appliances, including two built in ovens to accommodate cooking needs, and a large island in the centre with a built in range top. The kitchen leads to an open sunken office area that has a large oak roll top desk and chair, a computer desk on the other side, a cushioned wooden bench and table, and matching wooden wall shelving. This is the room where the home operator performs most of her administrative
functions. There are sliding glass doors at the end of the office that lead to a large wooden deck and kidney-shaped, inground pool, surrounded by a wooden privacy fence with lattice board on top. The living room is entered from the kitchen, and has country décor, a large sectional couch, big screen television, and stone fireplace. The dining room has oak hardwood floors and detailed trim, a large oak table, chairs and hutch, and is decorated in a red rooster pattern. The upstairs has four bedrooms for the two adult children, the home owner, and the live-in housekeeper.

The residents’ part of the home extends from the back of the original farmhouse and has two storeys, one at ground level and the other below. The residents’ section has been renovated twice over the years to increase the size of the dining and living rooms, and to accommodate for semiprivate bedrooms, thereby improving living conditions for the women who reside here. Renovations are ongoing, and repairs are often necessary, as this is a 140 year old farmhouse and addition that requires significant maintenance, both due to its age and changes in government standards (discussed further in the next chapter). On the main level each of the bedrooms has a window and a sliding glass door leading to a wooden deck. There is a set of stairs on the opposite end of this addition at the back that is used only in cases of emergency. Under this set of stairs is a doorway leading to the ‘transitional apartment’ located on the lower level, in which one woman resides. This woman is in the Transitional Program, which is a temporary supportive housing program operated through the HSC Program for people who are trying to reintegrate back into society and the workforce.

The walkway behind the home owner’s part leads to the two doors on the main level in which people enter and exit the residents’ part, via the kitchen or the craft room. This walkway and the driveway are quite busy because they are used by the residents, and the various workers and family members who enter the home, along with the staff members. The outside entrance to the kitchen is surrounded by a tall privacy fence, where a large white sign hangs: ‘Residents, Delivery and Staff Entrance.’ Behind the fence there is a glassed in ‘smoking’ structure that was built when the no smoking by-laws came into effect and the women were mandated to smoke outside. There are also benches and chairs where women sit along the pathway and outside. The other entrance leads directly to the craft room, and many residents exit and enter through this French style glass door.
Inside the entrance is the women’s kitchen area, which has two large open-concept adjoining rooms. The women’s part is modestly and pleasantly decorated with white and green ‘country flowers and white picket fence’ wallpaper, and pastel yellow walls and wood wainscoting. The dining tables hold four to six people each and are decorated with matching season-themed table cloths, and plastic pumpkins filled with leaves and sunflowers, and scarecrows. Today, bright and colourful ‘turkey’ and ‘Frankenstein’ wall hangings are strung from the ceiling to celebrate both Thanksgiving and Halloween. There are matching brown stacking chairs on light green tile flooring, and white ceiling fans/lights. On the far side of the main kitchen is a sliding glass door that leads to a large wooden deck where some of the women go to sit outside.

Entwined with the country décor and quaint atmosphere sits medical equipment, emergency lighting, and various signs that coordinate activities. It is apparent that the home is organized in such a manner as to facilitate the efficient monitoring and orderly provision of care for many people. The area where meals are served has an oak cabinet with a white counter top located opposite to a triple sink for dishwashing, and an additional small sink on the left. Above the sinks there are posters that instruct on proper sanitizing procedures for dishwashing with Javex, and ‘Proper Hand Washing Technique.’ All tables are equipped with bottles of hand sanitizer, plus there is a blow dryer to facilitate sanitary hand drying. A defibrillator is mounted next to this, along with a large steel First Aid box. A medication cart that contains the residents’ pills, daily report, and Medication Administration Record binders sits in the middle of the room.

On another wall there is a corkboard with various sheets pinned to it, including a ‘Daily Inspection Checklist,’ an ‘Activities of Daily Living’ weekly schedule, and one that indicates which day of the week each bedroom is to be cleaned, when furniture is to be wiped, and when and where dusting is to be done. This sheet instructs staff to check that bathrooms and kitchen floors are mopped daily, dining chairs, refrigerator, and stoves are cleaned weekly, and counter tops wiped after every meal and as needed. A ‘Cleaning Procedures’ sheet offers extremely detailed instructions on the stepwise approach to sanitary room-cleaning. ‘Ontario’s Workplace and Food Safety’ brochures, ‘Workplace Hazardous Materials Information System’ information, and an instruction guide ‘In Case of Accidental Poisoning’ are posted. A ‘Conflict Resolution’ sheet is also visible, along with a laminated Bill of Rights titled, ‘What to do if Your Rights
Have Not Been Met,’ with separate contact numbers listed for residents in both the Domiciliary and HSC Programs.

The other kitchen area has a white board with the weekly breakfast, lunch, supper, and evening snack menus posted, along with a separate note indicating coffee break is 10 a.m. and tea break is 3 p.m. On the far end, the cooking area has white cupboards with green countertops, two white stoves, an industrial type toaster in the corner of the counter, and a sink. There are six stainless steel teapots on a tray, and a large kettle sits on the stove to boil water for tea. On the wall above the stove is a poster from the public health department on food safety temperatures, with instructions to keep hot foods at 60 degrees or hotter and cold foods at 4 degrees or lower. There is another food preparation safety sheet, and a ‘Correct Hand Washing Procedures’ poster. ‘Food Proton Safety’ and ‘First Aid and CPR’ certificates for each staff member are also posted. In the corner is a large, locked upright industrial size refrigerator with a glass front. Today, the refrigerator contains 17 four litre bags of milk, nine cartons of eggs, cans of Glucerna, bulk cheese slices, large bags of oranges, three 10 lb bags of onions, a large container of margarine, big bottles of pop, a bin of radishes, a large bag of apples, celery, green peppers, a cucumber, and a head of lettuce. On the top shelf there is a plastic container with boxes of insulin.

A business phone sits beside the sharps containers. There is another corkboard with various phone numbers, including the local hospital, health care providers’ phone listings (including dentist, psychiatrists, family physician, laboratories, eye doctors, Community Care Access Centre, foot doctor, Ontario Disability Support Program office), the home owner, and the staff member who lives on-site. Intercom numbers are also listed, including those to the home owner’s living room and bedroom, the transitional apartment, and the staff apartment. Above the cupboard there is a wooden cabinet that is locked and labeled ‘PRN Medications.’ Envelopes with different labels, including ‘HSC,’ ‘Domiciliary,’ ‘Drug Store,’ ‘Staff to do,’ and ‘Appointments’ hang on another cupboard.

Off this kitchen area there is an entranceway with three doors, one of which opens to a full bathroom, another to a two-piece bathroom, and the third opens to one of the bedrooms. To the right is another entranceway that leads to more bedrooms. One bedroom has a convenient access route to the home owner’s section of the building, located between the two beds. The 13 semiprivate bedrooms are all tastefully decorated in country designs in a soft pastel green colour.
The twin size beds have flowered bedspreads with ruffles. Each woman has an end table and a dresser, and all of the bedroom furniture is either white or light oak wood. Each room has a television for the roommates to share, and each bedside area is individually decorated with pictures, knick-knacks, or craftwork created by the women.

The door leading downstairs is closed and has a big country folk art wooden ‘Rolling Hills’ sign on the side that faces the kitchen. This sign has a small white board and corkboard where the women with diabetes write their blood glucose results when they test. Beside the door a large ‘This is a Smoke-Free Building’ sign hangs by a big calendar with medical/dental appointment reminder dates and times. These kitchen areas are the busiest rooms at Rolling Hills, with women congregating here to have their meals and snacks, take medications, prepare to go on outings, join scheduled in-house activities, and sometimes just relax.

**A Typical Morning at Rolling Hills: A Vignette**

It is 6:45 a.m. when I first arrive, and I notice two women are already outside in the enclosed smoking room. Both say, “Hello,” unfazed as I walk by because they know who I am. Some of the women living at Rolling Hills, including these two, know and remember me as the ‘Craft Lady’ and as the ‘Social Night Coordinator.’ As always, the women are welcoming and it makes me feel good because they never seem to forget me.

As I enter the home it’s still early, yet a few women are out of bed and busily going about their usual morning routine. As I walk in the door three women jump up from their seats to greet me. Tulip, who has lived here for a relatively short time, follows me into the kitchen and continues to talk to me as I put down my purse and find a space that doesn’t interfere with the usual morning activities. Tulip is aware, as are all of the women, that I am here today to observe their morning activities for diabetes-related research, and immediately begins talking about what she usually eats in the morning, and what she does routinely to keep active.

Rose appears busy, and stops quickly to say, “Hello.” I respond, “Hi Rose!” Just like every other weekday morning, Rose is up by 7 a.m. to get dressed, make her bed, and start coffee. As I sit down in the kitchen, I see her go to awaken women, and then she comes back and proceeds to get all the cups of water ready for pill taking. It is 7:30 a.m. now and as I sit opposite the big table in the cooking area observing, the women begin filing into the kitchen for breakfast.
Most are dressed for the day, some saying, “Hi Ruth,” as they take their seats. By 7:45 a.m. Rose has the plastic cups half filled with water and is ready with a stack of paper medication cups. Meanwhile, another woman is making toast, and yet another is boiling eggs.

At 7:55 a.m. the staff member who works from 8 a.m. to 5 p.m. enters from the home owner’s part through the residents’ adjoining bedroom. She greets me by saying, “Hello” as she walks to the medication cart. She says, “Good morning!” to the women as she passes through. She has already received a verbal report from the home owner. Using a large set of keys, she opens up the medication cart and gets out a health card, because Anne is going for blood tests today. The health cards are kept for everyone in a single binder. The staff member informs me, “Blood work can be done here but she (the lab technician) was here yesterday, and missed Anne because she was on a religious holiday with her family.” The live-in housekeeper is escorting Anne in a taxi cab to the lab because the regular driver, the home owner’s daughter, is not available.

The bell is rung at 8:05 a.m., and echoes throughout the big home so all can hear and come for breakfast. The staff member calls one of the women, Lois, to come upstairs. Lois is told by the staff member, “You need to come to the table dressed, not in PJs,” trying to organize her for her appointment. The staff member proceeds to give oral medications, calling each person up separately. She reminds Lois, “You have Clozapine clinic so you have to get a move on it.”

Violet, who has diabetes and has lived here for many years, comes up to me and exclaims excitedly, “It’s donuts tonight for snack!” She says she likes donuts and then says, “We had cookies last night and cookies the night before…tonight is donuts, and Fridays we have chips and pop.” She tells me she is diabetic so, “…we have our own diet juice, and Friday’s we have our own diet pop.”

Meanwhile, another woman sets a bowl of hot hard boiled eggs on each of the tables and people start peeling them. The staff member continues to call people’s names for medications. She opens blister packs and drops the pills in a paper medication cup and gives them to each resident. Rose gives the water cup to them one at a time and watches them as they take their pills.
Mary, another resident, makes and butters the toast and puts it on the tables. While she is passing by me, I ask her how she does the toast. Mary explains, “I use two loaves of bread, one white and one whole wheat. Diabetics get whole wheat and the rest get white.” When I ask how much bread people eat, she tells me that each person is allowed to have two slices of toast.

At 8:25 a.m. the staff member continues passing out medications. Another resident comes up to the kitchen counter area, and starts to pour cups of coffee from the big coffee urn. She puts milk into some of the cups at the counter and some she leaves black. She then carries the coffee to each woman, and seemingly knows who gets one with milk and who gets black. When I ask why some get milk and others don’t, she explains to me, “These (the coffees with milk) are for diabetics, and others get creamer. Diabetics can’t have creamer so they get milk.” She also takes one sweetener for each of the people with diabetes, while all of the other women put their own powdered creamer and sugar in their coffee at the table.

Meanwhile, the staff member stops and tells me that she is taking “…a random blood pressure, as the woman was seeing stars.” She explains, “Yesterday her blood pressure was low so I wanted to check it before I give her blood pressure medication today to make sure it is ok.” She then proceeds to give out cigarettes to six people who she states, “…would smoke them all at once if they had the whole carton.” She also explains, “There is one woman who prefers hers to be locked up and given to her one by one as she is worried people will steal them.” The staff member then looks at Lois, who is still eating her breakfast. She states, “You have to be ready because the taxi will be here and you can’t be late,” to which Lois does not reply.

I inquire about the binders the staff member was writing in when she first came in. She unlocks the medication cart and shows me the Daily Report, Medication Administration Record book, and Patient Profile binders where they keep track of pills, daily resident reports, glucose readings, and demographic records. She shows me the contact list in the front of the Medication Administration Record binder to reach the house physician, local emergency department, and social workers, among others. Pills are organized in this binder by time intervals of 8 a.m., 12 noon, 4 p.m., and 8 p.m. She tells me that the staff is responsible for signing for pills once they are given to the resident. In the Patient Profile binder, each resident has a section with their unique profile, ‘Release of Information’ sheet, monthly blood pressure, weights, and extra information, including bath and Community Care Access Centre schedules. Each person with
diabetes has their own monthly sheet included for recording the blood glucose readings. She informs me that the ‘Daily Reports’ track pertinent information, such as residents’ whereabouts, if they have an appointment, blood work, or if there are issues that the next staff member coming on duty might need to know.

Peggy, a young 22 year old woman who entered this home at 18 years of age, now has a sheet of paper with her and is asking another resident if she is going to New Directions today, and then she proceeds to ask others who would normally go. New Directions is a program geared towards socializing, whereby people who attend participate in such activities as cooking, games, and discussion. She checks each name off on the sheet to indicate if they are planning to go. It’s now 8:35 a.m. and the staff member is reminding people, “It’s sheet day, so you need to strip your beds.” Certain rooms, according to room numbers, have their sheets replaced today, as indicated on the board in the kitchen. Most people are done their breakfast, and many of them take their dishes to the ‘dirty dish bin’ before heading off in various directions. Some go back to their bedrooms down the hall, some go outside for a cigarette, a few go into the craft room, while the remainder head downstairs to their bedrooms.

Rose puts the pill cups away, empties the coffee urn and cleans it out. The staff member locks up the medication cart and goes to get clothes for Lois, who is still eating breakfast. She finishes eating and attempts to go downstairs to her bedroom, but the staff member stops her and tells her to shower upstairs and she will get her clothes and a towel to make it quicker for her. Another resident finishes clearing dishes off the tables, and wipes them down before leaving the kitchen. There is a lot of activity going on with people busily working, completing their respective tasks while I watch.

By 8:45 a.m. most tables are clean, and everyone has left except for a couple of slower eaters. One resident comes out to the kitchen with her dirty sheets, the staff member unlocks the linen cupboard in the craft room and she gets clean sheets to make her bed. Meanwhile, the staff member stops to talk to Margaret and notices she has burn holes in her bathrobe. She says, “We’re going to have to watch you with your smoking, because I see you out there (on the deck off the kitchen) falling asleep with your cigarettes and that’s really dangerous.” Margaret replies, “I know, I know.” The staff member tells her, “Don’t get all defensive now.” The staff member leaves and comes back into the kitchen with a plastic mattress cover, and tells everyone upstairs,
“If you are changing your sheets and you notice you have a rip in the cover, come and get a new one because you can’t have ripped mattress covers.” She tells Michelle, a resident who is new to the home, that she just sanitized her bed, turning to me to explain, “I disinfected it because we do that before a new person moves into that bed.” She then proceeds to put a new mattress cover on a bed she is making.

Peggy goes outside, gets soaking wet in the rain, and comes bouncing in playfully asking anyone if they want a hug. She then tries to trick the staff member by telling her that she already had a shower so she doesn’t need one, as it is her scheduled bath day. She responds, “You aren’t getting away with that, nice try, now go have a bath.” Peggy, who looks and acts like a teenager, skips towards the bathroom while telling me, “I was caught,” and laughs.

One resident starts vacuuming the stairs now, while Rose puts away the powdered cream and sugar containers from the tables. The home owner calls on the phone from her part of the house, and the staff member asks her where Lois gets her blood work done when she needs a repeat for the Clozapine clinic. They talk briefly about the number of times she needs repeat blood work done. She then calls the health care provider at the Clozapine clinic to let her know which laboratory to fax the blood work requisition to so the resident can get her blood drawn.

At 9:05 a.m. another resident starts sweeping the kitchen, while Margaret uses vinegar to wipe down the kitchen chairs. Two women continue to do dishes. Violet sits in the kitchen eating her egg long after everyone has left. Another resident comes in and lets one of the other women know she needs her out of the kitchen because she is mopping now, and she is on a tight schedule for mopping the floor. She comments that the other resident who swept the floor missed all underneath one table, and proceeds to do it herself. She tells her, “Get your thinking cap on.” She tells another resident to, “Get out of the kitchen.” I let her know I will move too, and she says to me, “You’re fine here, but they (the residents) will keep wandering in and out of the kitchen if I don’t tell them.” The other women respond to her request by jumping up immediately and getting out of her way. By 9:15 a.m. the kitchen floors are completely mopped, the dishes are washed, dried, and put away, and the kitchen area is quiet.
**My analysis.**

Using an institutional ethnographic lens, centering on how work gets done, an initial sense begins to develop of how a group home for women with mental illness operates under the State’s administration. The vignette begins to shed light on certain social relations of accountability and risk management, the purposeful concerting and coordinating of work activities that keep the home operating in a manner that fits with stipulated regulations. Highlighted are the multiple layers of monitoring that take place, both by outside forces and by those at the local site. The above scenario also begins to point to the work and the conflict that is created in interpreting and aligning with governing bodies’ interests, while attempting to manage limited resources, time, and personnel. The group of people with diabetes is more complex and costly to manage, which makes this conflict much more visible, as will be introduced in this discussion and articulated further in the following chapters. Additionally, the varying degrees of cognitive functioning and sense of social ordering, the work of residents, and the conditions of control seen in this setting are introduced and positioned in relevance to diabetes care provision.

Rolling Hills is far from being a typical home, but rather is a supervised living establishment with many different vested interests attached. From the outside, it is a picturesque country farmhouse surrounded by beautiful gardens and lawns. On the inside, it is divided into two separate sections: the first being a conventional home for the owner and her family, and the second organized to provide housing for women with mental illness on a temporary or long-term basis. In many cases, Rolling Hills becomes their new home and the other inhabitants become their surrogate family. For staff members, it is a place of employment and often their residence as well. Rolling Hills is both a livelihood and lifelong abode for the owner and her children. Finally, since The Ministry of Health and Long-Term Care, The Ministry of Community and Social Services, and the participating municipality fund the housing programs provided by Rolling Hills, its operation is of great concern to these government bodies, and as such is under surveillance and subject to scrutiny by these agencies and others.

It is very apparent that outside forces govern Rolling Hills, and that the people at the local site are drawn into and participate in the organizing social relations of accountability. Daily work activities are carried out in a certain manner to ensure the residents have eaten and are clean and presentable, and the home is in a sanitary, orderly condition. As shown, much work is
involved in the morning routine, with residents volunteering to take on varying responsibilities in
the preparing and serving of breakfast and timely cleaning up afterwards. One woman makes the
toast, another boils the eggs, another makes the coffee, and someone else distributes it. Each
person takes her dishes off the table when she is finished eating, makes her bed, tidies her
bedside area, and so on. The staff member oversees the meal, gives medications, and prepares
residents for appointments, while coordinating with the residents the taking of showers, cleaning
of bathrooms, stripping of beds, replacing of mattress covers, doing laundry, and mopping of
floors to ensure things get done in a timely fashion. These processes, in large, are orchestrated to
satisfy governing bodies’ regulations, which focus on cleanliness, food and fire safety, and
resident basic needs. The scheduled routines keep a sense of order and efficiency, as
accountability to governing bodies is imperative.

Social relations of accountability are not only seen within the work processes, but are
visible everywhere at Rolling Hills. Organizing texts, including ‘Daily Inspection Checklist,’
Hazardous Materials Information System,’ ‘Conflict Resolution,’ and ‘Bill of Rights’ documents
direct activities at the local site. Bedrooms are numbered to facilitate laundry and bath duties,
and items are labeled and recorded in a certain manner. Documentation plays a large role, as
exemplified by the recording of blood glucose readings, and ‘The Medication Administration
Record Book,’ which is used as part of a stringent tracking process for both accountability and
risk management purposes. Texts, being powerful organizing agents, play an integral role in
these social relations at Rolling Hills.

People at the local site are not only responsible for keeping a clean and orderly
environment, but also for residents’ safety. As described, processes around risk management are
very evident and include fire safety. Monthly fire drills are carried out and documented as per
regulations. Throughout the building are such things as, ‘What to do in Case of Fire’ instructions,
fire alarms and extinguishers, EXIT signs at doorways, and emergency lighting. Risk
management processes around medications are also obvious. All medications are kept in locked,
secure cabinets, and a system of checking and documenting in ‘The Medication Administration
Record Book’ is used to reduce risk associated with drug administration. Food handling safety is
also of concern. Proton certificates show care providers have been tested and deemed competent
in food storage and preparation techniques. Risk management strategies for emergency care are also to be in place. CPR certificates are posted, indicating the staff is knowledgeable in emergency First Aid. A First Aid kit, defibrillator, and other assistive devices, such as handrails in bathrooms, wheelchairs, and crutches are also found at Rolling Hills. The social relations of risk management and accountability into which people are drawn and participate are numerous and varied. The vignette only begins to show how regulations organize group home care. This becomes increasingly clear over the next chapters.

Implicit and explicit rationing also plays a large role in how care is socially organized at the local site. The home operator is offered a certain per diem amount to provide necessities like shelter, food, and other services, while also providing a living for herself and her family. Her work is a complex process, with judgment and decision making being the results of budget restrictions and adherence to guidelines. There is clearly a conflict in this endeavor to organize work to align with the State’s interests, while also attempting to operate the home with limited resources. This was exemplified above in the creative use of personnel, which is often necessary, with the utilization of the live-in housekeeper as a medical escort to take a resident to the laboratory. The work of negotiating for services, products, and more funding is endless, as will be articulated in detail over the following chapters. Much work goes into organizing transportation and medical escort services in this rural setting, and this will be discussed further in its relation to diabetes care.

Everyone at the local site engages in rationing as part of budgeting work, which brings with it a developing sense of reduced funding provision. As seen in the vignette, cigarettes are rationed because they are expensive and are purchased out of the residents’ monthly spending allowance. Sweetener is also costly and is only given to people with diabetes. Those with diabetes have complex needs, and require expensive food products, which creates tension in view of budget restrictions. As will be shown, the rationing of food and other necessities is an everyday actuality, and because funding provision is extremely low, health disparities are created. Budgeting processes enter into every aspect of care, including dental work, clothing, hair, foot and nail care, and cosmetics. Restrictions around service provision and programming also create further disparities in health, issues that are revisited.
The monitoring that takes place at Rolling Hills is multilayered and extensive. The residents are watched, as exemplified in the above scenario when the care provider checked the woman’s blood pressure before giving her medication. Another resident needed to be observed because she was putting cigarette burn holes in her housecoat by falling asleep while smoking. In addition to physically observing residents, the home is equipped with monitoring devices like a defibrillator, blood pressure monitor, and weight scale. The care provider is supervised by the home operator, as she is responsible for ensuring the home is in a certain ‘inspection-ready’ order, meals and medications are prepared and given in a timely fashion, and that residents are ready for outings and appointments. There is also considerable monitoring of the home owner and the overall operations of the group home, as is evident in the organizing texts and in the morning work processes. The concept of monitoring is revisited because, in addition to playing a large role in the relations of accountability and risk management, it is significant in its role in the care of the women with diabetes in the home.

A further point of discussion, due to its relevance to the future planning of diabetes care, is the variance in levels of cognitive and physical functioning. Residents have varying cognitive capabilities, and these can change from day to day and also over the long term. Physical abilities also vary from person to person and may decline over time. Exemplified by Peggy’s behaviour when she got wet in the rain and then playfully tried to make the care provider believe she had taken a shower, the residents can act “childish.” Stealing can and does occur at times, particularly with such things as cigarettes, which are a costly commodity. Residents quarrel and tell on each other, either because someone has done something others feel she should not have done, or to seek attention. Work gets done, but patience is essential and sometimes reminding and coaxing is necessary. This was illustrated when the care provider attempted to get a resident ready for a clinic appointment and struggled to get her bathed and in clean clothes while trying to hurry her through breakfast. This was in the middle of giving medications to all of the women, stripping beds, bathing, and getting another resident ready for a laboratory appointment, while overseeing that the routine morning tasks the women were doing got completed. Awareness of these behaviours and the different degrees of capability is important for diabetes care, as both education and skills development training must be individually tailored and be responsive to the day to day (or moment to moment) variability.
There also appears to be a hierarchical sense of ordering among the group based on their level of functioning. This was exemplified when some women jumped up when told to move by the resident who was mopping the floor. This particular woman occupies the transitional apartment, so is considered “higher functioning” than the other residents. Some residents are able to accept more responsibility and often assist others who are less capable. One woman has the privilege of standing beside the care provider during medication administration to provide water and ensure other residents swallow their pills. This woman has also been entrusted with a set of keys to the refrigerator and food cupboards, which she proudly wears around her neck. Some also need to be watched more than others for safety reasons, as with the woman who fell asleep while smoking. Given the varying capabilities, it makes sense to grant greater responsibilities to those who want them and have the ability to carry them out, and to monitor more extensively those who need it. However, this creates a hierarchical ordering amongst the residents, which in my opinion is synonymous with that seen amongst other social groups. Although this is an interesting discovery, as is their social positioning amongst the care providers and the home operator, this is outside the scope of this diabetes-related paper. Future investigations into this phenomenon, as well as the struggles this population faces with social integration into the larger community, is warranted.

A further observation is that residents maintain basic, unpaid household jobs to keep the home operating smoothly. Rolling Hills is their home, and it seems logical for people to do housework as in every dwelling. Included in recommended activities of daily living are voluntary household chores, such as dusting, laundry, meal preparation, and tidying up (MOHLTC: Operating Guidelines for Homes for Special Care, 2003). However, two considerations unfold from these points. If the residents weren’t participating in housework, the home would not be able to operate as it does. The home owner cannot do it all alone and given the very limited resources on which the home is maintained (discussed later), paying staff to carry out all of this work would be unaffordable. Also, although their household jobs are meaningful and rewarding to the residents, as exemplified through the overt pride of holding the keys to locked cupboards, access issues preclude other opportunities for education or employment, to be addressed in later chapters. Of relevance for diabetes care, the lack of opportunities for exercise and for improved quality of life perpetuates disease development and impedes illness management, and this issue is revisited.
Finally, there are conditions of control that arise in the everyday life of group home care. At Rolling Hills, it is mandated that the medication cabinet be locked, in congruence with risk management strategies. Food cupboards, freezers, and the refrigerator are also locked so that food does not go missing. Health cards are kept in the medication cabinet for efficiency purposes and so they do not get lost, as they are difficult to replace. These practices have the potential for creating dependency and loss of autonomy for residents. In relation to diabetes care, freedom of choice is required for proper management of this illness. Lack of control over certain lifestyle choices creates inequities when attempting diabetes self-care activities, and as such is addressed in following chapters. Neo-liberal discourses that emphasize “freedom of choice” underlie the tendency of field workers and health providers to distribute responsibility to residents for not engaging in physical activity and this issue is addressed in Chapter 7, where exercise, as an integral component of diabetes care, is discussed.

Summary

Rolling Hills is a large, beautiful farm house located in a picturesque country setting, and although it is ‘home’ for many, it is in actuality a supervised living establishment meant to house the mentally ill. The women who find themselves here, the care providers, and the home operator are all drawn into and actively participate in certain relational processes that serve the government’s interests in the maintenance of this facility. A typical morning at Rolling Hills is extremely busy with many people coordinating efforts to ensure the home operates in a certain manner. The women must be fed and medicated, and appear clean and tidy. Documentation must be completed, and most importantly, the home must be in order and in a particular inspection-ready state. This chapter has opened windows for further exploration into these social relations of accountability and risk management, and into the tensions that are created in the manifestation of certain regulations. The rationing as part of the budget work, and the unique utilization of limited time and human resources all begin to point to these tensions. The driving forces responsible for organizing these social relations are investigated in the next chapter, alongside the discussion of the evolution of group home care.

The above vignette and description of Rolling Hills still leave the reader questioning such things as, “How is it that group home care has come to be socially organized as it is today?” “What are the State’s interests and how are these interests manifested in the governing
documents?” “What gets excluded in the transformative actions in attempting to align with the State’s interests?” Other questions that begin to surface include, “How is diabetes care, which is a complex chronic condition, fit into this social order?” “How do diabetes care activities connect to other work practices within the group home?” “How does diabetes care in the group home connect to that which is promoted in best practice guidelines for diabetes prevention and management?” The answers to these questions, among others, are discovered over the next chapters.
Chapter 5
The Care of the Mentally Ill: The Evolution of Group Home Care

In this chapter I offer an historical sociopolitical account of mental health care in Ontario, which includes the deinstitutionalization movement, welfare reform, and mental health reform. I argue that these sociopolitical forces have shaped how mentally ill adults have come to be cared for as they are today. Also in this chapter, I describe the evolution of the ‘Homes for Special Care’ and ‘Domiciliary’ Programs, as these are two of the government funded programs under which for-profit housing for adults with mental illness is provided. I follow with an analysis of the organizing texts, including the “MOHLTC: Operating Guidelines for Homes for Special Care” (2003), and the licensing documents titled, “Community and Health Services Department, Social Services Branch 2008 Hostel Compliance Checklist” (hereafter referred to as Hostel Compliance Checklist), and the “MOHLTC: HSC Residential Home Report, 2007” (hereafter referred to as Residential Home Report). In the analysis I highlight that one of the major interests of funding bodies’ in managing the population of mentally ill in Ontario is to contain costs, while distributing responsibility to those at the local site for carrying out certain regulations under restrictive conditions. The organizing texts are replete with accountability and risk management policies, which create conflict in their manifestation because some are contradictory, and budget constraints make others impossible to carry out. Finally, I draw attention to important aspects of care for overall health and wellbeing that are neglected in the texts that orchestrate group home care.

Care of the Mentally Ill in Ontario: An Historical Account

In the early 1800s, The County Asylums Act was passed by the British Parliament, enabling the first psychiatric facilities to be established (Psychiatric Patient Advocacy Office, 2003) in response to the societal problems of poverty, insanity and crime (Rothman, 1990). The first asylum in Ontario, The Provincial Lunatic Asylum (subsequently known as Toronto Lunatic Asylum, 999 Queen Street West, and Queen Street Mental Health Centre) opened on January 26, 1850 (Centre for Addiction and Mental Health, 2009). The Provincial Lunatic Asylum provided treatment, shelter, and custody for adults with mental illness, homeless people, criminals, and other marginalized members of society (MOHLTC: 2000 and Beyond, 2002). Other psychiatric hospitals were built throughout the province of Ontario over the next century (MOHLTC: 2000
Rothman (1990) explored the origins and development of American prisons and asylums in the 1820s to 1830s, and reported that they were considered protective environments, built to shelter and rehabilitate the dependent and the deviant, while attaining social order in an era of political, religious, and economic unrest. Over time the asylums lost their original reformatory design, with the focus declining from that of rehabilitation to custodianship and confinement of the chronically ill, hardened criminals, incurably insane, and decrepit poor (Rothman, 1990). Once admitted, people generally lived in the psychiatric hospitals with minimal or no hope of reintegration into society, as they were considered to be a threat or at minimum, a nuisance to the community at large (Rothman, 1990).

**Deinstitutionalization.**

The deinstitutionalization movement, which started as early as the mid-1950s (Smith & Hanham, 1981), was a process involving a shift away from traditional long-term hospitalization to community-based alternatives for people with serious mental illness (Krieg, 2001). Schissel reported there were intertwining catalysts for this radical change, which would allow the release of these members of society who, for so long, had been contained and controlled (1997). Within the medical field there was psychiatric commitment to extending beyond the asylum and into the community, thereby expanding the field of psychiatry (Schissel, 1997). As noted by Schissel, the civil libertarian lobby promoted the policy of community psychiatry because the community was purportedly a natural healing environment, unlike the perceived oppressive, inhumane, and overcrowded psychiatric hospitals of the time. Reaume, who used historical data from the Toronto Hospital for the Insane between 1870 to 1940 to write inpatient perspectives and experiences, reported that in the asylums the mentally ill were often abused (2009). They lived in physical and mental isolation, enduring tedious and miserable existences (Reaume, 2009). In addition, new psychiatric drugs that reduced symptoms of psychosis were introduced to enable patients to function and cope better in society (Krieg, 2001). Importantly, the perceived reduction in cost associated with long-term hospital care made it a fiscally appealing political move for the government, who could offload the responsibility to community psychiatry (Schissel, 1997). This shift also occurred alongside the court rulings for the ‘least restrictive alternatives’ to involuntary admission to psychiatric hospitals (Krieg, 2001). The passing of this doctrine meant that only those who were considered to be a threat to themselves or others could be admitted against their will.
Although the stated intent was to ‘normalize’ and improve the quality of life for those with mental illness by reintegrating them into society, the macro level political plan was not well laid out (Krieg, 2001). Adequate housing and community services were not in place to coincide with the release of people from asylums, which had an enormous impact on the mentally ill, family members, and society at large (Krieg, 2001). The mentally ill, many of whom had been institutionalized for long periods of time, had nowhere to go and no means to survive in society.

Piat (2000) used naturalistic inquiry to explore community opposition to deinstitutionalization, and to the implementation of supportive housing for the mentally ill. According to Piat, various forms of community housing like group homes, supervised apartments, and hostels, were created rapidly in order to meet the basic needs of this population, including the provision of food, shelter, and minimal care and rehabilitation. Although community living was supposed to be more humane than long-term asylum care, in actuality there was poor integration of the deinstitutionalized adults into communities, fragmentation of social services, negative community reaction, ‘ghettoism,’ and homelessness (Piat, 2000). Community opposition to group homes has been ongoing, with people often reacting negatively to the deinstitutionalized population living in their neighbourhoods (Piat, 2000; Krieg, 2001). This is better known as the ‘Not in My Backyard’ phenomenon (Piat, 2000). The deinstitutionalization movement did not enable reintegration into society or improved quality of life for the majority of people with serious mental illness. Rather, it led to different and more complex relations of marginalization.

**Welfare reform movement.**

Starting in the early 1990s, amidst the deinstitutionalization movement, government funding and provision of social assistance also changed considerably. To reduce expenditures, the federal government replaced existing programs with the Canada Health and Social Transfer, whereby provinces were given a block grant for health, welfare, and post-secondary education, and were mandated to form provincial policies around this limited funding (Gabel, Clemens, & LeRoy, 2004). In Ontario, social assistance payments were lowered, and new eligibility standards and more stringent work requirements were introduced to reduce dependency (Gabel et al., 2004). People with disabilities also had social assistance payments frozen under the Ontario Disability Support Program so that by 2001 income supports were worth 11.5% less than in 1991.
In addition to saving costs for the government, this system of social assistance was designed to offload fiscal responsibility to the recipients and their family members (Wilton, 2004). According to the Ministry of Community and Social Services (1998), the Ontario Disability Support Program was designed “…to recognize that government, communities, families, and individuals share responsibility for providing income and employment supports” (as cited in Wilton, 2004, p.29). Wilton reported that for many of the participants in his study the ability to receive more support from family members made little difference because they were reluctant to seek assistance, families were not able to help, or they no longer had contact with family members.

People with serious mental illness have unemployment rates between 70% to 90% (Canadian Mental Health Association and Centre for Addiction and Mental Health, 2010). Most are unable to find and maintain employment and must survive on their monthly social assistance payment, which limits access to proper housing, clothing, and appropriate food. Although this system of social assistance has meant a cost savings for the government, the Ontario Disability Support Program has kept recipients in poverty and made others increasingly financially responsible.

**Mental health reform in Ontario.**

In this section I summarize the Government of Ontario documents on mental health reform, which I have additionally listed in chronological order in the appendices (Appendix D). Policy directives on mental health reform offer contradictory messages that ultimately serve to satisfy the Ministry of Health and Long-Term Care’s interest in cost containment and accountability for fiscal spending. The guiding principles outlined in the documents that organize restructuring of the Ontario mental health system are as follows: 1) “The consumer is at the centre of the mental health system” and 2) “Services will be tailored to consumer needs with a view to increased quality of life” (Ministry of Health and Long-Term Care, Making it Happen: Implementation Plan for Mental Health Reform [MOHLTC: Implementation Plan], 1999, p. 4; Ministry of Health and Long-Term Care, Making it Happen: Operational Framework for the Delivery of Mental Health Services and Supports [MOHLTC: Operational Framework], 1999, p. 3). Although the person with mental illness is purported to be the central focus, I contend cost savings and redistribution of responsibility to ensure fiscal constraint are prioritized in policy
directives. I argue that cost containment strategies, like hospital bed closures, are instituted, while recommendations that would facilitate consumer health and wellbeing, like employment opportunities, income support, housing, and program support services, are yet to be effectively addressed.

The literature on mental health reform, generated by the Government of Ontario over the past 29 years, is implicitly guided by a sociopolitical will to reorganize mental health care in such a manner as to keep this population out of costly hospitals. It is much cheaper to provide community-based services at approximately $68.00 per day than it is to offer treatment to the same person with mental illness in hospital at approximately $481.00/day (Canadian Mental Health Association, 2004). Inpatient bed ratios are one of the main benchmarks used by the Ministry of Health and Long-Term Care for system restructuring (MOHLTC: Implementation Plan, 1999). As reiterated in the MOHLTC: Implementation Plan, in which the closing of additional provincial psychiatric hospitals is discussed, “The Ministry of Health will consider the mental health system balanced when the ratio of spending on community and inpatient services is 60/40” (p.7). This quote highlights the provincial government’s agenda to keep the care of mentally ill in the community, where services are less expensive. The predominate markers used to measure the success of mental health reform include higher community versus hospital bed ratios, closing of provincial psychiatric hospitals, reductions in mental health-related readmissions to hospitals, and reduced lengths of stay (MOHLTC: Implementation Plan, 1999). These suggest an interest in cost reduction rather than consumer wellbeing. Further, provincial and regional governing bodies, health care professionals, and service providers are all made accountable for achieving State goals as part of the political agenda to reduce costs. In placing primacy on cost reduction, consumers’ needs are given less consideration, contrary to what is proposed in the above guiding principles.

To coincide with this agenda to provide more cost-effective community care, changes were also made to the Mental Health Act. On December 1, 2000, Bill 68 (formerly Brian’s Law) was proclaimed and amendments to the Mental Health Act and Health Care Consent Act were implemented to support the government’s mental health reform process in ensuring alternatives to hospitalization (MOHLTC, The Time is Now: Themes and Recommendations for Mental Health Reform in Ontario [MOHLTC: The Time is Now], 2002). Changes to the Mental Health
Act and Health Care Consent Act included the addition of community treatment order provisions, and new commitment criteria authorizing involuntary examination, assessment, and detention at an earlier stage in a person’s mental illness (MOHLTC: The Time is Now, 2002). Community Treatment Orders and accompanying community treatment plans function mainly in Ontario to reduce length of hospital stay and rates of readmission.

The Government of Ontario mental health reform documents also ensure that provincial and regional governing bodies, health care professionals, and service providers are accountable for attaining certain goals, which are contingent upon funding provision. One of the main goals set out by the Ministry of Health and Long-Term Care is to, “…achieve clear system/service responsibility and accountability through the development of explicit operational goals and performance indicators” (MOHLTC: Implementation Plan, 1999, p.5; MOHLTC: Operational Framework, 1999, p.5). To ensure accountability, the Ministry of Health and Long-Term Care developed a policy framework, “Mental Health Accountability Framework,” which outlines expectations regarding the delivery of cost-effective, efficient services and the setting of performance standards and achieving measured outcomes (2004). According to the Ministry of Health and Long-Term Care, accountability is key to ensuring services and supports are delivered, and funding is used appropriately (MOHLTC: Mental Health Accountability Framework, 2004).

According to the Ministry of Health and Long-Term Care, all involved in the mental health system are expected to follow best practice models; enter service agreements; use such texts as common intake, assessment, and discharge tools and protocols to guide work activities; and to monitor and evaluate reinvestment dollars (MOHLTC: Operational Framework, 1999). The recommendations for a reformed mental health system include continued divestment of the provincial psychiatric hospitals, making policies and protocols, developing accountability and funding frameworks, systematic monitoring of the mental health system, and overcoming resistance to change in such areas as establishing standards, measurements, and benchmarks to improve performance (MOHLTC: The Time is Now, 2002). Regional models of decision making are also recommended for local service delivery systems to establish a single-point of accountability and responsibility. Further recommendations include evidence-based research to ensure cost effectiveness, accountability, evaluation, monitoring, innovation, and continuous
improvement (MOHLTC: The Time is Now, 2002). Service providers are drawn into and participate in these social relations of accountability by setting and meeting outlined targets and goals, thereby showing that the government dollars are being invested wisely so funding provision will continue.

Increased peer support, housing, education, employment opportunities, and income supports to facilitate health and wellbeing for those with mental illness are recognized as being required in this cluster of policy directives (MOHLTC: Implementation Plan, 1999; MOHLTC: Operational Framework, 1999; MOHLTC, Mental Health, Making it Work: Policy Framework for Employment Support for People with Serious Mental Illness, 2000; MOHLTC: The Time is Now, 2002). However, beyond this recognition, these issues are not addressed within the organizing policies, while the above initiatives that led to reduced government expenditures were strongly enforced as part of the reform process. For example, all of the provincial psychiatric hospitals are now closed (MOHLTC, 2012), yet there is still insufficient housing for the mentally ill (discussed later in the chapter), and as reported, unemployment rates are extremely high at 70% to 90% (Canadian Mental Health Association, 2010). Further, health promotion, illness prevention, and care of medical conditions as health components are excluded from the policy directives.

The Government of Ontario recognized that the mental health system is uncoordinated and fragmented, with gaps in service provision for those with multiple needs (MOHLTC: Operational Framework, 1999). The primary goal, according to the Government of Ontario, is to provide a seamless community-based mental health care service (MOHLTC: Implementation Plan, 1999; MOHLTC: 2000 and Beyond, 2002). This goal has been echoed throughout the policy directives since the early 1980s in such publications as, “Towards a Blueprint for Change: A Mental Health Policy and Program Perspective” in 1993, “Building Community Support for People: The Graham Report,” in 1988, the 1993 policy framework, “Putting People First: The Reform of Mental Health Services in Ontario,” and “2000 and Beyond” in 2002 (MOHLTC: Implementation Plan, 1999; MOHLTC: 2000 and Beyond, 2002). The described fragmented and uncoordinated mental health services have been an ongoing issue since the deinstitutionalization movement and the promised seamless community mental health system has yet to be realized.
Analysis of the Evolution of Mental Health Care in Ontario

The deinstitutionalization movement, welfare reform, and mental health reform are major sociopolitical events that have shaped the lives of people with mental illness in Ontario. This information begins to build the understanding of how it is that the mentally ill have come to be cared for in the manner in which they are. The deinstitutionalization movement, although meant to offer a more humane and higher quality of life for people with mental illness, was fraught with negative outcomes for this population. Community supports, such as housing, employment opportunities, and mental health programs, were not in place to coincide with the discharging of long-term patients of hospitals and asylums. This lack of community support has been an ongoing issue. The reduction in social assistance payments, as part of welfare reform, has meant a life of poverty for the majority of the mentally disabled who were already at a disadvantage with the above social barriers and constraints.

Mental health reform in Ontario, although promoted as being focused on consumers’ individual needs, is organized to protect the State’s interests, which are cost containment and distribution of responsibility among people directly serving the mentally ill. Those working in the mental health system are drawn into relations of accountability, with work being organized to meet certain goals such as bed closure targets. By focusing on cost containment, certain aspects of health in this population are omitted from these organizing texts. Health promotion, illness prevention, and medical care of comorbid conditions, integral parts of health and wellbeing, are not mentioned anywhere in the government literature on mental health reform in Ontario. The overall assumption is that this population only has mental health needs, and it is sufficient to merely meet basic needs such as shelter and satisfactory mental health care to keep this group functioning outside of hospitals.

Types of Housing and Services for the Mentally Ill

Currently there are 211 Ontario hospitals that provide various mental health services (MOHLTC: Hospitals, 2010). The programs of the last remaining provincial psychiatric hospital, Mental Health Centre Penetanguishene, were transferred to the Penetanguishene General Hospital in 2008 (MOHLTC, 2012). There are 359 community programs providing mental health services and supports including assertive community treatment teams, case management, crisis intervention, consumer and family self-help, rehabilitation programs, and supports for
There is a range of community-based supportive housing for adults with mental illness. Homes for Special Care are for-profit, private residential homes that are monitored by field staff working out of HSC offices located in nine hospitals across the province of Ontario (Interview with Laura, HSC field worker). Habitat services are for-profit, private Toronto boarding homes, which are monitored and administered through a mental health transfer payment agency, and costs are subsidized by Ontario provincial funds (80%) and the city of Toronto (20%) (MOHLTC: Implementation Plan, 1999). Domiciliary hostels are also for-profit, private residences operated through municipal agreements, and cost shared between the province of Ontario (80%) and the municipality (20%) (Raymond Chabot Grant Thornton Consulting Inc., 2007). Other housing options for the mentally ill include Dedicated Supportive Housing, which are non-profit subsidized housing spaces funded by the Ministry of Health and Long-Term Care with communal living accommodations and different levels of supports, for example, group homes and apartment units (MOHLTC: Implementation Plan, 1999).

Although different housing options exist for mentally ill adults, there are extremely long waiting lists and often beds are not available in desired locations, such as near family or close to amenities in cities or towns. “Access to high support housing and community mental health services and supports continue to be a serious problem due to long wait-lists and shortage of resources” (Centre for Addiction and Mental Health: From Hospital to Home, 2009, p. ii). According to the Centre for Addiction and Mental Health, up to 520,000 people with mental illness in Canada are inadequately housed, which includes 119,000 who are homeless (Centre for Addiction and Mental Health, 2012). Approximately 2.5% of the population of Ontario (about 300,000 people) are seriously mentally ill (Government of Ontario, 2004), which far exceeds the number of available beds/units in community settings. In Ontario, there are 7,900 beds/units available with supports for the mentally ill, and 2,476 residential care beds/units for a total of 10,376 beds/units (Canadian Mental Health Association, 2012).

**Homes for Special Care Program: Background information.**

I now focus on the government funded HSC and Domiciliary Programs through which Rolling Hills is licensed. Insight into the inception of the HSC Program is offered from a study participant with the pseudonym of Lolly, who was employed as a field worker in the HSC
Department from 1989, since retired. I also provide personal reflections of operating a group home in the early 1990s within the HSC Program as a backdrop to how standards for care provision have evolved over time. Current standards of care, as laid out by separate operating guidelines and licensing criteria, are then reviewed and analyzed.

The HSC Program is a community housing program for mentally ill adults funded by the Ministry of Health and Long-Term Care. Prior to the inception of the HSC Program, there were no structured community programs in Ontario (Lolly). Community housing in what were termed ‘Approved Homes’ existed, which were halfway houses where the stay was of short duration (Quinsey, 1985). Residents remained registered as inpatients of the psychiatric facility and would move into an Approved Home on a ‘Leave of Absence’ so, if necessary, they could be re-hospitalized within a couple of hours (Lolly). These Approved Homes were very haphazard, with anyone essentially being able to take in patients from the psychiatric hospitals, and offer only the basic of services, namely shelter and food (Lolly). People who were placed in these privately owned residential facilities were given room and board, and were expected to perform light duties either inside or on the farm, as the majority of these homes were located in rural areas. Lolly recalled,

These Approved Homes did start to grow...The initial, one person who would have one client living in there, would then have maybe two clients move in, depending on the size of their home maybe three clients move in. Maybe then eventually they would buy a bigger home and then have more clients move in. And then word of mouth...it was really word of mouth was probably the biggest thing uh, of I guess getting people who had homes in the country near the hospitals. And that’s how they kind of started. (Interview with Lolly)

The HSC Program was established following the introduction of the Homes for Special Care Act in 1964, alongside the deinstitutionalization movement (MOHLTC: Operating Guidelines for Homes for Special Care [MOHLTC: Operating Guidelines for HSC], 2003). The Act prescribed licensing and standards, fiscal arrangements and admission procedures for both nursing homes and residential care facilities (Quinsey, 1985). The HSC Program, being the first licensed program in Ontario (Ontario Department of Health, 1967), was initiated in order to provide long-term or permanent residential care to people who were being discharged from
provincial psychiatric hospitals, but still required supervision and assistance with activities of

The licensed residential home should be a private family residence, and provide
as close an approximation as possible to normal family living for the ex-patient.
In order to achieve this goal, the resident is not to be considered as simply a
boarder but rather as a member of the family...The attitude of the hostess is of
paramount importance, since the creation of the proper atmosphere is largely
dependent upon her personality and dedication...She should be a person who has
an interest in people, a wholesome background, and should show that she has an
understanding of the needs of less fortunate persons placed in her charge.
(Ontario Department of Health, 1967, p.3)

In 1967 the first Residential Home Manual was developed by the Ontario Department of
Health to provide guidelines for home operators to follow in caring for this population. The
personality of the hostess and her ability to provide good family care were emphasized as the
chief requirements for operating a Home for Special Care (Ontario Department of Health, 1967).
Training of the prospective hostess consisted of “…a short period of orientation to the needs of
the type of patient being proposed for the residential home” to assess her suitability to the role
(Ontario Department of Health, 1967, p.3). The HSC legislation did not specify any other staff
qualifications or standards, nor did it outline HSC Program objectives or contents (Quinsey,
1985). No special home standards were deemed necessary if seven or fewer residents were to be
cared for, and if more than this number resided in the home, fire safety precautions were to be
taken (Ontario Department of Health, 1967).

The above descriptions point to the profoundly gendered nature of the work of caring for
residents, and the positioning of women as caregivers. Gender relations were socially constructed
in the 1967 manual, as highlighted in the assumption that the care provider, titled ‘hostess,’
would be a woman. Embedded within the text was the societal belief that this was woman’s work
and she naturally would take on the responsibility for attending to resident personal care needs.
The hostess was to do the womanly work of bathing and feeding the disabled, just as she would
any other ‘dependent’ family member. Her disposition or attitude was one of the main criteria
used to assess her suitability to operate a group home. She was also to be from a ‘wholesome’ background to show her capability to provide a nurturing, supportive environment.

This type of care work also opened a new door for women to enter the workforce, as well as the world of business. Women could start earning a wage from home for the unpaid domestic work that they were already doing. This entrepreneurial opportunity was initially appealing to me because I had a two year old daughter and was pregnant when I decided to buy a group home. I was attracted to the idea that I could be at home raising my children while operating my own business, rather than working fulltime at the community hospital where I was employed as a paediatric nurse. As I recall, the field workers who interviewed me as a potential new home operator told me that as the woman, I was expected to be the main care provider and I would be held responsible for all operations of the group home and resident wellbeing. The interview was primarily focused on my demeanor, and my medical background was viewed favourably because nurturing was considered integral to being a nurse. I also recall being told that married couples were preferred so that a family atmosphere could be provided. I only knew of one group home in the HSC Program that was operated by a single man, who had been raised in the home and took over this responsibility when his parents reached retirement age. Rolling Hills has always maintained female home operators and care providers.

The notion of care work, as it was produced in the 1967 manual, also coincides with the longstanding low remuneration for services. There was an underlying assumption that the woman would look after her surrogate family as a natural extension of her usual family responsibilities. The hostess was considered a domestic caregiver and received whatever money remained from the monthly per diem that paid for all of the household expenses, including food, mortgage, and utilities. In most cases this was even lower than minimum wage. I discovered almost immediately upon taking possession of the group home that payment was extremely low, considering the sizeable amount of investment in the home and the license, and that the work was 24 hours a day, seven days per week.

Rural or farm locations were considered acceptable and in many cases desirable, according to the Ontario Department of Health (1967). As reported by Lolly,
I guess the rationale was it would be a healthier lifestyle, the clients weren’t that active. They had no interest in community settings. So it was, send them out to live in the country and live happily ever after. And the person who owned the home at that time, all they had to do was ensure the client was getting their meals, getting their laundry done and taking their medication. (Interview with Lolly)

This arrangement also kept the population of mentally ill segregated from society, as many people were not comfortable with their integration into communities. Many farmers became the first HSC home operators because they were already taking patients in on an informal basis through the Approved Homes Program, which transferred over once the HSC Program was implemented (Quinsey, 1985). In 1985 there was a total of 646 licensed HSC beds operating through Queen Street Mental Health Centre (currently named the Centre for Addiction and Mental Health), with only two homes in Toronto, totaling 42 available beds in an urban setting (Quinsey, 1985). According to Quinsey, the residential care facilities were minimally staffed with no organized support programs because they were originally designed for long-term stabilized patients. Quinsey reported that people had essentially been “…put out to pasture in rural settings without appropriate support services” (p. 11).

In 1993, after the publication of two important documents, “Building Community Support for People: A Plan for Mental Health in Ontario” (Graham, 1988), and the “Commission of Inquiry into Unregulated Residential Accommodation” (Lightman, 1992), The Community Mental Health Branch of the Ministry of Health hired The ARA Consulting Group Inc. to investigate the state of the HSC Program (The ARA Consulting Group Inc., 1993). At that point 2,014 beds in 193 homes were licensed under the HSC Program across Ontario (The ARA Consulting Group Inc., 1993). The size of residential care facilities ranged from 1 to 49 licensed beds, with the average capacity being 10 residents per home (The ARA Consulting Group Inc., 1993). Large variability was found between homes in relation to the availability and access to community activities. Community rejection was noted as a deterrent to resident involvement in the community, as well as the size and location of the HSC home, and the pre-disposition of the home operator (The ARA Consulting Group Inc., 1993). There were scheduled, routinized practices such as prescribed days and hours for bathing, eating, and bed curfews, and none of the homes had individual service plans in effect (The ARA Consulting Group Inc., 1993). The
absence of integrated supports was a major deficiency of the HSC Program, with individual service needs being achieved on a sporadic basis by the innovation of the odd home operator and HSC staff (The ARA Consulting Group Inc., 1993). Many residents lost their former support networks of friends and services due to the HSC home being located at a distance from the psychiatric hospital they were discharged from (The ARA Consulting Group Inc., 1993). In many HSC facilities, one house doctor paid routine calls to the home, so all residents were obliged to work with the same provider for convenience purposes. This undermined the private, confidential doctor-patient relationship with services being provided in the home, and eliminated the possibility of residents selecting their own doctor (The ARA Consulting Group Inc., 1993).

The Homes for Special Care Policy Review reported limited commonalities across the 193 residential homes in Ontario (The ARA Consulting Group Inc., 1993). According to The ARA Consulting Group Inc., the absence of quality assurance measures, standards of care, and effective monitoring resulted in the development of an unacceptable level of variability in the HSC Program. The ARA Consulting Group Inc. also reported the licensing provisions and the related Homes for Special Care Act were too general and focused primarily on fire safety and the administration of licenses. Recommendations included ensuring improvements in quality of care to residents by bringing all homes up to a standard of current best practice and into compliance with policy expectations. A further goal was to integrate the HSC Program into the continuum of community-based mental health and supportive housing services (The ARA Consulting Group Inc., 1993).

My reflections.

I owned and operated a group home in the early 1990s just as the above regulations were being imposed, and upon reflection, many of the observations found by The ARA Consulting Group Inc. were accurate. Care was routinized, with structured mealtimes, bathing, and laundry days, and scheduled outings, like Social Night, bowling, movies, and church. Resident activities were restricted, and quality of life opportunities were limited to working for ARC Industries for $5.00 per week. My home, like many others, was old and required numerous, major maintenance projects. The number of beds per room in the residents’ section varied from two to five, with two semiprivate bedrooms located in throughways and used as access routes to other bedrooms and the upstairs bathroom. The group home was operating like this when I purchased it, and these
Arrangements were typical because strict standardizing guidelines did not exist (except for the outdated version from 1967). The MOHLTC: Operating Guidelines for HSC were first introduced in 1990, as noted by Lolly.

Throughout the 1990s the regulations set out in these practice guidelines, such as new standardized bedroom sizes, stringent fire prevention protocols, and food handling safety measures, were enforced in response to concerns set out in the Homes for Special Care Policy Review (The ARA Consulting Group Inc., 1993). Although remuneration was not offered for required structural changes, home operators complied for fear that if they didn’t abide by the new rules their licenses would be revoked. Indeed, this had already happened on occasions of noncompliance. If changes were not made in the home in a timely fashion upon written request, further residents would not be placed. If this did not result in compliance, the license would be revoked, residents would be picked up without notice by a school bus arranged by the HSC Department, and they would be distributed to other homes within the program that had empty beds. Many operators at the time, including myself, struggled financially because per diems were low and homes often were not operating to full capacity, going for long periods of time with empty beds. Structural changes and renovations were expensive to undertake. This never made sense to me that beds dedicated for the mentally ill would be empty at any time, but I had at least one or two vacant beds the entire time I operated the group home. When I questioned Lolly, who was my field worker, her response was always the same; my home was up to standard, but there were few people who fit the criteria for the program. The Domiciliary Program was known at the time to be more flexible and placements within this program were easier to obtain. Many operators who were having a difficult time getting placements through the HSC Department were accepting ‘regional’ clients (through the Domiciliary Program), even though monthly per diems were less and this program offered no clothing, sundry, recreational, or medical escort reimbursements. This option, however, was deemed by the home operators to be better than maintaining empty beds.

I sold my home amidst enforcement of the new regulations under the HSC Program. At that time I had concerns that funding was insufficient to meet certain regulations, like the proposed staffing ratio of one to seven residents and the mandated square footage of bedroom space per resident. In my home expensive restructuring was going to be required to maintain a
license for 15 residents, as four beds were in throughways, and the bedroom where five men slept was deemed too small under the new guidelines. Additionally, the septic system that was originally designed for a single family was not suitable for this number of people, and major costly changes were needed to accommodate large amounts of laundry, constant toilet flushing, and many baths per week. Our mortgage was quite high because these homes are expensive to purchase, and the per diem amount barely covered this and expenses accrued in the day-to-day operations of the group home. My husband’s salary as a cement truck driver supplemented to make ends meet. We chose to sell because this was a 24/7 job that was extremely confining and it would take years before any sort of profit would be realized. This was a venture that was time and labour intensive, with little monetary dividends. The new regulations would only result in greater financial difficulty.

**Homes for Special Care and Domiciliary Programs Today**

There are 158 HSC licenses with a total capacity of 1780 beds currently in the HSC Program throughout Ontario (Homes for Special Care Listings, 2008). Some licenses were discontinued over the past decade due to noncompliance with imposed regulations that came into effect after the 1993 HSC Policy Review, and these licenses have not been reissued. The homes from which residents were removed either sit vacant, or the homes are reopened and residents are taken in through the Domiciliary Program or they pay privately. The HSC Program continues to be funded by the Ministry of Health and Long-Term Care. HSC staff members are employed by the facility in which they work, and the Ministry of Health and Long-Term Care offers each HSC department a budget that is based on the caseload within each catchment area. Homes are still for-profit, and some people own more than one group home. In such cases, hired managers live in and run the business in exchange for free room and board and an additional small salary. The number of beds per home still varies, as most of the original HSC homes are still in operation. For those who reside in these facilities in Ontario, social assistance in the amount of $47.75 per day or approximately $1450 per month (Government of Ontario, 2006) is paid directly to the home operators. All home and resident related expenses come out of this revenue.

Domiciliary hostels were originally created to meet the housing needs of impoverished and frail elderly, but the program evolved over the years to include vulnerable adults with a wide range of special service requirements who require limited supervision with activities of daily
living (Raymond Chabot Grant Thornton Consulting Inc., 2007). There are currently 310
domiciliary facilities in Ontario with over 6,000 beds (Raymond Chabot Grant Thornton
Consulting Inc., 2007). The Domiciliary Program is funded by the Ministry of Community and
Social Services and the local government. Many group homes, like Rolling Hills, are dual
licensed for both the Domiciliary and HSC Programs, to increase the likelihood of running at full
capacity. Both programs operate independently and yearly licensing inspections are done
separately. The Domiciliary Program is similar to the HSC Program with slight variances, such
as the clothing allowance, which is now $300.00 per year as opposed to $600.00, and there is no
payment for medical escort above the rate paid for mileage. Recently the Domiciliary Program
approved money for the Quality of Life Program, and now pays for residents to attend social
functions. The current requirements for operating a group home and the licensing process are
outlined next.

Licensing.

Obtaining a license to operate a for-profit group home today is a process that involves
several points of authorization and documentation. To obtain a license for the Domiciliary
Program, the operator is required to have a ‘Lodging House License’ to enter into a ‘Purchase of
Service Domiciliary Hostel Agreement’ with the Community and Health Services Department of
the regional government. To apply for a license the operator must submit floor plans, compliance
letters from the public health department and the local fire officials, and municipal approval to
operate a lodging house business within the specified location (Community and Health Services
Department, Regional Government, Bill No. 63, a by-law to provide for the issuance of licenses
for lodging houses [Lodging Houses By-law], 2005). Any license issued must comply with the
Lodging Houses By-law (Appendix E), authorized bed capacity must not be exceeded, and the
home must comply with zoning provisions. Each ‘Purchase of Service Domiciliary Hostel
Agreement’ is subject to compliance with the ‘standards of care’ set out in the Lodging Houses
By-law, including safety, supervision, hygiene, tenant agreements and files, medical and
pharmaceutical controls, and crisis management. The regional government ensures compliance
with the Lodging Houses By-law and the Purchase of Service Domiciliary Hostel Agreement
through regular inspections.
To obtain an HSC license from the Ministry of Health and Long-Term Care, the operator must complete an application and contrary to the older 1967 guidelines, there are many requirements, including police and credit checks, two references and inspection reports from the HSC office, the local fire department and Medical Officer of Health. Also required is a statement from the local municipality that the home complies with property standards, and information about any other license held, like a Domiciliary Hostel License (MOHLTC: Operating Guidelines for HSC, 2003). The potential licensee must also meet the requirements outlined in the Homes for Special Care Act, be deemed suitable (suitability factors are listed) by HSC staff, and there must be demonstrated need for the home (MOHLTC: Operating Guidelines for HSC, 2003). The application package is sent to the Regional Coordinator for the Ministry of Health and Long-Term Care, who uses the documentation and information from the HSC office to recommend to the Minister to accept or deny it (MOHLTC: Operating Guidelines for HSC, 2003). Upon receipt of an HSC license, the operator must remain in compliance with regulatory, legislative, and established operating guidelines at all times in order to maintain it (MOHLTC: Operating Guidelines for HSC, 2003).

The licensing process indicates how extra-local relations organize group home care. The application process creates linkages to, among others, fire officials (Ontario Building Code, 1992, Ontario Fire Code under the Fire Protection and Prevention Act, 1997), public health inspectors (Food Premises Regulation under the Health Protection and Promotion Act, 1990), Medical Officer of Health (Homes for Special Care Act, proclaimed in 2000, Health Protection and Promotion Act, 1990, among other texts), municipal workers (Municipal and/or Provincial Property Standards By-laws), HSC staff (Homes for Special Care Act, proclaimed in 2000, Health and Protection and Promotion Act, 1990, MOHLTC: Operating Guidelines for HSC, 2003, Residential Home Report, 2007), Regional Coordinator for MOHLTC (Mental Health Policies and Frameworks), and Domiciliary Licensing and Compliance Officer (Lodging Houses By-law, 2005, Hostel Compliance Checklist, 2008). Once a license is obtained, the home operator is drawn into increasingly complex social relations with the above regulating bodies, as will be shown next. Three texts in particular, the “MOHLTC: Operating Guidelines for HSC” (2003), the “Residential Home Report” (2007), and the “Hostel Compliance Checklist” (2008), are pivotal in orchestrating care provision in a certain way at the local site. Analysis of participant interviews revealed how work processes are coordinated through the interpretation
and enactment of these texts; the resultant sequences of work serve to accomplish goals and objectives outlined by the Ministry of Health and Long-Term Care and the regional government (which receives 80% of the funding for the Domiciliary Program from the Ministry of Community and Social Services).

**The social organization of group home care: Governing texts and everyday activities.**

Group home care today has been shaped by, among other forces, policies and program reviews, like the report by The ARA Consulting Group Inc. in 1993 that highlighted the lack of standardization across homes and the program deficiencies. The MOHLTC: Operating Guidelines for Homes for Special Care (2003) is the latest edition of group home care guidelines initially developed and implemented in the early 1990s in response to concerns about lack of standardization and conditions of care within the Homes for Special Care Program (a revised edition is to be disseminated in 2012). In contrast to the original guidelines from 1967, the newer version is an 80 page document that explicitly outlines the expectations of the Ministry of Health and Long-Term Care regarding the physical environment of the group home, residents’ basic needs, and staffing duties and training. Also described are the responsibilities of the home owner for administrative functions and risk management processes, such as fire safety and emergency planning (MOHLTC: Operating Guidelines for HSC, 2003). The Residential Home Report (2007) is the 12 page licensing document that stems from this text. Within the Domiciliary Program, the Community and Health Services Department of the regional government enforces the Lodging Houses By-law Policy (Appendix E), from which the Hostel Compliance Checklist (2008) licensing document stems. The Hostel Compliance Checklist is a 12 page form, including such sections as ‘Resident Files,’ ‘Safety and Security,’ ‘Transportation,’ and ‘Personal Hygiene.’ These three regulatory texts primarily organize operations of for-profit group homes that hold HSC and Domiciliary Hostel licenses. They draw the home operator into numerous social relations of accountability and risk management, as was seen above in the process of obtaining licenses. Other people involved with operations in different capacities, are also drawn into these relational processes that serve the governing bodies’ interests.
Social Relations of Accountability and Risk Management

Group home policies regulate systems of safety, reporting, and financial accountability. They do not promote resident health and wellbeing. Group home care guidelines are replete with regulations that demand stringent attention to such matters as fire and safety, hygiene, record keeping, and finances. However, illness prevention, health promotion, and medical management of comorbid conditions are not a focus in the regulations that coordinate care provision. At Rolling Hills work is organized to align with the policies in order to meet the explicit and implicit goals of the governing bodies. Some of the social relations of accountability and risk management that organize everyday activities are shown next.

Staffing regulations.

“Home Operator in relation to a Home for Special Care license application is the same as a ‘Person-in-Charge’ who, at any time, while on the premises, supervises services in the Home for Special Care” (MOHLTC: Operating Guidelines for HSC, 2003, p. 37). The home operator is responsible and accountable for all operations at Rolling Hills. She is responsible for supervising staff and is accountable to the governing bodies for hiring those who understand psychiatric illnesses, medications, fire and safety procedures, and who have CPR and First Aid training (MOHLTC: Operating Guidelines for HSC, 2003). Staff responsibilities are also listed in the guidelines, and include maintaining cleanliness of the home; assisting and observing for side effects in residents who do not self-administer medications; organizing social and recreational activities; and reporting complaints and/or incidents to the HSC office (MOHLTC: Operating Guidelines for HSC, 2003). Both operators and their employees are accountable to the State for adhering to the outlined job descriptions in the group home care guidelines, and as such are drawn into and participate in social relations of accountability.

Daily practices.

Everyday routine practices are also driven by the regulations set out in the governing texts. According to the Hostel Compliance Checklist (2008), residents are to have clean clothes, bathe and have laundry done at least once per week. As stipulated in the Residential Home Report (2007) residents are encouraged to have a minimum of two showers or baths per week. Bathroom washbasins, water closets, urinals, bathtubs, and shower stalls are to be cleaned and sanitized once per day and wastebaskets emptied regularly (Residential Home Report, 2007).
Bedrooms are to be cleaned and vacuumed on a regular basis (Residential Home Report, 2007). At Rolling Hills, written schedules are displayed, the bedrooms are numbered, and baths and laundry are done in a manner that complies with these regulations. Residents play a part in the process by tidying their bedrooms, keeping clean, and volunteering to do extra jobs, like vacuuming and dishes.

Texts stemming from the governing documents are displayed at Rolling Hills and are meant to organize staff work activities in a particular manner to ensure orderliness and cleanliness.

I have an inspection check list for my staff that I’ve done up, umm, for what I want them to do every single morning. And that tells them to, you know, go and check the bedrooms, you check the bathrooms, you check the paper towels throughout in places, you check the soap dispensers are filled. It’s about a forty-five minute check list. It takes longer to do the stuff, but just the checklist to go through the house and make sure everything is in orderly fashion. (Interview with Carol)

Staff completes the operator’s checklist daily because it is part of their mandated job description. The residents also participate in household chores, and take pride in ownership of these tasks. The field worker also is drawn into this process as she is accountable to the Ministry of Health and Long-Term Care for making impromptu visits, during which she inspects certain aspects of the home as part of her job description. This is exemplified in the next quote.

I’m looking for uhh dirt if you want to call it, things out of order, just a general overview as you walk into a home…just general cleanliness, it’s just an automatic part of my job that I do. Like the fan here, if there’s two inches thick of dust, I’ll mention it to the operator…I would mention it to the operator on my next visit if it’s still not, you know, fixed, resolved, repaired, I mention it to them again. But the third time I do something in writing. I send them a letter with my concern…I try to make arrangements, give them time whatever the severity of the problem is. Then if it’s still not done I have to take it to the Ministry of Health…we would stop placements in the home and that’s like way down the line. During inspection,
Field worker visits, during which the residents are monitored and the homes are examined, are generally ad hoc, and so it is imperative that things are clean and in a certain order at all times. This information enhances understanding of the work processes undertaken at Rolling Hills, as seen in Chapter 4, including the timely morning chores that ensure the home is inspection-ready every day at approximately 9:30 a.m. To avoid repercussions such as revocation of license, the home operator organizes everyday work practices to ensure the home meets the required standards. These regulations, in their manifestation, create routinized patterns of care with prescribed schedules for bathing, eating, and performance of laundry and other household chores.

The annual inspection.

Precedence is also given to tasks that are carried out to align with criteria for annual inspections (see Figure 1). Governing agencies enforce yearly group home assessments for license renewal. Group homes must pass inspections by the fire department, the public health department, and the HSC and Domiciliary Programs. Under the Community and Health Services Department of the regional government, the Licensing and Compliance Officer inspects the home once a year, using the Hostel Compliance Checklist (2008), and is responsible for licensing, the hostel agreement, and quality of life compliance monitoring. Those found not to be in compliance have 20 days to resolve the issue(s), which is determined at a follow-up inspection (Appendix E). Field workers from the HSC Department perform separate annual licensing inspections using the Residential Home Report (2007).

(Inspections) are once a year and we do not inspect our own homes. They’re picked out of a hat assigned by our supervisor or manager and...the form is 12 pages long, and you basically tick off the sheet and it’s in sections, so the bedrooms, the kitchen, the grounds, everything in the house. We go through we lift up the sheets and the covers to inspect the mattresses and pillowcases. If there are any deficiencies or repairs that need attention, the operator will get a copy...In the kitchen we’re looking at the dishes and the glasses. Are there any chips, and stains? Are there enough dishes? The cupboards and counter are they
clean? Is there anything broken? The food storage, is it properly put away in storage bins? Is it clean? There’s no dust or mouse droppings. Is there enough food? ...the list goes on and on. (Interview with Laura)

The inspection focuses on health and safety, paying particular attention to home maintenance.

The HSC field workers also check mandated structural features of the home. Bedrooms must be located at or above the ground floor, adequate in size (suggest approximately 65 sq.ft per resident and not less than 60 sq.ft) (Residential Home Report, 2007). The bed should not overlap a window or radiator, and must be in good repair with clean mattresses (Residential Home Report, 2007). No bedroom is to be used as a passageway to the common/dining areas (Residential Home Report, 2007). As noted, these regulations created tension when imposed in the early 1990s because the majority of homes were old and major restructuring was required to comply. No added funding was provided and these renovations were extremely costly. Carol undertook a major renovation during this period, as promises were made that premiums would be paid to homes with semiprivate bedrooms. The increase in payment never happened, although the guidelines stipulate preference for resident placement is given to homes with semiprivate bedrooms (MOHLTC: Operating Guidelines for HSC, 2003). Carol spends much effort and money on maintaining the home to align with health and safety regulations. She uses a linen service ($10,000/year), rents an industrial garbage bin and pays for a pick-up service ($8,000/year), hires a grounds keeper ($20,000/year), and contractors to paint, fix deficiencies, and maintain the building in a certain manner.

The inspection process also includes other government agents with the risk management focus on fire safety, emergency situations, violence, and food handling and medication safety. The home operator must produce for the field worker a report of the annual inspection by the fire department before the Ministry of Health and Long-Term Care will approve renewal of the license. According to Laura, “A letter goes out in September through the program directors for each area…to the home operators and the public health (department). It says to the home operators to contact the fire department to come and inspect their home.” Fire safety is a primary interest and home operators are mandated to comply with the Ontario Fire Code under the Fire Protection and Prevention Act, 1997. Rolling Hills operates according to standards set by the above act and by those outlined in the licensing documents. The residents and staff participate in
monthly fire drills and details are documented as required, and a fire plan has been
developed and is on file at the local fire department. All hallways are clear of debris and
doorways are never blocked as per regulations. Doorways that are to be used as fire escapes are indicated with
red ‘Exit’ signs above them and ‘No-Smoking’ signs are visible everywhere in the home.
Residents who smoke do so outside. Fire extinguishers are everywhere, and all staff is made
aware of locations and trained on how to use them.

Coordinating texts contain stipulations for management of emergency situations. Overall,
home operators are to ensure residents are in a safe, stable, peaceful environment, protected from
emotional, physical, and sexual violence and abuse (Hostel Compliance Checklist, 2008). All
staff and volunteers must be trained in emergency evacuation procedures; each home’s
emergency evacuation plan and back-up support plans are to be kept on file at the Regional
Office (Hostel Compliance Checklist, 2008). One staff member is to be available on or about the
premises at all times and emergency evacuation procedures should be posted in a conspicuous
place (Hostel Compliance Checklist, 2008). Staff should have training in First Aid and CPR
(Hostel Compliance Checklist, 2008). Home operators should keep First Aid kits available and
updated in a conspicuous place, and emergency telephone numbers must be posted by every
phone (Hostel Compliance Checklist, 2008). Residents are to be familiarized with emergency
procedures (Residential Home Report, 2007). The home owner is also to arrange for a physician
to be on call for emergencies when the residents’ usual physician is not available, and take
appropriate action in cases where an injury occurs (MOHLTC: Operating Guidelines for HSC,
2003). At Rolling Hills the staff is trained in First Aid and CPR and someone is always on-site.
As mandated, the ‘House Rules’ (Appendix F) sheet is signed by every resident upon admission,
and is posted in the common areas. Emergency phone numbers and First Aid kits are visible in
the main kitchen area, all in accordance with the outlined rules.

A system for the management of medication is required. The home owner is to ensure
medications are in a locked cabinet, keep a list of cabinet contents, which is to be updated
weekly, and have a medicine management system (i.e. blister packs and MAR sheets)
(Residential Home Report, 2007). The field worker inspects the records. “I’m also looking at
medication records to make sure…there’s some kind of a method in place for medication
sheets…” (Interview with Lolly). In the Hostel Compliance Checklist it is mandated that
prescription drugs be kept in a locked cabinet in a central location (2008). At Rolling Hills all medications are in blister packs in a locked cabinet in the kitchen, and a Medication Administration Record system is used by all staff to document and track medication administration activities.

The public health department is also drawn into the inspection process. “The home owner shall ensure that all food is stored and prepared in a sanitary manner. For homes having more than 10 residents, the kitchen shall comply with Food Premises Regulation under the Health Protection and Promotion Act” (Residential Home Report, 2007). According to Laura,

> Public health also pops into the homes...it’s public health regulation. I think the only time they call for an appointment is when they want to watch the operator and staff cook a meal. Here in [name of town], they pop in quite frequently from what I hear and they’re a little bit more strict. (Interview with Laura)

The home operator is accountable to the public health department for ensuring the safe handling and preparation of food, on which license renewal is contingent. Health inspections are impromptu, and thus staff must always be prepared. All staff involved with the handling of food must have the ‘Food Handling Certificate’ (Hostel Compliance Checklist, 2008). Kitchen countertops and food preparation surfaces must be kept clean. Cooking and eating utensils must be of sufficient quantity and in good condition, and a proper standard of dishwashing must be maintained to ensure cleanliness (Residential Home Report, 2007). Everyone at Rolling Hills strictly follows food risk management regulations. Residents wash their hands and use sanitizer before touching food, and wash dishes as specified. Care providers and the home owner follow food safety regulations to the letter, posting and keeping appropriate documentation, obtaining certification, and handling food as mandated. Further food regulations are outlined, which create tension in their manifestation due to budgetary constraints, an issue that is explored in Chapter 7.

Finally, documentation processes are textually organized, hooking people into social relations of accountability. Resident personal files are to be maintained and kept up-to-date (Hostel Compliance Checklist, 2008). The field staff is supposed to visit the homes at least twice a month, and review the home’s files and records every six months to ensure required records are updated (MOHLTC: Operating Guidelines for HSC, 2003). The Hostel Compliance Checklist
has 14 regulations about finances that direct the Licensing Officer to investigate per diems, trust funds, personal needs allowances, and other sources of income. Residents’ personal needs allowance is to be tracked by the Licensing Officer to ensure it is not used by the home operator for any other purpose than the personal use of the resident for whom it is given (Hostel Compliance Checklist, 2008). Per diems are to be verified to show that the operator was not overpaid and that funds were spent on meals, lodging, and services including personal hygiene supplies (Hostel Compliance Checklist, 2008). Within the HSC Program, the field worker is accountable for ensuring financial records are in order, and has the authority to request further auditing by the Attorney General if in question. Lolly, the retired HSC field worker, reports that

...reviewing paperwork, reviewing expectations we want for the Ministry from the home operator, records up to date... I’m looking at everything from financial type records ‘cause there’s a lot of financial things that are happening with the clients. The operators are expected to monitor the Personal Needs Allowance ...If I question anything of course I can call in an auditor from the Attorney General’s office to have a look at those. (Interview with Lolly)

The home operator is accountable for all funds provided by the governing bodies and is under scrutiny to produce evidence that spending is appropriate. Documentation and record keeping, according to Carol, takes up a large portion of her and her staff’s workday. However, she is extremely particular in these practices, as this documentation provides proof during inspections that she is in compliance, and is spending funds as stipulated in the texts.
Figure 1. Numerous agencies are drawn into and participate in the annual inspection process. License renewal is contingent upon compliance with each agency’s Acts, by-laws, and policies, as outlined in the texts that organize group home care, including the Lodging Houses By-law (2005), the Hostel Compliance Checklist (2008), the Operating Guidelines for HSC (2003) and the Residential Home Report (2007).
To summarize this section, people at the local site are drawn into complex social relations of accountability and risk management by intertextually mediated regulations that organize group home care. Fire safety, health and safety, hygiene, and financial transparency are central concerns of the governing bodies. To satisfy these interests, other regulatory agents, whose work is also coordinated by text-based regulations, enter into these social relations. The home operator is responsible and accountable for all operations of the group home and her work is organized by multiple outside forces, including but not limited to, the funding bodies and the public health and fire departments. Compliance creates much work because rules and regulations are numerous and are strictly enforced by those overseeing care at the homes. The group home care providers are also drawn into these social relations because they too are accountable to the home operator and to the funding bodies, who stipulate employees’ responsibilities within the governing texts. The residents also participate, both actively and passively, in their everyday routines and work activities.

**Attempting to Align with Regulations: Created Tensions**

As noted above, the textually mediated coordination of group home care results in stringent attention towards health, safety, and administration processes: however, health promotion and illness prevention, as important aspects of care, are overlooked. Further, there is an overarching interest in cost containment that creates tension in attempting to align with State interests. Rationing restricts access, limits the amount and type of care that can be offered, and makes opportunities unavailable, which leads to health disparities and social inequities.

**Overarching interest in cost containment: Restrictions on health care services.**

The current social organization of group home care has been shaped by such forces as welfare reform and deinstitutionalization, movements that were initiated by the government as a means to reduce associated costs. This implicit interest in cost savings is embedded within the current texts that direct group home care, and creates tensions regarding care provision. First, the home operators are paid amounts approximating that paid to those on social assistance, and with inadequate income it is difficult to align with guidelines, which limits the amount of care that can be afforded to the residents. Other explicit rationings that are delineated in the regulating texts further limit the amount and type of care that can be provided. These issues are exemplified next
by highlighting the regulations and showing how alignment is difficult through use of interview data.

According to group home care guidelines, homes should be staffed 24 hours a day with a recommended ratio of one staff to seven residents (MOHLTC, Operating Guidelines for HSC, 2003). The staffing ratio creates tension because the current funding is not adequate to support this regulation. The home operator is paid $47.75 per day for each resident. Rolling Hills houses 26 women, for which four employees would be needed on-site at all times. Even if employees and the home operator were to be paid minimum wage of $10.25 per hour, the total would be $984.00 per day. The funding formula, as outlined in the MOHLTC: Operating Guidelines for HSC indicates 59%, or $28.00/day per resident, is allotted to Administration, Program Support and Services (p.33), which totals $728.00 per day available for hiring of staff and administrative functions. This amount is $256.00 per day (or approximately $8,000.00 per month) less than is required to meet the recommended staffing ratio, and this does not take into account the funding required for employee benefits or administrative functions.

In order to attempt to align with the regulation, Carol built apartments on the property to enable staff to work and reside inexpensively on the premises in exchange for their labour. Thus Carol is able to claim that the required complement of staff is always on-site, because employees never have to leave the property. However, this is not an option for some operators, as building additions may not be feasible or affordable. Even though Carol has organized her home to ensure the staffing ratio is met, this is a difficult regulation to align with because staff is required to be on the premises at all times. Much work goes into juggling limited human resources for such things as medical appointments, laboratory trips, and emergency room visits. Also, the stipulation that staff must always be supervised essentially makes the home operator accountable for being on the premises at all times. This regulation is extremely difficult to enact as the home operator cannot feasibly be on the property 24 hours per day, seven days a week. Care providers are not required to be, nor does the current funding allotment allow for the hiring of regulated care providers. This creates further tension, as employees are not able to carry out certain work requirements, like medication administration. Lack of funding for proper staffing and regulations that restrict medication administration create health disparities for those with diabetes, which is articulated further over the next chapters.
Funding is restricted for services such as medical escorts and dental care. The Ministry of Health and Long-Term Care pays 40 cents per kilometer for mileage, or a flat rate of $5.00 for trips less than 10 kilometers plus $7.00 per hour (this amount was recently increased to minimum wage after home operators complained to the Ministry of Labour). The Domiciliary Program pays only mileage, which amounts to approximately $6.00 per trip. This makes it extremely difficult to hire people to escort residents, as the Domiciliary Program pays no hourly wage, and the mileage remuneration barely covers the cost of gas. Furthermore, the driver must have two million dollars of liability insurance on the vehicle, which is an additional deterrent because it increases insurance premiums. Carol pays the driver for services and then she bills the HSC Program because sometimes it takes months for reimbursement.

Considerable negotiation is required to obtain approval for escort services. In one case at Rolling Hills it took a crisis to finally achieve this goal. One resident was required to take a bus, unescorted, for weekly visits with her family and would often forget her insulin on the bus upon arrival at her destination, going for the entire visit without taking it. On one particular Christmas Eve, the resident became extremely ill and the family panicked and sent her home alone by taxi with dangerously fluctuating blood glucose levels. Carol explained,

*I kept going through Margaret’s HSC field worker. I kept relaying what was happening with her…after the crisis I finally got the government to approve the funding to have an escort when she travels. But they didn’t do it until a crisis actually happened.* (Interview with Carol)

The issue of reduced funding, and the monitoring and restricting of medical escort services is revisited in Chapter 6, as it poses health risks.

Dental care is also rationed and prior written approval is required for any related services. The Ministry of Health and Long-Term Care will pay for scaling of teeth every six months at last year’s fee guide rate (MOHTLC: Operating Guidelines for HSC, 2003). Each resident is entitled to a maximum of $1,500.00 per year for dental services (MOHTLC: Operating Guidelines for HSC, 2003). According to Laura, the HSC field worker, if dental work exceeds this limit, field staff will contact the Public Trustee, who approves the use of extra funds if the budget allows. Only basic dental services are approved by the funding agencies, and many procedures, like
crowns and bridges, are costly and exceed the maximum yearly allowance. Esthetic services, like teeth whitening and dental caps, are not covered under the program. Residents who develop large cavities, whereby simple fillings are no longer an option, must have their teeth pulled and are left with large spaces. Alternatively, the residents may have all of their teeth pulled and wear dentures, as this is covered.

Prior written approval from the Ministry of Health and Long-Term Care and the Community and Health Services Department of the regional government is required for the majority of resident services or items, and both the home operator and workers for the programs participate in the work of negotiating for resident service needs. According to Laura, within the HSC Program, each HSC office is responsible for its own budget; the field workers have a cost sheet (Appendix G) itemizing typically approved expenses including pharmacy items, dental work, glasses, clothing, foot care, outings, and assistive devices. All estimated costs for dental, eye care, and assistive devices, such as hearing aids, are to be submitted and approved by HSC field staff prior to having the service provided or purchasing the products (MOHLTC: Operating Guidelines for HSC, 2003). Part of the work of the HSC field staff is to monitor receipts and negotiate with pharmacies for lower prices, or obtain the item from the government pharmacy if available.

The HSC field worker spends much of her work day reviewing invoices to check how much various providers have charged for services and items. If she discovers an overinflated cost attached to an item or service, she takes steps to negotiate a cheaper rate. Laura gave an example of the process she follows if she feels a pharmacy has overcharged for boxes of disposable gloves.

*I myself would phone the home and say “listen, you can’t get the gloves anymore from the drug store. You have to get it from government pharmacy.” Then I would call the drug store and tell them this is what I’m doing. Nine times out of 10, they lower their prices.* (Interview with Laura)

Thus part of the work of the home operator and field workers involves monitoring of expenditures, and negotiating lower costs.
Certain services and items are either restricted or limited funding is provided. For example, foot and hair care are the only personal services that are paid for by the Ministry of Health and Long-Term Care, and insured services must be used wherever available (MOHLTC: Operating Guidelines for HSC, 2003). All foot care services must have a prescription, and are to be monitored and approved by HSC field staff (MOHLTC: Operating Guidelines for HSC, 2003). Residents receive a yearly $600.00 clothing allowance, and are encouraged to buy clothes that do not need dry cleaning (MOHLTC: Operating Guidelines for HSC, 2003). A maximum of $60.00 per person per year is paid for dry cleaning and the HSC field staff is to monitor expenditures (MOHTLC: Operating Guidelines for HSC, 2003). The HSC field workers also monitor purchases of personal care services and items (i.e. personal grooming, hairdressing, and cosmetics) and determine appropriateness, cost effectiveness, and the needs of the resident (MOHLTC: Operating Guidelines for HSC, 2003). Many services that are available to the general population, such as manicures or massages, are not accessible to residents in view of funding restrictions.

**Cost containment versus quality of life.**

*The Homes for Special Care Program offers unique opportunities within a residential setting for residents to enhance the quality of their daily living and personal growth and development through participation in a variety of activities and programs. (MOHLTC: Operating Guidelines for HSC, 2003, p. 27)*

Cost containment, rather than growth and development, is the impetus for decision making where quality of life activities such as education, recreation, and employment opportunities are concerned. While other regulations in the MOHLTC: Operating Guidelines for HSC (2003) delineate what the State will provide, this section contains vague statements, such as “residents may choose to participate,” (p. 28) and opportunities “should be available” (p. 31). Also, residents may choose to participate in structured programs (i.e. educational, vocational, recreational, social, etc.) to build or enhance living skills (MOHLTC: Operating Guidelines for HSC, 2003). However, there is no written financial commitment to support these programs. Similarly, although HSC field staff is responsible to develop with residents individualized program plans to enhance life skills (MOHLTC: Operating Guidelines for HSC, 2003), these plans cannot be realized without funding for transportation and programming resources.
The guidelines also stipulate, “Where residents choose to undertake recreational activities on their own (i.e. go to the movies, hockey, etc.), they should use their own Personal Needs Allowance” (MOHLTC: Operating Guidelines for HSC, 2003, p. 29). This is difficult to manage on the $125.00 per month that the residents receive. Quality of life initiatives are restricted to personal hobbies (cross-stitching, cards, journal writing), participating in household chores or menu planning, the in-home structured craft program, and scheduled weekly outings (movies, bowling, Social Night, New Directions, and shopping). This issue is revisited in Chapter 7 because rationings that create lack of opportunities for full social participation also result in health disparities where diabetes is concerned.

Other Interests Missing in Governing Texts

Although regulating texts indicate primacy is assigned to some interests, other important considerations like comorbid medical care, illness prevention, and health promotion are overlooked. Support is not provided for management of medical conditions such as osteoporosis, chronic obstructive pulmonary disease, arthritis, hypertension, and hyperlipidemia, which are prevalent in this population. Little space is devoted in licensing documents to the overall health and wellbeing of residents, outside their mandated yearly physical examinations and emergency care. This reflects the notion that only the basic needs of the mentally ill must be met in order to maintain a sense of wellbeing. Diabetes, a chronic medical condition, can be prevented and managed with weight loss and physical activity (Knowler, 2002), therefore lending itself to an illness prevention approach. Healthy lifestyle patterns would benefit all people living in the group home.

Summary

To summarize this chapter, mental health care in Ontario has been shaped by major sociopolitical forces, including the expansion of psychiatric care into the community in the wake of the deinstitutionalization movement, changes in mental health legislation, mental health reform, and social reform. The deinstitutionalization movement, although meant to improve quality of life for this population, merely reorganized and exacerbated existing social disparities. Deinstitutionalized persons with mental illness suddenly encountered withdrawal or lack of social services, homelessness, and high rates of readmission to psychiatric hospitals, among other consequences. Welfare reforms resulted in reduced assistance payments to this group; they
are further impoverished by social and practical constraints to finding and maintaining employment. Lack of community supports, fragmented services, and long waiting lists for supportive housing are ongoing issues resulting from mental health reform.

Rolling Hills, one of the available supportive housing options, is a government funded, for-profit residential care facility for women that provides shelter, food, and minimal rehabilitation, with 24/7 supervision. The HSC and Domiciliary Programs, under which group home care at the local site is organized, regulate operations through the enforcement of certain guidelines and licensing criteria. The operating guidelines and the licensing criteria evolved over time, necessitating stringent monitoring of home and client safety, cleanliness, and administrative processes. In the operating of the group home, field workers and the home operator, among others, are drawn into and participate in numerous social relations of accountability and risk management. These textually mediated relations assign primacy to meeting residents’ basic needs, such as safety, provision of food, and hygiene, while neglecting other aspects of care, such as ongoing care of chronic medical conditions, illness prevention, and health promotion. Unfortunately, medical comorbidities are commonplace in this population but no direction or support is provided for care of residents with complex health needs.

Similar to social assistance payments, funding for this housing program has remained low, which restricts the amount and type of care that can be made available for the residents. The home operator has to factor in such constraints as a limited budget, time restrictions, and lack of human resources in decision-making processes. This creates tensions for home operators as they enact the regulations. Restrictions and monitoring of services and items, such as medical escorts, dental care, hair care, foot care, clothing, and personal hygiene products are further rationings that undermine health and quality of life for residents. Essentially, the home operator and field staff are responsible for carrying out stringent regulations without sufficient resources. Educational, vocational, and recreational initiatives are not accessible without commitment to financial support for programs or transportation. The overarching interest in cost containment and risk management creates and sustains inequities in health, which is articulated further in the next two chapters, as it impedes diabetes care provision and outcomes.

In the next chapter I explore the social organization of diabetes care and its fit with the particularities of this population. I will also reveal how the regulatory stipulation against
medication administration by the unregulated group home staff results in devolution of this responsibility to the residents. As I will explain, the residents with diabetes are required to take responsibility for self-care practices, which leads to unsafe situations, health disparities, and further social inequities.
Chapter 6
Points of Disjuncture in the Social Organization of Diabetes Care Provision and Group Home Care in Ontario

In this chapter, I discuss my analysis of the social organization of diabetes care. First, I use data collected during pilot observations to illustrate how texts and work practices at a community diabetes clinic can accomplish the exclusion of adults with mental illness. I then examine how the “Canadian Diabetes Association 2008 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada” (CDACPG), an authoritative text that is used nationwide, directs care for this high risk population. Finally, I explore diabetes care practices at Rolling Hills to illuminate the disconnect between the social organization of health services for diabetes care and the actualities of living with both diabetes and mental illness in a group home setting.

Diabetes Care: A Community Diabetes Education Clinic

The community diabetes clinic where the women from Rolling Hills receive services is a regional centre for adults, who are taught by clinicians to self-manage as recommended in the “Canadian Diabetes Association 2008 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada.” At the clinic, the work of registered nurses and dietitians is focused on assessing biomedical markers, and providing patients with the information and skills to perform diabetes self-care activities to achieve certain targets and goals. In order to align with the Ministry of Health and Long-Term Care stipulations for funding, work is also organized to enhance patient volumes, reduce labour costs, and enable shorter wait times. Practice also is organized around professional and administrative rules and regulations.

Patient care: A typical assessment appointment.

In this section I explore the interface between diabetes care provision and the needs of women with diabetes and severe mental illness, drawing on interviews with nurse and dietitian clinicians. As pointed out in the prologue, the initial contact at the diabetes clinic is two hours in length. Clinicians gather extensive patient information at this appointment, including dietary habits, medical history, and laboratory results. In fact, the interview with the dietitian revealed that the person is asked a minimum of 65 questions from a ‘Nutrition Assessment’ form and the
‘Daily Food Intake Record’, including such topics as weight issues, alcohol intake, restaurant eating, meal patterns, snacking, emotional eating, physical activity, and consumption of ‘junk’ food. The person is then given standardized nutritional information and instructed on healthy lifestyle habits, with the assumption this knowledge will be absorbed and implemented in daily routines. In the following quote the dietitian indicated that this appointment can be cognitively, physically, and emotionally overwhelming.

...too much information for the first visit can potentially leave me with a lot of information, but I must also be cognizant of the fact that they are also spending an hour with the nurse. The nurse spends the time going through (such things as) when they should be testing their sugars, the blood sugar targets, talking about the complications of diabetes, asking them 101 questions. And I think they can be quite overwhelmed...to come and sit in an assessment can be really quite draining. (Interview with registered dietitian)

Diabetes assessment appointments are involved, with numerous forms to complete, questions to answer, and information to absorb. Once all of the questions are asked and forms are completed, patients are taught how to make diabetes-related changes. They are encouraged to start measuring food; make healthier choices by reading labels for fat, fibre, and sugar content; add nutritious snacks; reduce portion sizes; and set goals with the dietitian.

The nurse then sees the patient and asks questions on medical and social history, as well as work patterns, and types of physical activity. She reviews laboratory results, measures weight and blood pressure, tests blood glucose, and takes an A1c (which gives an indication of blood glucose control over the last three months). She then chooses an appropriate glucose meter and teaches the person how and when to test, record results, and treat hypoglycemia. The patient is also taught how and when to take prescribed medications or insulin. Another teaching segment is devoted to recommended guidelines for physical activity and suggestions for implementing personal fitness routines. Both short and long term goals are discussed in addition to the nutritional goals already set with the dietitian. The interview with the registered nurse suggested this barrage of information might be difficult for patients to absorb.
So if it’s a new patient, a lot of this information is overwhelming, and sometimes kind of just getting them to...work through a meter and to know when to test their sugar is a lot for them to learn on the first time, and when you want them to record. I often give them a little booklet and highlight what I want them to test...

(Interview with registered nurse)

The person is expected to immediately act upon recommendations, including glucose testing and tracking, medication management and insulin injection if required, initiating exercise, learning symptom awareness, and further goal setting, such as weight loss. There is more information to learn at subsequent visits and class sessions are encouraged. Later, there are recheck appointments, during which adherence to recommended self-management activities is determined. Assessment of biological status, based on CDACPG (2008) targets, is carried out at follow-up visits by reviewing glucose levels, laboratory results, weight gain or loss, and blood pressure control. If a change of medication is required, or if there are other diabetes-related concerns, recommendations are made and it is the patient’s responsibility to follow up with the physician. Otherwise, they continue to attend follow-up visits at the diabetes clinic.

Changing work practices for people with mental illness.

Clinicians’ ability to assist people from group homes is limited, in view of how health services for diabetes care are socially organized. First, the forms used in the clinic do not include sections for the collection of important information regarding special needs, thus providers are not reminded to address individual patient requirements. Next, it is assumed that people with diabetes are able to make diabetes-related changes. However, this group cannot exercise full agency because there are many facets organizing diet and activity. This is compounded by the fact that guidelines and rules for practice channel clinicians’ activities, and create barriers to addressing unique needs. Furthermore, residents from group homes often attend appointments alone, creating barriers to information sharing.

The following interview excerpt highlights clinicians’ struggles in attempting to use the assessment form to gather pertinent information about people with special needs.

... someone with some other needs from a special group, whether it is cultural, as in language, or...with special needs in the mental health community, not a lot of
area there (on the form) to say that...and who you should contact...So, where (on the form do) you put the caregiver and how do you get to there (the end goal)? How do you change this up for that person? So, I’m finding that I’m ah writing in extra places here (shows me a small white area on the form)... because there again you’ve got to um consider the level at which the person is able to take in some information...and whether or not it’s the ah caregiver that has more of the information. (Interview with registered nurse)

The assessment form was not formatted to capture such information as special needs, living arrangements, or the person’s cognitive and physical ability to make lifestyle changes. Also, there was nowhere on the form to report potential group home care provider involvement, or important knowledge about the patient revealed by that provider. If these particularities are not captured, appropriate diabetes support may not be considered.

The forms used to record statistics for the Ministry of Health and Long-Term Care also do not facilitate tracking of special needs groups. People with complexities, like mental illness, are placed in the same category as the general population with diabetes. The dietitian explained what statistics are captured.

...keeping track of our stats...we are getting the demographics that we need, so their initials, what type of diabetic they are, um age breakdown, sex, whether they are being seen by the nurse/dietitian team...(or) separately by the nurse and the dietitian...whether they have been seen in the fiscal year, whether they’ve been seen in another program or by us previously um or whether they are a new client to us...no show appointments...any cancellations. (Interview with dietitian)

Clinicians are extremely busy in their everyday practice seeing as many patients in a year as possible, in order to maintain funding from the Ministry of Health and Long-Term Care. Much of this time is spent filling out forms to track patient visits, cancellations, and no-shows. The lack of attention to special needs groups in the Ministry of Health and Long-Term Care forms results in no extra time allotment for those who may require intense or modified care provision. Time constraints produce barriers to creative clinical practice that goes beyond typical
diabetes care provision, like setting up conferences with group home staff, or becoming knowledgeable on how group homes operate to better serve their needs.

People from group homes often attend the diabetes clinic unaccompanied, which poses problems for the clinicians in attempting to ensure information sharing can and actually does take place, as reported by the nurse clinician:

*I have another lady from a group home that doesn’t come with a caregiver. So there again my concern would be the message in what I teach here, and what is actually going on at the group home and the message there. There you need to ask her permission, can you talk and just confirm with them, and she does, she agrees to that, and that is that other communication back and forth ’cause she actually is on insulin and um is able to manage that, give it to herself, but I think at times she possibly maybe doesn’t eat as she should and um so I always try with her to...support her in her independence in coming here but also let her know we need the communication to flow with the staff there as well so that the same story is flowing from us to her to them and back. (Interview with registered nurse)*

Information sharing may not occur between the resident and the group home care provider, who is responsible for making any required changes. Pertinent knowledge about the individual and contextual conditions of the group home may not be shared with clinicians. Thus, clinicians may not be aware that the person lives in a group home setting or that there are added constraints. Furthermore, consent is required to communicate personal health information to group home staff, and the resident may not wish to give this consent. A further system barrier is that hospital approval and arranging of extra time is required for clinicians to go into the community to the group homes to provide services.

In practice, I witnessed a resident going through an entire assessment appointment without anyone realizing that he lived in a group home and had major constraints that limited his ability to work with recommendations. When residents attend alone, information might not be shared with care providers at respective group homes after the visit, or the information that is shared may not be utilized (it might not fit into the menu, be too expensive, or might not be
covered on their social assistance program). This issue is revisited later in this chapter because it is a concern shared by the field worker who oversees operations at Rolling Hills.

To summarize this section, diabetes care provision is organized by processes of documentation, institutional accountability for privacy of patient information, and intensification of work practices to increase volume of patients seen in the clinic. People with special needs, like those with mental illness who reside in group homes, have inflexible contextual conditions, and suffer cognitive and physical limitations, and therefore do not fit into this social organization of diabetes care.

**Diabetes Care: Overview of Clinical Practice Guidelines**

Next, I review the “Canadian Diabetes Association 2008 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada” because this document is one of the main texts organizing care at the above diabetes clinic, and is used by health care providers nationwide. Following the overview, I provide an analysis of this text’s application to the needs of the population of interest.

The “Canadian Diabetes Association 2008 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada” was preceded by the 1998 and 2003 guidelines, and was written by and for healthcare professionals to be translated into practice to assist in defining, classifying, screening for, preventing, and managing this chronic condition and associated complications. It also offers direction for care of children with diabetes and special groups, such as pregnant women (CDACPG, 2008). The diabetes practice guidelines are disseminated to members of the Canadian Diabetes Association, diabetes education clinics, and other health professionals across Canada, and are also available online. Endocrinologists, certified diabetes educators, family physicians, and pharmacists are familiar with and utilize the outlined recommendations. Diabetes educator certification is based on both knowledge and application of this text in practice. In the above diabetes clinic, I know from personal experience that every endocrinologist and diabetes nurse and dietitian clinician has a copy of the latest guidelines and follows the outlined screening tests, recommended targets, and considers the various highlighted treatment options. Other texts that are used as teaching ‘tools’ in clinical practice, like assessment forms, glucose and A1c tracking sheets, medication pathways, various fact sheets
When I open the text, as a diabetes nurse clinician, I encounter imperatives that command attention be paid to the physiological aspects of the illness and its management. The document is prescriptive in its delineation of how the work of diabetes care should proceed for health care professionals. Like all other members of a diabetes health team, my work is to decipher the document and use other connecting texts to teach the patient the complexities of the illness, assess biomedical markers, and to provide knowledge and support (like referring to the social worker or to an endocrinologist) in self-management efforts. It includes such sections as ‘Prevention of Diabetes,’ ‘Organization of Diabetes Care,’ ‘Self-Management Education,’ ‘Physical Activity,’ ‘Nutrition Therapy,’ among others. Upon consideration, the reader of the text recurrently encounters the following themes; ‘diabetes has to be self-managed,’ ‘self-management procedures must be taught and learned,’ ‘diabetes self-management has to be supervised by health professionals,’ and ‘special populations require additional support from health professionals.’

**Diabetes has to be self-managed.**

The diabetes practice guidelines contain statements endorsing the self-management of diabetes as a central strategy to confront a predicted illness epidemic. The projected rise in the incidence and prevalence of diabetes in Canada, and the related cost and burden on the publicly funded health care system, form the rationale for a transition from the traditional Acute Care Model to the Chronic Care Model of disease management (CDACPG, 2008). In the document, research-based evidence is cited to support the Chronic Care Model as the organizing framework for providing efficient and effective diabetes care. The Chronic Care Model requires a greater level of self-management than the traditional model of care (CDACPG, 2008, p. S3). The use of this model of care for continuous quality improvement in primary care settings is also supported through results from a randomized controlled trial, which is identified within the text as Grade A, or gold standard evidence (CDACPG, 2008).

To further emphasize the importance of using this method to deal with the purported epidemic, a section is dedicated to the ‘Organization of Diabetes Care,’ in which the person with diabetes is identified as being responsible for disease management, while the diabetes healthcare
team’s job is to provide support through patient education, monitoring, and recall (CDACPG, 2008). Health care professionals’ work is to support “…the learner in interpreting and acting on the results of self-monitoring of blood glucose, making informed management decisions about insulin, medication, nutrition, physical activity and other lifestyle issues; and including daily preventive practices such as good foot care” (CDACPG, 2008, p. S20-21). Another identified function of the diabetes health care team is to provide the patient with access to the tools, such as medications, devices, and supplies that are required to achieve glucose, cholesterol, and blood pressure targets (CDACPG, 2008). Thus, the patient takes responsibility for illness management, while the diabetes health care team takes on a supervisory role in the promoted social organization of diabetes care.

**Self-management procedures must be taught and learned.**

The diabetes practice guidelines contain directives to clinicians to teach self-management skills. The objectives of self-management education are “…to increase the individual’s involvement in, confidence with, and motivation for control of their diabetes, its treatment, and its effect on their lives” (CDACPG, 2008, p. S25). Diabetes education programs are to include skills training, coping strategies, problem-solving, goal-setting, and case management (CDACPG, 2008). Skills training consists of self-monitoring of glucose and interpretation of results, taking medications as recommended and adjusting as required, making dietary choices, and incorporating an exercise regimen (CDACPG, 2008). ‘Empowerment’ is supported because it is believed to be crucial in ensuring that the person becomes proficient at informed decision making through participation and collaboration (CDACPG, 2008). Group education is also recommended as there is evidence that it is as effective as individual education and promotes efficiency in service delivery (CDACPG, 2008).

Within the text are directions for health providers to teach specific topics. Essential knowledge includes hypo/hyperglycemia management and prevention, physical activity, pharmacotherapy, healthy eating, monitoring of pertinent health parameters, and surveillance of comorbid conditions and complications (CDACPG, 2008). For example, hypoglycemia (blood glucose of less than 4 mmol/L) is highlighted in the text as a medical emergency causing confusion, coma, or seizure, along with having long term ramifications, and as such it is imperative to both prevent, recognize, and treat in people taking insulin and/or insulin
secretagogues (CDACPG, 2008). Secretagogues are oral medications that stimulate the pancreas to produce more insulin and consequently increase the risk for hypoglycemia. Specific guidelines are given for treating hypoglycemia in conscious and unconscious people, as well as risk factors for severe hypoglycemia. Those at risk for this acute complication are also to be taught to recognize and self-treat and take steps towards prevention. In order to establish primacy in organizing work around these knowledge areas, research-based evidence is provided to show the repercussions of neglecting each problem and the benefits of achieving optimal targets.

Among essential learning for the person with diabetes is the meaning of the glycosolated hemoglobin (A1c), or the indication of average blood glucose test results over a two to three month period (CDACPG, 2008). A1c should be measured every three to six months, with recommended levels of ≤ 7%. To achieve this goal, fasting or before meal glucose levels between 4.0 to 7.0 mmol/L and two hour after meal readings between 5.0 to 10.0 mmol/L are required (CDACPG, 2008). Thus, the person has to learn how and when to test blood glucose levels. Frequency of testing is based on the type of diabetes, treatment type, and individual capacity to use the results to modify behaviours or adjust medication (CDACPG, 2008). For those with type 1 diabetes, self-monitoring of glucose is recommended at least three times per day, both before and two hours after meals (CDACPG, 2008). For people with type 2 diabetes who take insulin once daily, plus oral antihyperglycemic agents, testing once per day at alternate times is recommended (CDACPG, 2008). More frequent self-testing is required to make treatment or behavioural adjustments when not achieving glycemic targets (CDACPG, 2008). Glucose monitoring is to be carried out by all people with a diagnosis of diabetes.

The text also contains instructions for the diabetes health care team to inform all people with diabetes “…that regular exercise is a key part of their treatment plan” (CDACPG, 2008, p. S37). The cited research findings illustrate that both aerobic and resistance exercises should be included in a physical activity routine that is spread over at least three days of the week, with no more than two consecutive days without exercise (CDACPG, 2008). An accumulation of a minimum of 150 minutes per week of moderate-to-vigorous intensity aerobic exercise is recommended (CDACPG, 2008). The definition of aerobic exercise is, “Rhythmic repeated and continuous movements of the same large muscle groups for at least 10 minutes at a time” (CDACPG, 2008, p. S38). Examples of moderate activity are biking, brisk walking, dancing,
continuous swimming, raking leaves, and water aerobics (CDACPG, 2008). For vigorous activity, examples include brisk walking up an incline, jogging, aerobics, hockey, basketball, fast swimming, and fast dancing (CDACPG, 2008). Resistance exercises, or activities that use muscular strength to move a weight (i.e. weight lifting), are to be included in the regimen three times per week in addition to aerobic exercise (CDACPG, 2008). Statements within the document encourage people with diabetes to incorporate an exercise routine as part of the treatment plan.

Nutrition therapy is considered central in the self-management of diabetes, and the list of nutritional considerations is extensive (CDACPG, 2008). The document delineates in detail the amount of carbohydrates, protein, and fat a person with diabetes is to be taught to consume in a day. The text includes the suggestion that people with or at risk for diabetes have nutrition counseling by a registered dietitian and follow Health Canada’s (2007) “Eating Well with Canada’s Food Guide” (CDACPG, 2008). The dietitian will teach them about portion sizes, as well as the benefits of ingesting high fibre and low glycemic index foods (CDACPG, 2008). To further help control blood glucose levels, dietitians will also instruct people with diabetes to plan their diets to ensure a consistency of carbohydrates and proper meal spacing. Inclusion of snacks is based on a complicated consideration of metabolic control, treatment regimen, risk of hypoglycemia, and potential risk of weight gain (CDACPG, 2008). Thus, people with diabetes are expected to follow extensive and complex nutritional recommendations.

The text also includes instructions for health care professionals to assess people’s weights. All overweight and obese people with diabetes are advised to achieve and maintain a healthy body weight through initiation of a healthy lifestyle intervention program (CDACPG, 2008). The guidelines contain evidence that a weight loss of 5% to 10% improves insulin sensitivity, glycemic control, blood pressure, and cholesterol levels (CDACPG, 2008). The goal is to lose one to two kilograms per month through a negative energy balance of 500 kcal/day in order to attain and maintain a healthy body weight (CDACPG, 2008). Pharmacotherapy for weight loss, such as Xenical (orlistat), is recommended when dietary modifications fail, and bariatric surgery might also be considered (CDACPG, 2008). Thus, weight loss and maintenance of a healthy body weight is also expected as part of disease management.
As outlined in the diabetes practice guidelines, all of these knowledge areas are to be taught in self-management education programs, and all people with a diagnosis of diabetes are required to learn and incorporate them into everyday diabetes self-care practices.

**Diabetes self-management has to be supervised by health professionals.**

The diabetes practice guidelines contain detailed instructions for the health care professional to take a supervisory role in the long-term management of the condition. Recommendations include use of systematic organizational interventions such as electronic databases, clinical flowcharts with automatic reminders, and recall for diabetes metabolic control and complications risk assessments (CDACPG, 2008). “Regular reinforcement through diabetes self-management education should be integrated into standard diabetes care…ongoing rather than time-limited diabetes education sessions are beneficial in the long-term management of all forms of diabetes” (CDACPG, 2008, p. S21).

The text also includes recommendations for follow-up care in all aspects of illness management. Periodic re-education on correct glucose monitoring technique is suggested (CDACPG, 2008). Also, nutrition therapy should be “…regularly evaluated and reinforced in an intensive manner, and be part of self-management education programs” (CDACPG, 2008, p. S40). For insulin therapy, “…initial and ongoing education is recommended that includes comprehensive information on how to use and care for insulin; prevention, recognition, and treatment of hypoglycemia; sick-day management; adjustments for food intake and physical activity; and self-monitoring of blood glucose” (CDACPG, 2008, p. S46). Medication management also involves re-evaluation and adjustments as the disease progresses, with weight gain or loss, changes in food intake and levels of activity, and stress, among other factors (CDACPG, 2008). Ongoing follow-up with the health care team is also recommended for planning dietary and activity changes to facilitate weight loss for those who are deemed overweight (CDACPG, 2008). Diabetes work is complex and extensive, and also includes continuous monitoring and treatment of other risk factors, such as dyslipidemia and hypertension. Routine, ongoing screening and biological evaluation by experienced professionals is part of the lifelong treatment of the disease and its complications.
Special populations require additional support from health professionals.

Further evidence-based recommendations for comorbid conditions, such as coronary artery disease, retinopathy, neuropathy, nephropathy, and erectile dysfunction are outlined in the diabetes practice guidelines. For example, if kidney disease is present, the person should have laboratory testing every six months, a referral to and ongoing care by a nephrologist, and a medication that protects the kidneys (CDACPG, 2008). Special populations listed as needing extra attention are as follows; a) diabetes and pregnancy, b) diabetes in the elderly, c) diabetes in the Aboriginal populations, and d) high risk ethnic groups (CDACPG, 2008). These groups are monitored more stringently, have tighter targets, and modified and often more complex treatment plans than the general population of people with diabetes. Special populations have added complexities and therefore require added support. Those with mental health disorders are not included as a special population.

Summarizing, in the diabetes practice guidelines it is delineated that diabetes work should be organized by using health sciences research to support the claim that a certain method of care, the Chronic Care Model, is the best way to deal with the problem. Within this model, considerable self-management is required, while the health care provider assumes a surveillance role. Health care providers’ knowledge is required to interpret the text for the individuals with diabetes, who are required to follow the prescribed, complex treatment plans. People with added complexities are even more dependent on health care professionals to decipher the practice guidelines and to help them devise self-management strategies that combine with care for other health problems. Part of the process, as explained in the text, is for people with diabetes to keep track of biomedical markers linked with outcomes (weight, blood pressure, blood glucose, A1c, waist circumference), thereby necessitating the use of other texts such as glucose log books and A1c tracking sheets, among others. These records facilitate their ongoing communication with health care professionals. Also, further linkages to different health care professionals, such as ophthalmologists, nephrologists, cardiologists, podiatrists, and neurologists are created, depending on biomedical markers. Overall, the practice guidelines identify diabetes as a multifaceted, challenging chronic disease that requires extensive knowledge and skills, commitment, resources, and a substantial support network to successfully manage.
Diabetes Clinical Practice Guidelines: My Analysis

Using an institutional ethnographic lens, I offer an analysis of the “Canadian Diabetes Association 2008 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada” for its ability to inform diabetes care in people with severe mental illness. The diabetes practice guidelines is a ‘boss’ text (D. Smith, personal communication, August 14, 2009) that is framed in biomedical language and discourse. Consequently, it legitimizes the authority of health care providers to best instruct patients on management of the problem. This authoritative text serves as a point of reference in the coordination of activities across local sites, as it is used by all Canadian health professionals responsible for diabetes-related care. With its intertextual references to evidence-based medicine, which is an important knowledge relation, it draws practitioners into relations of evidence-based decision making (Mykhalovskiy & Weir, 2004). Readers of the diabetes practice guidelines are prompted to ration care by working with the Chronic Care Model, thereby providing effective, efficient services to reduce health care costs. Further, the text standardizes and decontextualizes the problem, thereby overlooking contextual circumstances and constraints to diabetes management. Within the recommendations a notion of agency is also produced with an imbedded assumption that everyone can accommodate for and participate in diabetes self-care activities. No alternatives to the self-management model are available for those with cognitive or physical limitations: This model is a poor fit for anyone who is unable to exercise full agency. Also, as suggested by Mykhalovskiy and Weir, the discourse of evidence-based medicine can facilitate social exclusion, among other things. Mentally ill adults are missing from the list of special populations in the text, even though the widespread use of atypical antipsychotic medications heightens their risk for diabetes. There is a large body of literature that connects diabetes to the use of atypical antipsychotics, as shown in the review of the literature. However, mentally ill adults with comorbidities who reside in group homes are missing from the health sciences literature, and as such are excluded in the diabetes practice guidelines.

The “Canadian Diabetes Association 2008 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada” is an organizing text that standardizes care,concerting and coordinating diabetes practices as it is used at local sites across Canada. Its agenda, which is to manage the problem in a certain way, is delineated with the use of such phrases as ‘standardized service provision.’ In the text it is reported that,
Diabetes and its complications increase costs and service pressures on Canada’s publicly funded healthcare system. Because of poor compliance to evidence-based recommended management regimens, diabetes and its complications significantly contribute to the cost of primary healthcare, and add to waiting times for treatment in emergency departments and surgeries. (CDACPG, 2008, p. S2)

Words like ‘effective,’ and ‘efficient’ are used to describe what is considered to be optimal care within the prescribed Chronic Care Model. Health care providers are instructed to use this text as a means to providing cost-effective and efficient services, thereby reducing societal burden associated with provider noncompliance and resultant costly complications. Government decision makers are also meant to use the text to make funding decisions for improved efficiency in health care delivery (CDACPG, 2008). Evidence-based medicine is connected to the political economy, informing health care professionals and policy makers on how to standardize care to reduce associated costs.

Medical expert knowledge and authority are legitimated because the diabetes practice guidelines are presented using terminology that requires expertise to decode. The text is based on dominant health sciences research to establish confidence in the guidelines to inform clinical practice. It has to be translated and interpreted by a health care professional because it is not written for the lay person. This increases reliance on health care professionals for help with disease management. Also, as seen in the overview, the person with diabetes is drawn into and participates in extensive and complex diabetes care activities that are supposed to have positive outcomes, based on evidence. He or she must learn considerable information, develop new skills, and make major lifestyle behaviour modifications. Ongoing communication with diabetes experts is necessary to monitor the disease process and to make periodic adjustments to the prescribed treatment protocols, which creates further dependence on health care professionals.

Diabetes self-management, as an integral component of the Chronic Care Model, is promoted as the best way to deal with diabetes (CDACPG, 2008). This method of illness management assigns responsibility and accountability to the afflicted individual. Health care professionals, following the guidelines in which the notion of full agency is produced, use self-management education to impart the required knowledge and skills to control progress of the disease. The person is assumed to be able to and has the time, capability, and financial resources
to monitor, incorporate a certain diet, exercise, and orchestrate medical appointments, among other diabetes-related activities. This notion of agency does not fit for the mentally ill, but also is not suitable for some others. Many people are not able to carry out the expected self-care activities to the extent that is required to achieve biomedical definitions of success. Mentally ill adults suffer from cognitive constraints and side effects from psychiatric medications, which may impede learning. Also, if teaching strategies are neither conducive to particular learning needs nor sensitive to disabilities or limitations, learning may only be partial or distorted. For example, the guidelines encourage patients to self-test blood glucose levels before and two hours after meals, find patterns of hypo/hyperglycemia, and then take appropriate action to correct these deviations. This analysis of the diabetes practice guidelines is followed by the exploration of self-care practices at Rolling Hills, where I highlight the disconnect between such recommendations and the actualities of everyday activities in group homes. Some people need alternative methods of care to those proposed in the guidelines, or at the very least, modifications within the Chronic Care Model to accommodate for limitations.

The document also standardizes and decontextualizes diabetes as a unitary problem. So, although the recommendations are evidence-based, they may not be feasible or even possible to implement if contextual constraints remain invisible and are not considered. For example, many of the severely mentally ill adults in group homes are on the Ontario Disability Support Program, which denies access to some of the recommended medications and treatment regimens. The diabetes practice guidelines suggest implementing lifestyle interventions, including physical activity and dietary modification, to improve glycemic control and enhance weight loss. Additional treatments, such as behavioural therapy, pharmacotherapy, and surgery are recommended if regular lifestyle intervention strategies are not successful. All of these treatment options are inaccessible for residents of group homes with serious mental illness because they do not meet eligibility criteria for bariatric surgery and they lack coverage for the recommended pharmacotherapy (like orlistat) under their social assistance program. Eligibility criteria for bariatric surgery are numerous: The individual must be smoke-free for six months, attend a weight loss program, and adhere to a special diet with supplements prior to and post-surgery (not covered by social assistance), attend many compulsory medical appointments (access issues), and have psychological evaluation and therapy (Ontario Bariatric Network, 2010). Therefore, the document cannot be used in the development of lifestyle interventions for this group, nor does it
contain accessible alternatives for attaining weight loss. The standardized, decontextualized recommendations do not fit with certain particularities.

Also, in decontextualizing diabetes, important circumstantial constraints are overlooked. It is assumed that the person with diabetes is independently able to begin self-care practices once given the necessary tools, such as a glucose meter and knowledge of prescribed medication, exercise, and nutritional recommendations. However, this assumption may be erroneous. Even if a group home resident has knowledge related to diabetes care, the living arrangements work against attempts at self-management. The resident does not have control over grocery shopping or individual meal planning, and thus cannot make recommended changes where food choices, portion sizes, and timing of meals are concerned. Some people do not have control over aspects of diabetes care, in view of contextual constraints that are essentially overlooked in the organizing text.

The text also contains instructions for the health care provider to have the person arrange many ongoing medical appointments with the diabetes health team, family physician, endocrinologist, ophthalmologist, and podiatrist, in addition to laboratory tests every three to six months. If complications are present, further appointments are advised. The assumption is that people are able to orchestrate these activities. However, navigating the health care system is difficult for most, and the individual with mental illness who lives in a group home encounters particular barriers and constraints. Appointments are organized by the group home operator on a certain schedule, transportation is difficult to arrange, is expensive, and prior approval for medical escort must be obtained for each appointment. By ignoring contextuality and individuating responsibility for disease management, constraining elements are not addressed and thus continue to interfere with diabetes care and outcomes.

Finally, possibly due to the lack of ‘gold-standard’ health sciences research in this area, the people with severe mental illness are excluded as a special population that requires additional support. Adults with schizophrenia are listed as being at risk for diabetes due to genetic predisposition (CDACPG, 2008). However, the connection is not made in the text between the widespread use of atypical antipsychotic agents and the heightened risk for those who are prescribed these medications. The added constraints that come with mental illness and certain social circumstances that further increase their risk, such as low income, are also not recognized.
Health care professionals may not even be aware that this population requires special attention if the best practice guidelines do not highlight it. The clinicians in the clinic of reference were unaware that atypical antipsychotic medications are linked to the development of diabetes until I brought this information forward. Also as noted, the clinicians have little awareness of the social organization of group home care, or how best to provide services to the mentally ill. In congruence with the practice guidelines, alignment with the Ministry of Health and Long-Term Care requirements for funding is required, and ‘effective,’ ‘efficient’ services are mandated to deal with the diabetes epidemic. Restrictions limit the amount of time available to modify or intensify care for those with particular needs. That persons with severe mental illness are not recognized by the organizing text of diabetes care undermines equitable delivery of care, but social relations of cost efficiency create and sustain further inequities.

Summarizing this analysis, the “Canadian Diabetes Association 2008 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada” is one of the major driving forces for diabetes management nationwide. This text draws on the intertextuality of evidence-based discourse to establish authority in directing health care practice. The document offers basics such as the standard definitions, diagnoses, classifications, screening tools, guidelines for nutrition, and various biological targets outlined to guide best practice. However, its ability to inform care of mentally ill adults is limited. This group is missing in the text, aside from the acknowledgement of added risk for diabetes with a diagnosis of schizophrenia. Additionally, self-management of the disease, as the only method of care, is promoted, assigning responsibility for illness management to the person with diabetes. The representation of diabetes management within the text also standardizes and decontextualizes the problem, thereby overlooking barriers and constraining elements that impede diabetes self-care attempts. Social and contextual constraints are many and varied, and include, but are not limited to, cognitive and physical disabilities, restrictions to certain treatment options, and budgetary limitations. Self-management education that is not sensitive to these impeding circumstances is relatively useless.

**Diabetes Care Regimens at Rolling Hills**

Next, I explore the diabetes regimens at Rolling Hills by using notes from observational studies taken during two different ‘blood testing days’ at the residence. I highlight how the work of glucose testing and insulin injection fit in with other group home routines. I also point to the
cognitive and physical limitations that impede the women’s diabetes self-management practices. Additionally, the vignettes begin to illustrate how care provider activities are orchestrated to align with the regulation that stipulates they do not administer medication, while attempting to maintain resident safety during insulin injection.

It’s 7:30 a.m. on Wednesday, and Rose informs me, “It’s blood testing day, when all the people with diabetes test their blood sugar levels.” The supplies, which consist of alcohol, cotton balls, and Freestyle meters and a One Touch Ultra 2 meter in a basket, and a sharps container, have already been taken out of the cupboard and placed on the middle table in the main kitchen. Everyone seems to know who is supposed to do a test, and as they enter the kitchen from different areas in the home, some stop at the table and use the One Touch 2 meter in succession. After finishing, each walks across the room and writes her blood glucose reading beside her initials on the white board. One of the women proudly shows me her result, which is 6.3. Other women point to theirs to show me that they have completed the task.

It is now 7:50 a.m. and the board is filled with various initials with the time and glucose readings beside them, such as 5.7, 5.9, 9.0, and 10.4. The staff member walks in from the home owner’s part through the bedroom saying, “Hello” as she heads directly for the medication cart, unlocks it and pulls out a book. She then proceeds to call out for the blood glucose readings, which she records in the book as Peggy, a resident who assists with this work, yells numbers and the person’s name to which it belongs as follows; “Mary, 9! Anne, 5.9! Tulip, 5.7! Rose, 6.1!” Peggy tells the staff member, “The residents are not taking out their test strip.” Peggy then gets the supplies and proceeds to test Vita, who doesn’t do her own glucose testing. Vita sits quietly as Peggy puts a test strip into the glucose meter, takes her hand, wipes off a finger with an alcohol soaked cotton ball, and uses the lancing device to poke her finger. She then squeezes Vita’s finger to draw out blood, and puts the strip to the drop of blood to obtain the result. She then writes Vita’s result on the white board, and tells the staff member the number.

Michelle, who is a new resident with diabetes at Rolling Hills, comes to the table from her bedroom and takes her own blood glucose reading using the meter. She follows the same steps as the other residents without hesitation. She informs me, “I just learned on the weekend. I have had diabetes for about a year, but have never taken my blood sugar before, and have never used one of these machines.” Susan, another staff member, taught Michelle how to test her own
glucose. Michelle tells the staff member her reading is 6.6. Peggy now takes the basket of supplies and the sharps container and puts them in the appropriate cupboard.

Meanwhile, the staff member takes out an insulin pen from the medication cupboard and prepares the insulin for Margaret by twisting the numbered dial, which indicates ‘units’ of insulin. Once she gets to the proper number of units to be given, she inserts it into Margaret’s skin, and has Margaret push the plunger to inject it. Another resident who requires insulin prepares her own and the staff member looks at the dosage to ensure it is correct, after which the resident inserts the pen as the staff member checks to ensure she has a “fatty part of skin” to inject it in. Once all blood glucose readings are taken and recorded and insulin is given, oral medications are given as per the usual routine.

**Another Wednesday.**

At 7:55 a.m. the staff member enters the women’s kitchen to begin the workday. As she walks through, she inquires if all of the diabetics have done their blood sugars. Anne says, “No,” and she proceeds to get the sharps container, the basket with the meters, and strips from the cupboard. The staff member informs the women that she did remind them yesterday that today is Wednesday and is blood testing day. The staff member only finds Freestyle strips at first, and so Anne uses a Freestyle meter. Anne states, “I like using the long one (the One Touch strip)” and struggles to get the smaller strip in the Freestyle meter. She then shakily puts in a new lancet in the lancing device. She gets a drop of blood after squeezing her finger, and then asks the staff member for help getting the blood to the strip.

Meanwhile, Tulip, who looks sleepy this morning, uses the One Touch meter, and gets the lancet device ready, but has a hard time getting a strip into the meter. She says, “It won’t go in.” I notice that she is trying to put a Freestyle strip into a One Touch meter. The staff member finds the container of One Touch strips. Tulip puts one in and then tries to put the drop of blood on top. It doesn’t work. She tries again, and once more puts the drop of blood onto the top of the strip, but it is supposed to be placed in the front of the strip, as I know from experience. She gets another strip and I explain the drop of blood needs to be in the front of the strip, not on top. On the third try she gets a drop on the strip and obtains a result. The staff member does Rose’s and May’s blood glucose tests. Mary tries to do her own test, and gets the drop of blood on the top instead of the side, where it is supposed to go on the Freestyle meter strip, and then she has the
staff member put the drop in the right spot after her attempt fails. Peggy does Violet’s test for
her. The staff member informs me that Peggy and another resident help with blood glucose
testing. Once the supplies are returned to the cupboard, the staff member proceeds to dial up the
insulin dose after putting on a needle tip, and has the resident inject her insulin into her abdomen.

The above vignettes shed light on glucose testing and insulin injection regimens at
Rolling Hills, and how these diabetes-related activities are coordinated with other daily routines.
All residents admitted to the home with a diagnosis of diabetes are taught almost immediately
how to use the glucose meter and are shown the routine of writing the result on the whiteboard.
This result is then recorded by the staff members in the appropriate spot in each resident’s file
and kept for tracking purposes. The woman with diabetes is also put on the group home’s
‘diabetic diet’ (the diet is discussed in Chapter 7), and added to the list of residents who get
quarterly A1c blood tests.

Determining glucose testing times and days are the responsibility of the home operator,
who in doing so considers several points, such as physician recommendations, if the resident is
on insulin, and usual blood glucose levels. She has those with fluctuating blood glucose levels,
and women on insulin check more frequently.

_We have two that are very brittle, so their blood sugar needs to be taken four
times a day so we have a spot in our MARS book where she would have to record
the blood sugars every time meds are given 8 a.m., noon, 5 and 8 p.m. at night.
Then we have our more stable diabetics and these are the ones that are not
insulin dependent. We still keep a record to see where their blood sugars are at._
(Interview with Carol)

Wednesday is the particular day of the week that has been chosen for testing glucose levels,
which are done at 8 a.m. and 5 p.m. for the women with diabetes who are on oral
antihyperglycemic agents or diet alone. Women with prediabetes are not asked to test their
blood glucose levels nor do they follow the ‘diabetic diet,’ as they are deemed only at risk for
developing diabetes. Glucose testing and recording is a regular practice taken up as one of the
usual routines at Rolling Hills, along with quarterly A1c testing, done by a laboratory technician
who draws blood at the group home. The A1c is reviewed by the family physician, who makes any required medication adjustments based on the reading (Interview with Dr. P.).

If a glucose reading is above normal, the care providers and home operator try to determine what the resident has consumed. Carol reported,

*You have to sit and educate with them and try to figure out what they’ve taken, and 9 times out of 10 they are going to tell you nothing…there’s that history that every time you go shopping on Tuesday your blood sugars go up so you know something’s going on.* (Interview with Carol)

Susan noted that if a blood glucose reading is elevated she might give a smaller portion size at the next meal. The out-of-range glucose reading is recorded in the MARS book, which is shown to the family physician at his weekly visit. According to Carol, staff notifies the family physician if concerned about glucose readings. With low glucose readings physical symptoms of ill health are much more rapid, and care providers are aware of the necessity to respond quickly with sugar (in juice or water), to call 911, and record the reading and action taken, as indicated by Carol. Work practices in response to one resident’s fluctuating blood glucose levels are discussed further in Chapter 7.

The glucose monitoring process goes quickly, with each woman entering the kitchen and testing her blood glucose prior to sitting in her designated chair to wait for pills to be given and breakfast to be served. Some days run more smoothly than others. Side effects from psychiatric medications include lethargy, difficulty concentrating, and tremors, all of which can impede the actual work of testing. As seen in the second vignette, women might forget to test their blood glucose levels despite reminders, and sometimes they might be unable to do the task independently.

*We have tried to teach them...but you still have to assist them and watch over them, but 80% we have taught to do it (glucose monitoring), which is important because when they go home with family members or go on trips they know how to do it...It’s more taxing to teach them than to actually do it (ourselves), but we have taken that time...* (Interview with Carol)
The staff member, residents with diabetes, and other residents coordinate their efforts to get blood glucose testing done in a timely manner so pills can be given, breakfast can be eaten, and other chores can be undertaken.

This glimpse into the testing and insulin regimens is informative. Work is organized at the local site to accommodate people with diabetes. Glucose testing is carried out, and people are taught to monitor themselves and are watched more stringently by others (especially if categorized as “brittle” or insulin dependent). From a diabetes educator’s perspective, the residents are encouraged to carry out diabetes activities that may enhance their sense of autonomy. However, I began to see that the task of glucose testing and insulin injection, which are only two of the many aspects of diabetes care, are difficult for some residents and sometimes assistance is required, which takes time and patience. This creates pressure because it competes with other household tasks to align with regulations, such as maintaining the home in inspection-ready condition, as well as getting baths, bed making, and laundry done. One care provider is responsible for ensuring all activities are completed promptly, and as such directs two residents to help with some of the glucose testing. Support is not offered in medical management.

**Diabetes Self-Care: Participant Concerns**

In this section I use interview data to further explore the tensions created in attempting to align with State-mandated regulations that impede proper medical management. I also highlight problems that arise from the assignment of diabetes self-care responsibility to the residents with diabetes, and regulations that restrict the use of medical escorts. I illuminate the experiential knowledge through which the providers make diabetes-related decisions, which further brings attention to the lack of State support for formal education. Finally, the disconnect between medicine and psychiatry is brought into view, as a critical disjunction that intensifies this population’s risk for developing diabetes.

Diabetes self-care activities, including glucose monitoring and insulin injection, are the responsibility of afflicted residents, as mandated by the Ministry of Health and Long-Term Care. This is a housing program, and care providers are not to assume responsibility for medication administration. Tensions are created with care providers attempting to stay within the guidelines and not take on responsibility for care, while maintaining resident safety in the everyday world of group home life. Among other issues, homes vary in providers’ knowledge about diabetes, the
organization of the work of diabetes care, and the amount of knowledge transfer between residents and care providers, all of which may lead to health risks and disparities. These issues are discussed under the following subheadings: ‘the work of insulin injection,’ ‘variability among group homes,’ ‘diabetes self-care: an example,’ ‘utilization of medical escorts,’ ‘lack of formal education,’ and ‘medical/psychiatric disconnect.’

**The work of insulin injection.**

The people overseeing care and those at the local site participate in complex practices in order to stay within the boundaries of group home guidelines. They avoid direct medication administration, while also ensuring resident safety by monitoring insulin injection. At Rolling Hills, as shown in the above vignettes, the care provider prepared the insulin pens and, through an automatic process, drew up the proper amount of insulin for two residents. She helped insert one pen, and watched as the residents injected the insulin. In her work practices, she operated within the bounds of the regulation against medication administration by not actually injecting insulin, but assisted with this difficult task for safety reasons, to ensure the women inserted the needle correctly and received the proper dosage of medication. Another staff member, who does not inject the insulin, shared her trepidation with the liability issues involved in this work.

*I have to watch them dial in, shake it up, put the needle on everything and most I can do is make sure they’re giving themselves the needle, where before I could give them the needle... (resident’s name) has a hell of a time. She wants to drive that needle right through her friggin’ arm. Now (another resident), she does it pretty good but her vision is so bad that I have to check that she dialed it right. I have to check that there’s no air bubbles in it anyway and it was so much easier when I could give it... But watching them struggle trying to turn this thing! (Resident’s name) has never gotten the amount right, ever... she’s supposed to have 15 (units) in the morning and she usually dials 20 (units). She can’t screw the little needle on the end, and they never get the air bubbles out... I’m watching (resident’s name) and she bends the needle in her arm... Now if someone like (resident’s name) had to give herself her own needle... who’s going to give her needle? There’s no way she could... They don’t even understand the concept of the needle. (Interview with Phoenix)*
Highlighted is the very finely tuned local knowledge of individual residents’ capabilities. The care provider was detailed in her description of resident abilities, explaining who is able to do what and who might hurt themselves and how best to coach at different steps of the process. Care providers were cautioned by the home operator against doing more than assisting with insulin injecting because, as unregulated health care workers, they are not qualified to administer medication or perform regulated acts. If an incident occurs resulting in a lawsuit the operator and care providers could be held accountable and face repercussions. In the operator’s case, this could result in potential loss of license and livelihood.

**Variability among group homes.**

The medication administration regulation also creates variability across the group homes in how blood glucose monitoring and insulin injection, as everyday work practices, are carried out. In the following quote, the field worker, who oversees the operations of six group homes, made evident the variability around these tasks.

> According to the (HSC) guidelines they (the home operators) are not supposed to be responsible, and I only know a few homes that do actually keep the (glucose) readings, and in one home in particular the doctor has requested it. They all work different...The residents are supposed to do it themselves. They have the book. The homes that don't monitor, they will sometimes keep the records. This one home in particular has it on the fridge...some of the homes do watch to ensure that it’s being done properly...Here it’s amazing. (Interview with Laura)

Glucose monitoring, as a routine practice, varies among group homes in the extent to which it is performed as a result of a restrictive regulation that implies repercussions for carrying out this task.

Similar to glucose monitoring, insulin injection, as an everyday practice, is differently handled in each home.

> ...actually I have two or three. One, a family member comes once a week or twice a week and pre-fills the syringes. Another one, the doctor or is it the pharmacist, one of the two gets it ready for him...The third one, and it’s not coming from me,
a home operator gets the syringe ready with the insulin, just gets it ready and the resident then will inject. (Interview with Laura)

As the person responsible for overseeing the group homes, the field worker has insight into local particularities, knowing how each operator gets around the regulation and the complex practices in which they participate to ensure that insulin is injected safely. She too exploits technicality in a regulation that generates variability and unsafe situations.

However, these processes only serve to create and sustain inequities that go beyond that of glucose monitoring and insulin injection. The group home guidelines distribute accountability for resident safety to the home operator, but conversely assign responsibility for medication administration back to the resident. The Ministry of Health and Long-Term Care does not support the home operators with a policy referring to medical management for residents who cannot assume this responsibility. Rather, admission into this ‘housing’ program is rejected if the individual with diabetes cannot self-manage. The field worker must, as part of her role, find placements, and realizes many residents cannot manage the entirety of diabetes self-care. She also is aware that being denied admission into the HSC Program limits placement options to nursing homes. So, she uses her knowledge of home operators and her insight into the ways each of the homes are operated to make decisions about placements so residents will find appropriate care. In contrast, however, field workers do not purport to have knowledge of home operators’ or care providers’ involvement in glucose testing or insulin injection outside of assisting or supervising, as they too can be implicated if discovered they have knowledge of these practices. This creates tensions because the residents may falsely indicate they are able to self-manage to get placement. Those who are not capable of self-managing may find themselves in a group home where the home operator does not assist, leaving them to struggle on their own.

Residents with diabetes are not accepted by some of the home operators within the HSC Program. As reiterated by Laura, it is difficult to find homes that will accept residents who have diabetes, especially those who are on insulin.

I’m going through that now but...all I can do is ask the homes. They say, “No,” then they say, “No.” Bottom line it’s the home’s decision. Either A, they will take
the responsibility, or B, they won’t, and it is a big responsibility. I know some homes bend over backwards. (Interview with Laura)

The people with diabetes are a more expensive and a more difficult group to care for, due to the added responsibility of illness management.

...with diabetes pills, giving insulin, testing, you’re talking it takes an extra couple of hours a day, seven days a week for diabetic care and of course we aren’t compensated for it. What the government would just say is, “Don’t take them then. Don’t take the diabetics,” because they don’t want to have to pay anything extra for them. And where else are they going to go? They have major psych issues accompanying their diabetes. They need this type of housing, but they just have the other medical care that goes along with it. (Interview with Carol)

The effect of the complicated rationings and regulations is to intensify people’s marginalization because home operators are not supported in medical management or in diabetes care provision. The home operators that do choose to risk liability, and take on the added responsibility that accompanies management of this disease, do so unsupported by the Ministry of Health and Long-Term Care, the Ministry of Community and Social Services, and the regional government.

The family physician who visits the group home was unaware that residents with diabetes are required to self-manage diabetes care activities. He also was unaware that home operators and care providers are not to administer medications: he shared his concerns.

I have a problem with that...Most of these residents are in a home for a reason so that they may not be the best at looking after their own medications. Certainly some of them wouldn’t be very proficient at giving themselves insulin...The same with monitoring blood sugars, it’s not the easiest thing in the world to do and I know if the home owner is monitoring it then it gets done properly, which I think is very important to trying to maintain these patients as best we can. I’m really not sure of their (governing bodies) rationale for that, unless I assume the Ministry of Health and the Ministry of Community and Social Services don’t want the home owners providing care because they would have to pay them at a
The physician has insight into resident cognitive and physical limitations, and questioned the sensibility of distributing responsibility of such complex tasks without consideration of support that may be required. Highlighted once again is the reference to cost savings as a State interest that overrides other interests, specifically the residents’ health, safety, and overall wellbeing.

According to Carol, home operators previously raised the issue to the Ministry of Health and Long-Term Care, requesting extra funding for such things as special food, staffing, and support services to enable proper diabetes care provision. The process for requesting approval requires documentation and much negotiation. All written requests outside those that can be dealt with within the HSC Department (by the field worker, manager or program director) must be approved by the Ministry of Health and Long-Term Care HSC Program Coordinator, who is positioned in the Negotiations and Accountability Management Division, Provincial Programs Branch of Community Services and Forensic Mental Health. If in question, the Program Coordinator takes the request further within the Ministry of Health and Long-Term Care to receive approval or denial, and communicates the response back to the field staff or home operator. Carol has, on occasion, contacted the Senior Program Consultant within the same division at the Ministry of Health and Long-Term Care, who again confers with others to provide approval or denial. When requests are made for more money, the home operators are reminded by those working within the Ministry of Health and Long-Term Care that if the HSC Program becomes too costly to operate, it could become unsustainable and the Ministry of Health and Long-Term Care could choose to stop the entire program. Thus, much careful negotiation occurs amid concerns about pushing too far, deterring the home operators from requesting support.

**Diabetes self-care: An example.**

In this next quote the HSC field worker shared her distress about a resident’s safety. This particular resident was from another group home that does not assume any diabetes care activities. Laura reported that the resident is responsible for taking her own insulin, blood glucose readings, making medical appointments, and taking these readings periodically to the doctor for review.
She can do numbers. She can write her name. She knows a few words here and there...I don’t think she, and this is just my personal observation, that she gets the whole problem with the diabetes. This is one who calls me four or five times a day...and tells me her blood sugar levels are 22 point something. I tell her to tell staff or the (home) operator. She’ll call me back in about an hour or two and say it’s at 27 something. And I know she cheats. I do know she cheats. I’ve seen her. The other residents tattle tale, ‘cause it just doesn’t change that quick. She has gone to the diabetic clinic, but again they’re not aware she can’t read. They give her all this information. But she just doesn’t want people to know she can’t read. (Interview with Laura)

The resident remains silent about her illiteracy at the diabetes clinic appointments, which has far reaching implications. She may not be able to a) interpret the offered written information, so cannot follow important instructions for diabetes care, b) keep diaries as requested for monitoring purposes, or c) utilize contact information to call the clinic if concerned; all of which may result in out-of-control glucose levels, with no record keeping to enable pattern detection and medication adjustments, and importantly no means of obtaining assistance. This highlights the disjuncture of the social organization of diabetes care provision for this group. Forms do not readily facilitate the capture of pertinent resident information, and the people involved in her care do not accompany her to appointments. Thus, her illiteracy remains a secret, and she does not receive information in a manner that is useable. Also, rather than involving the care providers at the group home with her out-of-range glucose readings, the resident calls the field worker. In the quote the field worker alluded to the resident’s patterns of cheating, expressing that other residents tattle on her. She also indicated this particular home does not assume responsibility for diabetes care. The resident ultimately reaches out to the field worker for support, as no other options are available. No one in the home assists her in her self-care activities; consequently she is further marginalized in the process.

This anecdote also points to the ironies and contradictions of rigorously monitoring certain aspects of group home care, such as fire and food safety, and meticulous home and resident hygiene, while ignoring safe diabetes care. For example, fire safety legislations are strictly enforced, and people at the local site carry out numerous related activities and processes
to ensure resident safety during a fire. However, this resident has unsafe blood glucose levels that jeopardize her physical safety, and she does not receive assistance because of the way the regulations organize group home care. It is illogical to strictly enforce rules that ensure minimal risk of exposure to fire or other hazards, while neglecting important aspects of health and wellbeing. At Rolling Hills, diabetes work practices do not centre on such things as balancing of diets, levels of activity, glucose levels, and medication/meal timing, as described in diabetes practice guidelines. Rather, work activities revolve around efforts to circumvent the medication administration policies, while maintaining resident safety without State support.

**Utilization of medical escorts.**

Both the regional and provincial governments discourage the use of medical escorts due to the cost of this service. The Domiciliary Program provides very little funding for medical escort services and the Ministry of Health and Long-Term Care distributes accountability to field workers for monitoring and restricting usage.

*The local HSC office shall only consider approval of a claim for an “escort” when a resident has a medical appointment and because of physical or mental disability, illness or infirmity cannot safely go on his/her own…The HSC Field Staff in monitoring transportation costs should ensure that the most appropriate and economical means of transportation is utilized…Taxicabs should only be used when there is no other transportation available…and is to be authorized and closely monitored by the HSC Field Staff.* (MOHLTC: Operating Guidelines for HSC, 2003, p. 24-25)

Also, as stated previously, medical escort utilization requires prior written approval, which is given only if deemed necessary. Even if approved, the amount paid is not sufficient. Carol reported, “The Domiciliary (Program) gives you 21 cents a kilometer which…from my place to (town) is $6.00. It’s really tough to get someone in for $6.00 and no (additional) escort (payment), so that wouldn’t even cover their gas cost.” The Domiciliary Program does not offer an hourly rate for medical escort service, and on the Hostel Compliance Checklist (2008), the operator is to confirm that residents utilize public transportation whenever possible for dental and medical appointments (p. 8). It is not possible to use staff for medical escort services because they are needed on the premises to care for residents in the home. The home operator also has
time restrictions, and cannot feasibly escort residents to all of their appointments or emergency room visits (that generally take no less than eight hours), although she does take them to all of their psychiatric appointments. As seen in Chapter 4, creative use of limited human resources is often required to escort residents to appointments; Carol hired her daughter for this role, and at times asks the housekeeper to fill in. This lack of financial support for the utilization of medical escorts results in residents often attending appointments alone. The field worker shared concerns in regards to residents being unaccompanied at diabetes clinic appointments.

_Also the diabetic clinic, this particular resident again, I would’ve liked someone to have gone with her, be it me, the home, a family member, knowing she can’t read because the clinic is not aware of this. And it’s not just that she can’t read. Other residents just don’t comprehend what’s being told to them. I’ve never been to a diabetic clinic, but I’m assuming it must be overwhelming for most people._

_(Interview with Laura)_

From personal experience as a previous home operator, I find some people with mental illness have difficulties describing ailments, often remaining silent or agreeing with whoever is asking them questions. Dr. P. echoed, “Obtaining histories and formulating a differential diagnosis is difficult as they often cannot answer pertinent questions, contributing to less than optimal treatment.” Funding limitations and restrictions on the use of medical escort services result in lack of important information sharing, potentially resulting in health risks.

**Lack of formal education.**

Although the women at Rolling Hills are known to be at risk for and many do have medical comorbidities, the care providers and home operators are not supported in attaining formal education to manage these conditions. The underlying assumption embedded within the organizing texts for group home care provision is that residents only have mental health problems. In the group home, however, there are residents with diabetes who must be cared for, and a structured process for medical management of this condition is in place (as seen in the above vignettes).
The process of diabetes-related knowledge sharing.

Carol has attained experiential knowledge over the years of caring for people with diabetes in the home. She learned insulin pen and glucose meter usage from residents that had them when they entered the home, and through reading package instructions. She also assimilated information from verbal discussions with the family physician, and through written materials brought back to the home by residents after their diabetes clinic appointments. “Medical conditions, they (funding bodies) don’t educate us on that. So we have to go and find our own information and a lot of the information unfortunately that we’re given doesn’t apply to the homes because of the cost factor” (Interview with Carol). Nutritional information gleaned from diabetes experts is not deemed by the home operators to be useful due to the added cost associated with dietary recommendations.

Diabetes care is a structured process that is organized by Carol through use of experiential knowledge, and carried out by staff members, who, in turn, gain knowledge and skills on the job. For example, Carol gave this description:

Today I got up around 6:30...I had a staff member in that’s only here one day a week. So basically I had to oversee her giving morning meds and I had to teach her how to do the insulin because she had never done the insulin pens before. On top of that on Wednesday mornings and afternoons we record our blood sugars for our diabetics so I had to teach her how to test blood sugars. (Interview with Carol)

A sheet is posted in the kitchen so that staff members can read what to look for if a resident’s blood glucose is dropping low, or if they are too high. She also reviews with staff her understanding of how to treat a ‘low,’ and what to do if a resident’s blood glucose is too high. Once trained by Carol, staff teaches other staff members and the residents how to use glucose meters, and how to monitor for signs and symptoms of out-of-range blood glucose levels.

Staff members enter into this role with varying degrees of diabetes-related experiential knowledge. Phoenix stated,
My grandmother was a diabetic (laughs) so I kind of know what to look for umm and everything I’ve read about it, diabetes, when the blood sugar’s really low that’s when they’re heading for a coma or possibility of a coma…I used to give my grandmother her needles…Her eyes got so bad she couldn’t see the needles anymore. It’s in my family. (Partner’s) father is a diabetic too. (Interview with Phoenix)

There is awareness among the care providers of the seriousness of this disease, noting blindness and hypoglycemia as associated complications, and that family history increases risk for developing the condition.

Another staff member previously owned a residential care facility and worked at two group homes for her mother-in-law. She described her process of gaining diabetes knowledge.

Oh, (I learned) just through our elderly clients (at previous job). It was all hands on…we had insulin diabetics there and I learned how to do the blood sugars, and the repetitiveness of it. It just becomes so familiar…(mother-in-law) would just fly, like you saw how urgent it was, and she used to tell me when she was a student nurse how they would just pound it into their heads about the insulins and (glucose) being low. She always used to say low is dangerous. (Interview with Itty Bitty)

This care provider also associated the use of insulin with added potential of hypoglycemia, and its significance for urgent action.

Susan, another care provider, had no previous diabetes experience.

Umm basically I think from my own point of view coming in here basically it was stark naked with no experience at all…I was a mortgage broker before I came here, and then office experience before that. So there was nothing in the health care field at all other than working with (my) kids, which is great because (here) you’re working with little kids in big bodies. That’s the way I always look at it. (Interview with Susan)
Staff members gain local knowledge and understanding of how to care for the residents and how to relate to individual particularities, which is essential. However, the strength of this knowledge varies from provider to provider and depends on biographical experience, knowledge gained from previous work, and availability of on-the-job learning.

**Disconnect between experiential knowledge and best practice guidelines.**

As indicated above, diabetes treatment decisions are based on experiential knowledge. Fine-tuned experiential knowledge is superior in its ability to inform individual particularities. However, formal knowledge about diabetes is also required as an adjunct to ensure health and safety. Participants were concerned about the limitations of experiential knowledge, particularly when conflicting messages were given to residents when decisive responses were needed for fluctuations in blood glucose levels.

*The people here are hearing from Carol, they’re hearing from me, they’re hearing from whatever other staff is on, and depending on their degree of experience, everybody has a little bit different opinion or approach as to how they’re gonna do something…everybody (needs to be) on the same page because they need to hear that. They don’t need to hear, “Well, you can have a chocolate bar, that’ll put your sugar up” (to treat hypoglycemia) and somebody else saying, “No, that’ll take too long you need to do this.” Everybody’s opinion needs to be the same. Everybody’s advice needs to be the same. (Interview with Susan)*

Care providers voiced concerns that different messages may be given to residents. Participants, including the residents, also expressed their desire to have more diabetes-related knowledge to better manage the condition in the group home. Without having access to formal knowledge, there may be confusion over how best to treat acute complications if they arise at the local site. For example, there is a specific safe and effective treatment for hypoglycemia that does not lead to weight gain. Having formal knowledge may benefit the women with diabetes and reduce health disparities if utilized in such a manner that blends with the highly particularized local knowledge. Also, echoed throughout the interview data was the desire for formal education on healthy eating, which may assist with the prevention of diabetes and the
management of the condition in the residents who are already afflicted. The complexities around food provision are discussed further in the next chapter.

**Medical/Psychiatric Disconnect**

The women in the group home require both medical and psychiatric care, and these are organized separately. This poses issues for diabetes prevention and management. The family physician takes care of the majority of the residents’ medical needs, while two psychiatrists manage most of the mental health needs at Rolling Hills. The psychiatrists follow best practice guidelines for mental health care. In doing so, the newer atypical antipsychotic medications are prescribed because they provide relief of psychoses without the extrapyramidal side effects associated with the older agents. First generation antipsychotic agents were known to cause tremor, muscle rigidity, restlessness and flat affect (Canadian Pharmacists Association, 2012). According to Dr. P., “The vast majority, out of 26 patients, 20 of them are on atypical antipsychotics. Those are all prescribed by the psychiatrist that sees them.” However, the psychiatrists do not screen, nor are preventative measures in place to counteract the known metabolic side effects associated with these medications. When asked if the psychiatrists screen for any metabolic risk factors, Dr. P. responded, “No, not normally, the psychiatrist doesn’t order blood work as far as I know, nor does he watch weights or blood pressures.” Thus, people are prescribed atypical antipsychotic medications by psychiatrists and monitored by the family physician as their weights and blood glucose levels climb until they eventually develop associated metabolic illnesses, including diabetes.

The problems of weight gain and development of diabetes with the use of atypical antipsychotic agents have been recognized since the introduction of these medications. Lolly, the retired HSC field worker shared what she recalls.

...When new meds came on-site in the 2000s...we’re given some sort of literature to look at...read sort of as a check off list, and then kind of ignore...because the doctors know what they’re prescribing...we...start seeing the clients gaining weight...And that grew to the point where we could pin-point people, they must be on Risperdal or Clozapine or something...we start to notice...an increase in high blood sugars...We kind of know maybe it’s the medication...GP’s (general practitioners) continue to renew the medications. We had a psychiatric
consultant... who would see them about every three or four months. He noticed it too, the weight gains and the higher blood sugars and he was well aware that it was because of the medication. But what do you do with that?... Do you resolve to the fact that that’s the way it is? They have to take their medication, so they have to gain weight and they have to have higher blood sugar? (Interview with Lolly)

This quote highlights the increasing awareness of the risks associated with the use of atypical antipsychotic medications since their introduction. However, it also shows the inaction on the part of those overseeing the program and the psychiatrists providing treatment to initiate proper screening processes, to make potential changes, and to provide education for care providers. Although atypical antipsychotic medications are known to cause diabetes, they continue to be prescribed as part of best practice guidelines. Monitoring for associated risks is not integrated into the everyday psychiatric practice, nor is preventative action taken, although the American Diabetes Association put these recommendations forth in 2004. Over time, these individuals often develop medical conditions, like diabetes. They remain on the atypical antipsychotic agents, and antihyperglycemic medications are prescribed. Eventually insulin is added when the oral agents fail to control the medical condition that was precipitated, in part, by the psychiatric medications. Essentially, those who provide care for the mentally ill have placed their patients at risk for chronic, life-threatening, debilitating medical conditions, and subsequently have not taken steps to reduce the iatrogenic health disparities.
Psychiatric and medical care is organized separately, which creates health disparities for people with both medical and mental health needs. Additionally, although the Ministry of Health and Long-Term Care financially supports both mental health care and diabetes care provision, there is no connection made in policy documents.
Summary

To conclude, this chapter has made visible the points of disjuncture in the prescription of diabetes care in the best practice guidelines and subsequent treatment modalities in clinical practice, to that which is seen within the group home setting. Diabetes practice guidelines do not facilitate best care for mentally ill adults who reside in group homes because the text is presented in a format that decontextualizes and individuates the problem. Furthermore, mentally ill adults are not recognized as a population that requires special attention. Also illustrated, both diabetes and group home care guidelines and the resultant sequences of action are organized by regulations and restrictions that ultimately ration the amounts of available care, money, and opportunities for health. In effect, this leads to health disparities. It is ironic to have policies stipulating strict surveillance of homes’ cleanliness, and fire and food handling safety processes, while neglecting other health threats, such as diabetes. Further, some regulations governing group home care are contradictory and create unsafe situations in their manifestation. Instead of organizing diabetes activities around meals and medication timing, glucose levels, and activity levels, as prescribed in diabetes guidelines, work is organized around regulations regarding medication administration, safe insulin injection, and budget restrictions. Exclusionary processes are also seen because some homes do not assume diabetes care responsibility and others do not accept residents with diabetes. All of these processes create and sustain inequities in health-related care for the mentally ill, an issue that is revisited in the next chapter.

Finally, instead of linking treatment regimens, both psychiatric and medical care practices are organized separately, potentiating health disparities. Those treating and overseeing care in group homes are aware of the risk associated with the use of atypical antipsychotic medications, but do not take preventative measures. Thus, metabolic changes occur, with noticeable weight increases and the development of such conditions as diabetes. Atypical antipsychotic agents continue to be given, and further medications are prescribed to address the medical conditions. Over time, these chronic conditions worsen and associated complications develop. Key components of diabetes prevention and management are dietary intake and physical activity. Budget restrictions and other forms of rationings factor heavily on decision making regarding these practices, with cost containment overriding competing interests that would promote health and wellbeing. This issue is explored in the final findings chapter.
Chapter 7
Dietary Intake and Social Participation: Rationing and Regulations

In this chapter, I examine the regulations and rations that organize physical activity and dietary intake in group homes for people with mental illness. Funding bodies have an overarching interest in cost containment: This creates social conditions that not only impede exercise attainment and dietary balance, which are integral components of diabetes management, but perpetuate health disparities and social inequities. Extreme budgetary restrictions make meeting nutritional recommendations impossible, which results in poor dietary intake. The residents also lack agency over important aspects of health such as food choices and health promoting opportunities, like joining a fitness centre or working in the community. The lack of State financial commitment for important quality of life initiatives makes recreational, vocational, and educational opportunities unavailable, which results in severe inequalities. However, neo-liberal discourses that emphasize the right to freedom of choice are used to distribute responsibility to residents for not participating in exercise. Additionally, since quality of life opportunities are not available, the interest in and significance of food is heightened because it brings pleasure in the absence of more stimulating or rewarding experiences. For those with diabetes, these conditions generate conflict with recommendations for the monitoring and control of dietary composition and intake. This issue is investigated, as it also brings to the forefront the individuation of diabetes as a problem, similar to what is observed in the diabetes best practice guidelines and in the clinical setting.

Rolling Hills: Structured and Unstructured Activities

In this section, notes taken from observations made during different intervals throughout the 24-hour period are combined to describe a composite day and night in the lives of Rolling Hill’s residents. This is followed by a synopsis of scheduled activities to provide an overview of how everyday activities are organized.

It is 6 a.m. and as I enter the kitchen at Rolling Hills I hear the radio playing a song on a local FM radio station. Two women are up in the craft room, one in her pajamas sleeping upright in a chair and the other sitting on the loveseat. As I sit down in the kitchen, Elizabeth is getting
up to go to the bathroom. She sees me, comes out and says, “Oh, hello,” to which I respond, “Hello Elizabeth! How are you? You’re up early!”

Another woman is up, already dressed in her shorts. She states, “I need toilet paper or something,” as she looks in kitchen. She goes off to a bathroom with paper towel as she asks me, “Is it warm out today?” I tell her it’s damp and cool. Elizabeth gets up to go to the bathroom again and then back to her bedroom.

At 6:25 Rose comes out to the kitchen already dressed. She sees me and says, “Hello, hello! How are you?” I say, “Hello Rose!” She carries on getting the coffee ready and putting out the cups and water for pill taking. She goes into the craft room and sees a woman up, and asks her twice “What are you doing up already? Are you ok?” She takes her arm and walks her back to her room. She asks her, “Did you sleep in your clothes?”

Shortly thereafter, the woman Rose escorted to bed is up again, now sitting at the table in the kitchen. She appears dazed, staring straight ahead and at times dosing on and off. It is obvious that she has some cognitive disability and Rose watches out for her. Two more women are already outside having a cigarette in the smoking enclosure.

The woman who is cutting grapefruit states, “I wish we could get blueberries. I love blueberries.” Then she says, “What are you doing Barbara! Don’t use so much paper towel! That’s a waste.” It’s now 8 a.m. and although the staff member’s workday is just beginning with her entrance into the kitchen, many of the women are awake and have been busy for a while. The usual morning routine starts with distribution of medication.

It is 10 a.m. as I enter the craft room where a number of the women sit and watch television at various times throughout the day, and a couple of women are on the couch now. In the middle there is a ‘Lazy-Boy’ rocking chair, where I find Mary sitting every time I visit, like today. Right now she is half-asleep in her chair and will remain there until lunch.

As I walk through the upstairs hallway I see some of the women are lying on top of their already made beds. In the lower level there is another living room; Rose has the ironing board set up along the one end and is ironing a jacket. On the other side of the living room there are two steps that lead to the staff office, two bedrooms, and a hallway that houses five chest freezers and
the snack machines that were brought into Rolling Hills. One machine contains pop; it has two slots for Diet Coke, and the rest are filled with regular pop. The other machine has chips and chocolate bars and all items cost $1.00 to purchase.

At 11:30 a.m. it is still quiet in the common areas. Three residents are making bologna sandwiches for lunch and one woman is boiling water for tea. At 11:45 a.m. the bell is rung and the residents enter the kitchen from different areas. The staff member opens up the medication cart and calls out names one at a time to take pills. People eat quickly, drop their dirty dishes in the plastic container, and then disperse from the kitchen. By 12:05 p.m. the women who are responsible for cleaning up start to wipe the tables and wash the dishes. Some women go to have a cigarette outside. As I wander through the house, I see that a few women are resting on their beds, and another is sitting at the side of her bed doing cross-stitching. In the craft room, two women are playing a card game, two are on the couch watching “The Price is Right,” and Mary is sleeping in her chair.

The rest of the afternoon continues to be quiet until 3 p.m. when snack is served and a lot of women appear all at once in the kitchen, taking their respective seats for tea and cookies. As they finish, each puts their cup in the dish bin and two women proceed to do the dishes and wipe the tables. Again, some women go outside for a cigarette, while others go to sit in the craft room, and still others go to their bedrooms. Once more it is quiet at Rolling Hills until suppertime.

At 5 p.m. supper is served after pills are given, and before long most are finished eating. Two women do the dishes and a couple of others clean up the tables. There are still a few women eating, the ‘slow eaters,’ as the weekend staff member has nicknamed them. By 5:30 p.m. a few women are sitting in the craft room in silence. Mary is asleep in her chair. Three women are outside talking and having a cigarette in the smoking shelter. A couple of others are outside on the deck off the kitchen smoking, and the rest of the women are in their bedrooms.

At 6 p.m. I notice two women have their pajamas on and are already waiting in the kitchen for evening snack. It is quiet and it stays like this until more people start to enter the kitchen at 7:15 p.m., coming from different areas, again taking their seats and waiting for pills and snack. I notice many are in their pajamas. At 7:30 p.m. the staff member returns and opens the medication cart. The women come up one at a time, take their pills, get their cup of juice, and
sit down. Most women go straight to bed, and after dishes are done and put away, the kitchen is quiet once again.

It is 8 p.m. and I notice one woman sitting outside in her pajamas, housecoat, and winter coat having a cigarette in the smoking shelter. Others are inside in their coats over pajamas, and when I ask why, one woman responds, “We go outside to have cigarettes so we just keep our coats on.” The rest of the women have gone to bed after taking their pills and having their bedtime snack. The house is very quiet and it is now only 8:30 p.m. on Friday evening. A few women stay up and watch a movie on Peggy’s laptop computer, and I join them on the couch. Peggy tells me she is now sponsoring a child overseas, and shows me his picture. She explains that she was approached by a person at a kiosk while at the mall, and it made her feel good giving her allowance for this cause rather than spending it on treats. Peggy is extremely energetic, and would like to work. In discussion with Carol, I discover that she had arranged for employment for Peggy at the Humane Society, but funding for transportation was denied by the Domiciliary Program.

The only activity that happens after everyone retires is the occasional woman getting up to go to the bathroom. One woman wakes up through the night and sits on the couch, sleeping in this position until Rose takes her to her spot at a kitchen table for breakfast.

My analytic notes.

The above observations shed light on how a typical 24-hour period unfolds at Rolling Hills. The women who live here are up early every weekday between 6 to 7:30 a.m. and they retire early, with a few staying up late in the common areas. Most are in bed shortly after 8 p.m., even on weekends. Their days are organized around medication administration, meal and snack times, morning chores, and scheduled outings. Breakfast and pills are given at 8 a.m. so the home can be in order by mid-morning. Dishes are washed almost constantly, as 26 women are eating six times a day. Typically, between meals, after dishes are done, and after the morning cleaning and bathing routine, the group home is quiet. Many occupy themselves by watching television, with a few sleeping in upright positions on couches, chairs, or sitting or lying on their beds. Many smoke, and are observed sitting outside having cigarettes, either in the shelter or on the decks. Some pass the time by playing cards, reading, writing in journals, and cross-stitching. Many of their activities, however, are done while sitting, resulting in little expenditure of energy.
There is a desire amongst the women to feel worthy, which was expressed by Peggy by her offering of spending money to sponsor someone less fortunate than herself, and by wanting some form of employment. At Rolling Hills all of the women are unemployed. Employment opportunities are lacking, and even if the women do find work with the home operator’s assistance, transportation fees are not covered by the HSC or the Domiciliary Programs.

The residents continued to participate in the process of rationing in the above observations. To avoid overuse of toilet paper and the added strain on the septic system, each resident is supplied with two rolls per week, which they carry with them when they use the bathroom. One woman finished her roll of toilet paper and was caught having to use the bathroom early in the morning, so decided to grab paper towel instead. Also, while making breakfast one woman watched and told another to stop using so much paper towel, in an attempt to conserve supplies. She also remarked how nice it would be to have blueberries, a more expensive fruit that is sold in small quantities, and thus is not purchased. This rationing, as part of budget work, is articulated further in the section that explores food provision. The snack machines, as they concern the people with diabetes, are also revisited later in the chapter.

**Structured Activities**

Next, I explore structured activities that are meant to provide opportunities to socialize and attain physical activity. Interview data is also used to discover exercise experiences of women living with diabetes.

On most days Carol has at least one activity organized for the women at Rolling Hills. Activities are structured into the weekly routine as follows; Sundays is ‘church’ and ‘movies’ (alternate Sundays), Tuesday is ‘shopping,’ Wednesday is ‘New Directions,’ Thursday is ‘craft program’ and ‘Social Night Dance,’ Friday is ‘bowling’ or ‘shopping,’ and Saturday afternoon is ‘craft program.’ The craft program, also called the Quality of Life Program, is the in-home activity meant to offer opportunities to practice life skills. The scheduled out-of-home activities take place on the same day and time each week. The residents sign up to participate, and their names are checked on the invoice, which is used for billing The Ministry of Health and Long-Term Care for applicable costs. Generally, the same women go on most of the outings, while others go only occasionally. A few do not leave the home except for mandatory appointments and the annual picnic and Christmas party. Staff does not accompany residents on these outings.
Rather, physical and mental wellness and suitability to go on an outing is determined by the home operator and care providers. The outings that provide exercise are discussed next, along with the budget work in which residents participate while shopping for clothes.

**Shopping.**

Shopping trips are scheduled twice per week and are meant to give the women at Rolling Hills an opportunity to do something they enjoy outside the group home, while getting exercise. The trip to the local strip plaza is organized to coincide with Friday morning bowling, so the women have a choice of participating in one or the other. The amount of physical activity obtained while shopping is captured through residents’ experiences, derived from notes taken during an observational study at the mall.

The bus lets the women off in front of Zellers for their shopping day. Mary is out today shopping for winter tops with her $300.00 bi-annual clothing allowance (this includes tax, leaving an actual amount $261.00 to spend). She is visibly short of breath as she walks around pushing a shopping cart, looking at clothes. She has walked from the bus to the women’s clothing section, which is to the left just beyond the front entrance. She searches through all the racks of tops, and tells me, “I’m 3X and I can’t find any long sleeve shirts.” I find three tops in her size, and she decides to buy them because there are no others. I notice her at 11:50 a.m. sitting on a bench inside the mall, trying to catch her breath. She has just returned from the food court upstairs, where she got a burrito for lunch. The food court is about a five minute slow-paced walk from Zellers. She has her one bag of purchased items and is waiting to go home. The bus comes at 1:15 p.m. and she will, between now and then, walk to the front of Zellers to wait for the bus outside.

Another two women, Lola and Jai, stop to have a cigarette outside upon arriving at the mall, then promptly go to the Zellers restaurant just inside the entrance. These women are roommates and they do everything together. They have coffee, Pepsi, and hamburgers and spend the entire morning sitting in the restaurant. Around 12:30 p.m. they venture out to look at the costume jewelry, which is on display at the front of Zellers just outside the restaurant where they have been sitting. They buy some jewelry and then walk out and sit on the pavement against the wall of Zellers for the remainder of the time, having cigarettes and watching for the bus.
Bonnie tells me she doesn’t have any money. She stays around the front of Zellers until 12:30 p.m., at which point I give her $1.50 and she happily sits in Zellers restaurant enjoying her coffee until the bus comes. All but one of the other women spend the majority of their time in Zellers shopping for clothes. Some residents assist those who are less capable, while others shop alone. Carol has set up accounts at Zellers so the women do not need to carry large amounts of cash and she does not have to pay out-of-pocket for the purchases. At this store, the account can be paid once approval is given and funding dollars are received (which is often months later). The women who have items to purchase begin lining up at 1 p.m. at Customer Service. Violet has a shopping cart full of clothes and keeps the cashier busy switching items that have already been rung through in favour of other items. Her allotted $300.00 is spent quickly and she, like the other women, has to leave many items on the counter. The cashier is patient, and seems seasoned at helping these clients with their clothes shopping. She has each of them sign for the clothing before they leave to catch the bus.

*My analytic notes.*

The shopping trip is an opportunity that can enable exercise, but as noted above, the women generally only ventured from Zellers to the food court and back because their clothing accounts are in this store and they can also purchase other affordable items. A few of the women did not do any walking aside from going in the front doors to Zellers restaurant. None of the women went throughout the entirety of the mall. Residents also participated in budgeting work around clothes, and cashiers at this economical store joined them in this work. Given the low funding entitlement for clothes, stores that have more expensive, higher quality items are unaffordable. This store will also wait for payment, which works well with the clothing allowance, as it is paid to the home operator after the bill is received and approved. Noteworthy, the field workers in the HSC Program, as part of their work, monitor expenditures and check residents’ closets and drawers to determine if new items are necessary. In my opinion, this process is an unnecessary invasion of privacy, in view of the extremely low funding allotment for clothes. In contrast, it is unlikely that the maximum $600.00 per year is enough to cover clothing costs.
Social Night.

Social Night is the most anticipated weekly event, held on Thursday evenings. On this particular night, there are 15 women from Rolling Hills attending the dance. At 6 p.m. the school bus stops at the end of the driveway and they walk down to get onboard. When the women arrive at the hall they disembark, and a few stay out front having cigarettes while they wait for their acquaintances from other homes to arrive. People get dropped off one school bus at a time, with a total of five buses and approximately 120 people attending tonight’s event. Everyone seems to have their own routine, either entering the building or standing outside for a cigarette.

The hall is sectioned off and the dance is in the far hall, a big room that is dimly lit. The disc jockey is set up on the south wall, and the dance floor is in the middle, and the snack bar is on the west wall. The women from Rolling Hills are seated in different areas, some taking a spot with others from their home, while others are scattered, mingling. Anne and Violet, two women with diabetes, line up at the snack bar as soon as they enter the hall and purchase large bags of potato chips and regular pop before they take a seat with their male friends.

When the music starts to play people from Rolling Hills do not get up to dance right away. After a short while, a couple of the women get up to dance with partners. Most of the women choose a spot and sit there for the evening, getting up every so often to go outside to have a cigarette or to go to the snack bar. The younger three women from Rolling Hills sit together and dance in a group for a few songs throughout the evening, with a couple of them occasionally dancing with men. A few other women, including Violet, Anne, and Rose from Rolling Hills, sit and socialize with their male friends, getting up periodically to dance. The dance lasts for two hours and people automatically start making their way outside to the buses about 8:15 p.m. By 8:30 p.m. the buses are loaded up and everyone is driven back to their respective group homes.

My analytic notes.

The Social Night dance is another opportunity for physical activity while socializing with other residents. Many of the women from Rolling Hills got up to dance periodically. A few of the women danced more often and more actively than others. They also wandered out to have a cigarette every so often, and made a trip or two to the snack bar. The residents view Social Night
as their opportunity to socialize with men and other women outside of the group home. As reported by study participants, they also enjoy buying the treats, having a free coffee, and chatting while listening to the music. However, beyond this planned social activity with residents of group homes and New Directions (a meeting place that residents attend), there is little contact with other people. Also, because this is a rurally located home and easy access to transportation is not available, there is little opportunity for the women to do things outside the scheduled activities.

A Synopsis of Rolling Hill’s Activities

To summarize, the women at Rolling Hills are generally very sedentary. Walking is encouraged (as will be discussed next) and in good weather it is structured into the routine twice per week when feasible. There are evident attempts to engage the women in physical activity, and the home operator is mindful of the benefits of exercise and recreation. Exercise videos are visible amongst other DVDs, and a karaoke machine sits in the craft room. Carol purchased an air hockey table and a ‘Wii Fit’ game system, which they use “…sporadically in the beginning then it wears off” (Carol). There is a pool table downstairs, and outside there is a basketball court. There is also a walking path in the back of the property. The home itself is spacious with two large common areas, and 13 acres of property to engage in various activities, such as outside games and gardening, if desired. Carol stated that only a couple of the women maintain an interest in the gardens. Carol has a swimming pool for personal use, but for insurance reasons, residents are not allowed to enter the enclosure.

Activities like Social Night, shopping, miniature golf, and bowling trips are structured into Rolling Hill’s routine. However, as shown, minimal exercise is often attained, depending on the resident and on their physical limitations. Other outings, such as going to church, the movies, and New Directions, do not offer opportunities for physical activity. However they do enable engagement in enjoyable pastimes for the women outside of the home, while fulfilling spiritual needs and providing entertainment. The residents anticipate and enjoy the scheduled outings. The in-house craft program focuses on baking, cooking, and making crafts, and exercise is periodically fit in. The governing bodies do not offer funding for social, vocational, or educational opportunities that would enable interaction with people outside those living in or
affiliated with the group homes. As noted, if residents are able to find employment, transportation is not available.

The busiest times at Rolling Hills are meal times and weekday mornings. Some women keep active doing their respective jobs, like preparing food, setting tables, doing dishes, wiping furniture, and mopping floors. A few women choose to take on many chores and several do the minimum of bed making and bathing, which is also dependent on physical and cognitive limitations. Most of the women spend the majority of their time sitting, either in the common rooms or bedrooms, or outside, often while smoking: Of the 26 residents at Rolling Hills, 18 smoke, as reported by Dr. P. Other hobbies include cross-stitching, reading, writing in journals, spending time on a laptop computer, and watching television.

**Physical Activity: The Women’s Perspectives**

This section uses interview data to explore patterns of exercise within the group of women with diabetes. Among the 10 participants, seven shared their everyday experiences related to obtaining exercise, two declined interviews at the outset of the research, and one woman did not address physical activity. Any perceived barriers to exercise are highlighted, as this may affect their ability to engage in certain activities.

At Rolling Hills, the women with diabetes are encouraged to walk, and they are aware of its importance for illness management. Michelle, a young woman who is considered obese by health providers, commented,

*...the reason why I came here in the first place is because at home I’d fall asleep at 3 or 4 (a.m.) and I’d get up at 3 or 4 in the afternoon and it wasn’t good and my mom didn’t like that...(staff member) makes me go for a walk after every meal. I try to, but sometimes I find that I don’t want to go...umm ‘cause I’m lazy.*

*Interview with Michelle*

Michelle’s understanding was that her lifestyle behaviour patterns resulted in placement at Rolling Hills. She is aware that she is expected to go for walks and stay awake through the day, and she is frequently reminded of these expectations by staff.

Mary, a middle-aged woman, who is also considered obese, stated,
I do not do much. I just sit down in my chair...It’s in the living room...Sometimes I read, and sometimes I just listen to the music...I should be walking, but I don’t...
Yes, Dr. P. (says I should), but I don’t walk...I don’t know why...It’s just the activity itself (I don’t like). (Interview with Mary)

Mary is aware that exercising would improve her health, and she too is constantly reminded of this by the physician and others overseeing care. When I asked her if there is anything she would like to see included in her day that would help with activity, she stated, “I would like there to be more that I do, that’s the only thing that I would like.” Mary emphasized that she is bored and wants something more stimulating to do with her time.

Anne and Tulip walk inside the home and up and down the driveway for their main exercise, while Rose keeps busy doing household chores.

I walk...sometimes down the driveway and sometimes through the house a hundred million times. I’m always going back and forth, you know, from my room to different places and uhh I go up and down the stairs a little bit. (Interview with Anne)

...I listen to my walkman to play music...if it’s good weather I walk up and down the driveway about 30 times...when it’s my laundry day I do my walk up and down the stairs...I’d rather try to keep myself busy instead of always making other people tell me what I should do. (Interview with Tulip)

These two quotes indicate that the women have absorbed the message that exercise is an integral component of diabetes management. They also point to the lack of opportunities available for keeping busy, aside from walking, hobbies, and doing chosen chores. The other women with diabetes also described their exercise experiences as primarily doing household tasks, such as dishes, vacuuming, and food preparation, and attending scheduled outings.

The women explained that physical limitations restrict activity. Rose reported,

...I don’t (walk outside) in the winter time because um subconsciously I do always have that fear of falling. I’m well aware that I cannot do any more damage to my
hip or to my leg... One leg’s shorter than the other by about an inch. (Interview with Rose)

Margaret, who has become increasingly frail and has poor vision due to diabetes complications, stated,

_ I go for a walk after lunch. It’s down the driveway and back. That’s all I can handle right now and Dr. P. said that was fine. “We don’t want you to happen to fall,” you know, ‘cause I’ve had a lot of falls. (Interview with Margaret)_

Anne uses a cane for assistance, and Violet is unsteady, and has broken her foot three times.

To summarize exercise patterns in this group, the majority of the women living with diabetes at Rolling Hills have knowledge of the importance of physical activity for illness management. Walking is the primary form of exercise offered, but some women resist engagement. Other in-home activities include hobbies and household chores that the women volunteer to do, like meal preparation, vacuuming, and dishes. Most of the women with diabetes engage in the weekly out-of-house activities, which offer mild exercise through walking while shopping, dancing at Social Night, or bowling.

**Physical Activity: Perceptions of Those Providing Care**

...the residents don’t own homes. They don’t have a regular family life. They’re in a group home setting. That’s their home...They don’t work. They don’t go to school. So this just automatically answers the question (that they have more sedentary lifestyles than the general population). (Maria, Hostel Worker, Domiciliary Program)

There was consensus among care providers and those overseeing care that group home residents are inactive, and for overall health and wellbeing they must increase levels of activity. They also acknowledged that residents have few meaningful, fulfilling opportunities in which to engage. As reported above, they do not work or go to school (due to cognitive limitations, lack of available jobs, and/or access issues), and in many cases do not have social interaction with family or friends. However, residents are often faulted for lacking motivation, instead of viewing this problem as stemming in part from budget restrictions that serve cost containment interests of
the Ministry of Health and Long-Term Care, the Ministry of Community and Social Services, and the regional government. In this section I present the care provider perceived barriers to exercise. I then highlight how implied rationing within the group home care guidelines creates tension. Alignment with the outlined regulations regarding physical activity and quality of life is not possible given the lack of funding. Also, Mary’s statement, “I would like there to be more that I do, that’s the only thing that I would like,” is expressed by others and this data is presented under the separate heading ‘something to do and places to go,’ to show how, without prospects for social participation outside the group home, it is difficult to sustain motivation and interest.

Among the residents, those with diabetes who are considered overweight or obese are encouraged to walk to lose weight.

...So today’s Wednesday and it’s the first morning she didn’t climb back into bed for a couple of hours...She’s very compliant. She knows she’s not to lie on the furniture, but she sat up in the craft room and slept all morning...I’m trying to get her on a routine of walking after every meal while the weather’s good... And every time I went in there, “Have you had your walk yet?” and she’d just shake her head, “No.” And so finally it’s was about 11 o’clock I got her up to do dishes. (Interview with Itty Bitty)

Staff members understand that weight loss positively influences health, and so they encourage the residents who are overweight and have a diagnosis of diabetes to exercise. Walking is the primary activity offered at Rolling Hills, and the residents do not readily integrate this exercise into their routine. Lack of motivation is the suggested reason for this lack of engagement.

Field workers also encourage residents to walk to lose weight and to reduce the risk of associated illness, reiterating the theory that lack of motivation is the root cause of inactivity.

If the resident is not willing to participate, again, there’s not much we can do. Some homes, it’s through the doctor. I’ve tried. The staff has tried to get them to just walk, you know, to the end of the driveway one day. Then do it twice, or go to the corner. And it’s like pulling teeth. Again, it depends on the resident. And some of these, especially the women, get so big it’s hard for them and I think this is what holds them back. They get out of breath just walking from their room to get
to the kitchen. And you try and explain the reason you’ve got to exercise.

(Interview with Laura)

Although the providers and staff promote exercise, there are few available options besides walking and some residents choose to not participate. As Laura suggested, there is reluctance to enforce physical activity because it would infringe on residents’ freedom of choice. The next quote also points to the awareness among those in charge that residents have little opportunity for participation in stimulating, interactive activities.

When the majority of your clients are schizophrenic it’s hard to motivate them and have people being active when in the household there’s very little to do other than going from maybe couch to kitchen, to their room and back. You know you can only…encourage so much. We can’t force anybody to do anything. (Interview with Lolly)

Although the right to individual choice is ostensibly privileged where exercise is concerned, it is also the pivot that shifts responsibility to the resident if she chooses not to engage in walking. There are no available options that offer full social participation, like going to a park or community events, or joining team sports. Even if approval is given to cover the program cost (if applicable), transportation fees are not provided. Societal attitudes also complicate this intersection of issues:

…the other thing is a community perspective. “Oh there’s a home and they make them do 10 sit-ups a day, isn’t that cruel?”…We certainly have been exposed to that…or “they make them all walk around the block every day. Isn’t that demeaning?”…and these are things that come up and being beneficial to someone’s health is just a minor detail, you know, you have that, as I say, that community perspective. (Interview with Lolly)

Thus, health benefits of physical activity are also balanced with negative community reaction. In this quote, societal attitudes appeared to take primacy, according to this former employee of the Ministry of Health and Long-Term Care.
Care provider time restrictions further limit the ability to look beyond mandated responsibilities.

_We have to remember they (the home operators and care providers) are very busy people because they have to run the basics of the home, the food supplies, the medication, the daily cleaning, cooking, so umm this (exercise) is just above and extra added onto their daily duties._ (Interview with Maria)

Licensing is not contingent on resident attainment of exercise, whereas other tasks must be completed to meet certain regulations (as reported in Chapter 5), and priorities are set accordingly. Budget limitations also restrict the feasibility of hiring extra staff to supervise exercise.

_Exercise is extremely time-consuming because of the encouragement you have to do and you don’t just go and say, “Let’s go for a walk.” You’re a half an hour talking people into going for a walk...I have to pay extra staff to come in because they’re leaving the property...And it’s that taking the time to collect them up...You’re dragging them off their beds. They don’t want to do this._ (Interview with Carol)

My observations, which were confirmed by Carol, are that in general the women walk slowly a total of 10 minutes per day. As reported earlier, the funding allotment is already approximately $8,000 per month lower than required to meet the stipulated staffing ratio (based on four employees on the premises 24 hours per day at minimum wage of $10.25/hour), hence Carol cannot afford extra staff to manage an exercise program.

Canadian weather is also perceived as a physical constraining element to obtaining exercise at Rolling Hills. The women tend to go up and down the driveway because it is a paved surface. “…you’re living out in the country. You’ve got the icy conditions. You know, it’s very, very difficult to walk on that driveway in the winter” (Interview with Susan). The primary location for obtaining exercise, the driveway, is off-limits for approximately six months of the year, due to unsafe conditions.
Further, weather constraints and not having opportunities for exercise or full social participation is perceived as creating health disparities.

_I find from January ‘til April you notice a massive difference in health and mental attitudes...Blood sugars go way up, the weights go way up, because they’re not getting outside...They’re fighting with each other because they’re not getting out and about as much. They’re stuck in the house._ (Interview with Carol)

Along with physical changes, the noticeable decline in mental health was reported with the increased confinement and isolation during winter months.

This actuality contradicts a governing principle, which states, “The development or enhancement of life skills shall be encouraged through a range of structured basic skills developing activities, social and recreational experiences, and vocational training which reflects individual needs, desires, interests, and abilities” (MOHLTC: Operating Guidelines for HSC, 2003, p. 28). The HSC Program is supposed to, “...promote and enhance quality of life” (p. 4) and provide environments that allow residents to, “...grow and develop” (MOHLTC: Operating Guidelines for HSC, 2003, p. 4). Yet, isolation and lack of opportunity for personal growth and development are actual outcomes of an overarching interest in cost containment. These social conditions perpetuate symptoms of mental health distress, thereby increasing health disparities.

Further, within the group home care guidelines, the following regulations deal with resident attainment of physical activity. These regulations cannot be actualized in a climate of funding restrictions.

_The Home Owner/Home Staff, in cooperation with HSC Field Staff, shall be aware of programs and activities, which promote adequate levels of fitness within their communities...Residents are encouraged to participate in activities and programs, which are of interest and appropriate to them and their level of fitness, if they so choose...The Home Owner/Home Staff, in conjunction with the HSC Field Office, shall assist residents to access resources and activities appropriate to their needs and interests, if so requested._ (MOHLTC: Operating Guidelines for HSC, 2003, p. 30)
The regulations stipulate residents are to have knowledge of and be able to access exercise opportunities. Responsibility is distributed to the home operator and field workers to facilitate this process, but the onus is also placed on residents to choose to become involved in programs and activities of interest that are appropriate for their level of fitness. However, there is no written commitment by the Ministry of Health and Long-Term Care or the Community and Health Services Department of the regional government to provide financial support. At a regional council meeting, where all requests are addressed for the Domiciliary Program, a home operator asked to use the monthly $50.00 per resident (which is already provided for recreational activities) for gym memberships. This request was denied, and the cost of transportation refused, as reported by Carol. Without funding for transportation and to cover the cost of exercise programs these processes cannot be carried out.

The field worker acknowledged that the Ministry of Health and Long-Term Care does not provide funding for transportation or for gym memberships for the residents. “…We promote it but…You know, one wants to join the gym, we don’t cover that cost. The bottom line is, we say, ‘Go walking, be it a short walk. Walk to the kitchen 10 times’” (Interview with Laura). Highlighted again is the lack of opportunity for meaningful activity due to lack of funding provision for exercise initiatives. In this light, resistance to engage in this form of exercise seems reasonable; maintaining motivation and interest given a lack of interesting options would be difficult.

Field workers are aware that group homes in urban areas have more opportunities than the rural ones. This inequity was linked directly to cost by the retired HSC field worker.

(They are) drastically, drastically (different). In the city there’s just access and availability. You know even if there’s a cost to attend a program, it’ll be quite a bit cheaper than having a very rural setting with someone wanting to go somewhere. And it’s usually the rural settings where we get into the (school) bus load of clients going somewhere…again community perspective is it’s demeaning (adults riding in a school bus), and it’s very expensive…definitely the urban settings, much cheaper all the way around. (Interview with Lolly)
Societal attitudes and cost containment shape decision making about exercise. Residents living in urban group homes are able to walk or use inexpensive public transit to access amenities and community programs. Lack of financial support creates and sustains inequities by making similar opportunities inaccessible for residents in rural settings. However, when another rural home operator proposed purchasing a bus if the HSC Program would approve reimbursement for the cost of gas and driver wages, this request was denied due to conflict of interest, with concerns centering on the home operator potentially making a profit (Carol).

**Something to do and places to go.**

...it’s the freedom is pretty hard...We can’t get anywhere we’d like to go ‘cause of the cost, ok? And I would love to see the bus come so that we would have the chance to go downtown (to the park that has a little lake) in an afternoon and spend a couple of hours and come back...Just to go down there and walk and have a coffee, it’s just a change. That would be nice. (Interview with Margaret)

The residents voiced their desire for a simple change in routine, for example, to be able to leave the home for a short period of time and get coffee. This modest wish requires easy access to transportation, which is unattainable in a climate of cost containment.

Sometimes the care providers attempt to do something out of the ordinary with the women.

*We’ll get the music going, and Peggy will get them dancing around the kitchen or the craft room...we turn it up, we don’t keep it low, we turn it up and all of the sudden they start coming out of the woodwork. And they’ll be up there dancing.*

*(Interview with Phoenix)*

A different, livelier activity that involved music and interaction with the care providers changed the level of enthusiasm and many of the women readily engaged.

In another rural group home, men became involved in vegetable farming as a form of exercise and as a way to collect income.
Now we have a farm like setting that the clients were very involved in the farming...They had a reward with seeing what they did with the farming...They could go to a farmer’s market and sell their produce and keep the money. It kept them outside, kept them active, kept them very, very healthy physical wise, more so than other homes. (Interview with Lolly)

Residents, like the general population, are more likely to engage in activities that are stimulating, entertaining, or rewarding. Highlighted is the observed improvement in overall health and wellbeing in residents who were given the opportunity to participate in a physical activity that offered not only exercise, but also the experience of seeing the produce grow and being able to enjoy eating the foods. The residents also participated in selling the excess food at the market, gaining social and money handling skills along with the benefits of earning a wage.

To summarize, physical activity at Rolling Hills, other than for scheduled outings, is limited by location and budgetary restrictions. The residents tend to be very sedentary, in spite of attempts to engage them in walking and other in-home activities. They obtain approximately 10 minutes of low intensity exercise per day, which is less than the recommended 150 minutes of moderate-to-vigorous activity per week (CDACPG, 2008). Although group home care guidelines state that resident quality of life is a priority, alignment with related regulations is difficult due to the overarching government interest in cost containment. Funding is not available for transportation for recreational, vocational, and educational opportunities, and the cost of programming may not be covered. Although the right to freedom of choice is used by those overseeing care as a means to devolve responsibility to the residents for not engaging in walking, in actuality the women do not have the option to join a gym, attend a community event, or take a walk in the park. Negative societal attitudes are also factored into decision making over exercise for health benefits by those overseeing care. Further, aside from the socializing with residents from other group homes at Social Night and New Directions, there are few opportunities for full social participation.

Social Night, the one activity that enables social interaction with other residents, was suspended as of July 11, 2011 until further notice. This decision was made by the HSC Department upon realization that the resident to staff ratio was too high, posing potential safety concerns. Rather than increasing funding for the Social Night to hire more staff, home operators
were informed to arrange, provide, and absorb the cost for escorts for this program and other outings. Carol, as part of her work within the Home Owner’s Association contacted the Senior Housing Analyst at the Ministry of Health and Long-Term Care, who, in turn, spoke with the HSC Department. After review of the guidelines, the residents were allowed to continue all other outings unescorted at the operators’ discretion. However, eight months later as I write this thesis, Social Night remains on hold. This was the main activity that offered residents some social participation.

**Diabetes and Dietary Intake: Rolling Hill’s Actualities**

In this next section I explore the imposed budget restrictions and regulations that affect dietary intake within the group home. Along with exercise, dietary intake is central in the management of diabetes. The Operating Guidelines for HSC (2003) stipulates that residents’ nutritional intake must follow recommendations in Canada’s Food Guide. It is also recommended in the “Canadian Diabetes Association 2008 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada” that this text be used to direct nutritional care for those with diabetes. Although Rolling Hills is mandated to use this document, group homes operate on a limited budget, which creates tensions in the attempted implementation of these recommendations. Residents with diabetes cost more to feed and there is no financial support from the funding bodies for substitute food products. Furthermore, food takes on a preeminent role in the lives of the women at Rolling Hills because they lack other pleasures to look forward to. The exaggerated significance of food is explored because it creates conflict when dietary restrictions are necessary for management of diabetes.

**The financial and social organization of diet at Rolling Hills.**

At Rolling Hills, the operator must provide food for a large number of people on a limited budget. As noted, Carol is paid $47.75 per day for each resident. The Ministry of Health and Long-Term Care funding formula is outlined as follows; 59% for administration, program support, services, 4% for raw food, and 37% for accommodation (MOHLTC: Operating Guidelines for HSC, 2003, p. 33). Thus, according to this formula, $1.91 per resident per day is allotted for food. According to Rolling Hill’s financial statement for the 2009 year, $115,975 was spent on food and supplies, with approximately $85,000 of that amount being paid out for
residents’ food alone, which works out to $9.00 per day for each resident. The home operator pays out five times the amount provided for food in the State funding formula.

The Ministry of Health and Long-Term Care’s budgeted allotment for food determines purchasing and menu development, with cost savings being a necessary overriding consideration. Carol does all of the grocery shopping and oversees the monthly food order. To reduce costs, economy grade food is bought in bulk, sale items are purchased in large quantities, and wholesale companies are used. Whole steers are bought from a butcher throughout the year to provide better cuts of meat while saving on cost. Even though it is more expensive than powdered milk, fresh milk is always purchased for use in cereals, soups, and puddings. Affordably priced fresh fruits and vegetables are also bought. As I have indicated throughout this thesis, everyone at the local site engages in budget work to ensure supplies are rationed, waste is avoided, and supplies last until the next food orders are placed. Also, to reduce cost and confusion, meals are generally not tailored to individual needs or preferences. Rather, the same meal is prepared and served to everyone. Residents are allowed to purchase and prepare their own substitute meals, or make a sandwich. The menu at Rolling Hills is discussed next alongside Canada’s Food Guide.

The daily menu: An analysis.

According to the diabetes guidelines, people with diabetes or prediabetes should consume the following amount of carbohydrates, protein, and fat per day; carbohydrates (45-60% of energy), protein (15-20% of energy), and fat (35% of energy) (CDACPG, 2008). Due to the increased risk of coronary artery disease in people with diabetes, restriction of saturated fat to 7% of total daily intake is also recommended (CDACPG, 2008). They are advised to follow Health Canada’s “Eating Well with Canada’s Food Guide,” the 2007 version of Canada’s Food Guide. Recommendations for the number of servings per day within the main food groups for females between ages 19 to 50 years of age are as follows: vegetables and fruit-seven to eight servings, grains-six to seven servings, milk and alternatives-two servings (three for females ages 51 years and over), and meat and alternatives-two servings (Health Canada, Eating Well with Canada’s Food Guide, 2007). I compared the menu at Rolling Hills to these recommendations.

The diet at Rolling Hills offers plenty of variety and a large amount of food, as indicated in the six week menu, a sample of which is shown in the appendices (Appendix H). For example,
on Friday of week one, breakfast includes two slices of toast and cereal. Lunch consists of pancakes and syrup, and an oatmeal muffin, and the supper meal includes fish sticks, French fries, corn, and ice cream for dessert. Cookies are also offered in the afternoon and popcorn before bed on that same day. This aligns with the group home care guidelines, which stipulate three meals and two snacks be provided every day. However, due to the extremely low funding allotment, alignment with nutritional recommendations is impossible.

In examining the diet for essential nutrients, dairy products are lacking. It is recommended that women in this age category have two to three servings of milk products per day. Taking into consideration that milk is used for cereal, cream soups and puddings, instead of getting the recommended 14 to 21 servings per week, they are on average getting six to seven. Also, the recommended number of servings per week of vegetables and fruit totals 49 to 56, and at Rolling Hills they are receiving approximately eight servings of vegetables (including the vegetables in the soup), and two servings of fruit, for a total of 10 ‘vegetables and fruit’ servings per week (residents with diabetes receive more fruits, which are often substituted for the sweet desserts). These findings are not surprising, in view of the severe budgetary restrictions, because milk, fruits, and vegetables are expensive, especially for a group as large as this one. As noted, milk alone would cost approximately $700.00 per month for the residents to each have the recommended three glasses per day.

The diet at Rolling Hills is also low in fibre. Soluble fibre slows down digestion and absorption, thereby improving blood glucose control and post-meal glucose peaks (Rosenthal, 2004). Diets low in saturated fat and cholesterol, and high in fruits, vegetables, and grains with soluble fibre can also prevent heart disease by lowering blood cholesterol, and can reduce the risk of colorectal and estrogen-related cancers (Rosenthal, 2004). Incorporating fibre-rich foods into the diet may also prevent obesity by increasing satiety, thereby assisting with weight loss (Li & Uppal, 2010). People with diabetes should consume 25 to 50 grams of fibre per day, and those without the condition should have at least 26 to 35 grams per day (CDA, 2012).

Finally, three meals and desserts, plus two snacks per day are offered to align with the policy, “Residents shall receive three meals a day, with snacks available between each meal” (MOHLTC: Operating Guidelines for HSC, 2003, p. 13). The home operator follows the regulation because her license renewal is contingent on ensuring the mandated number of meals
and snacks are provided. Field workers also participate in the process, even with the knowledge that this regulation leads to health disparities.

Really, you know, three snacks a day, it’s too much. And most of it’s two, you know morning and the afternoon, but then a lot of the homes do give them something in the evening. So, I mean that’s a lot of food in the day. I know that I can’t eat that much and I love to eat. (Interview with Laura)

Those overseeing care also participate in these social relations of accountability, as they are mandated to ensure this basic need is met.

This regulation plays a role in creating frequent opportunities to eat, because home operators’ interpretation is that it must be followed regardless of whether it may be contraindicated for health reasons. As a diabetes educator, I am aware that regular meal spacing is required and snacks are often incorporated into diabetes regimens. However, the women eat frequently, and of concern is the amount of carbohydrates and fat that is consumed in the process. Some entrée items, like meat pies, fish sticks, wieners, bacon, and luncheon meats are unhealthy choices. Most of the desserts, which include ice cream, muffins, donuts, cake, and pie, are also not optimal choices. The snacks include cookies, chips, and chocolate bars. A diet that is higher in carbohydrates and fat increases the likelihood of weight gain, and works against diabetes management. This is further compounded by the sedentary lifestyle.

Overall, the low funding provision for food impedes healthy eating. Alignment with nutritional recommendations is not possible, given the current per diem amount, of which only $1.91 is allotted to raw food. Recommended daily servings of such items as milk, fresh fruits, and vegetables, which are more expensive, are unattainable. Further, the policy that stipulates a minimum number of meals and snacks prompts home operators to comply by resorting to more affordable foods that are higher in carbohydrates and fat.

**Diabetes-related dietary accommodations.**

At Rolling Hills the women with diabetes are served the same meals as the rest of the home, but are given; a) smaller portion sizes, b) milk in coffee/tea instead of powdered creamer, c) diabetic Jello and pudding, d) fruit or a very small piece of a sweet dessert, and e) Sugar Twin
as a sugar replacement for coffee/tea and cereal. Also, second helpings are not given to this group. Some desserts are made with Sugar Twin, and birthday cakes are only iced on ¾ of the cake, and the women with diabetes get pieces without icing. Snack time changes include substituting diabetic choices for regular cookies and freezies. Additionally, Monday evening chocolate bars are replaced with a diabetic bar. Friday and Saturday evenings diet pop is substituted for regular pop, and everyone receives popcorn and chips. Although they are meant to positively affect diabetes outcomes, these changes may be relatively ineffective considering the amount of food the women consume (snacking as an issue is explored further). Also, treating this group differently from the rest of the residents creates social tensions, as discussed later in the chapter.

**Diabetes: The added cost.**

Residents with diabetes are considered more costly than others, because substitute food products, among other things, are expensive. No compensation is provided for added expenditures. Furthermore, the residents who have diabetes understand their food needs are both different and more costly.

_I guess that I really know my diabetic decisions. Like yesterday I just went ahead and did what I should do. I got the sugar in me fast and decided I’m not going to wait ‘til supper to eat, and I had some macaroni and umm I just got it and put it in the oven. Any food we want we have to pay for it ourselves, but we can have it, right? Now there are sauces...I know I shouldn’t have it... (the care provider) says, “I make one meal and that’s it”...I say, “Look, I’m a diabetic. I don’t wanta eat this. Could I make”...even grilled cheese is not good for me, right? It’s got all the butter on both sides. But living with people here we have to go with it. We can’t speak up and say, “No, this is what I want”...Can’t do it. Like tonight it’s fish and chips. We shouldn’t have that...I ask (care provider) if I can make Kraft Dinner again. And I buy it and I have ½ a serving...what should I do?...we buy it if we want it. But then the other girls say, “Well, how come she can do that?” You know, like, you can’t win....Corn is very, very sweet, ok?...Peas are ok. We should be having brussels sprouts....the green vegetables... (Interview with Margaret)
The home operator and the residents participate in the purchasing of extra food products to manage diabetes. If residents with diabetes desire meal replacements, they use their monthly allowance to purchase them. As noted, some residents have knowledge of how to treat symptoms of hypoglycemia with sugar, followed immediately by a meal or snack. This resident’s knowledge of diabetes appropriate food choices is evident. She knows corn is considered to be a starch that will raise blood glucose and that green vegetables are better for glycemic control. She also works on a limited budget, however, as is evident in her purchasing Kraft Dinner, which is affordable but still an unhealthy food choice. Margaret also comments on her marginal position in not having full agency to make diabetes-related food choices. Other women with diabetes were also concerned about being treated differently because this creates tension with other residents.

The home operator pays extra money for diabetes food products, which are more expensive because they are not sold in bulk size, and the price is inflated for special items.

*Diabetic products are a lot more expensive. There are certain things, like I get diabetic puddings and Jellos...diabetic cookies. I do tend to give the diabetic chocolate bars but they are extremely expensive. Diabetic juice, massively expensive...when you are cooking for this amount it sure is a lot cheaper if you can buy big portions and you can’t with the diabetic products. You can’t get the big cases like I can for the other clients so that really is a problem. Your diabetic pancake syrup...is probably five times the price of regular pancake syrup.*
*(Interview with Carol)*

Furthermore, fruits and vegetables are more expensive during winter months, which must be taken into consideration, as noted next in this quote that highlights more budget work around food.

*They either get a much smaller portion of a regular dessert or...diabetic desserts or...they’ll get a fruit...(taking into consideration) availability of fruit too, right? This time of year there’s a ton of fruit but in the winter time we will probably be just getting bananas and oranges and if there isn’t a lot of them by the end of week, you’ve used them up then you know they’ll get a real plain Jane dessert, or*
sometimes they have to go without, which they don’t like. (Interview with Itty Bitty)

There is no financial support within the programs for food required by the people with diabetes, as reported by the field worker. “As far as the food, you know, the diet cookies, the jams, the sugar free puddings, whatever, a few homes will buy it. We really don’t pay for the foods…” (Interview with Laura). Within these housing programs, the governing bodies do not recognize diabetes as a condition that requires additional support.

With the added responsibility that accompanies this disease and the risk of liability, the out-of-pocket food cost is another deterrent to accepting people with diabetes into the home, or to continue caring for them once diagnosed with this illness. Further, the residents do not have control over food choices, which goes against self-care attempts. As noted, some of the residents have diabetes-related knowledge and voice their preference for agency in decision making regarding food choices.

The Significance of Food

As previously noted, food plays a significant role in the lives of the women at Rolling Hills. I show next that food compensates for reduced quality of life that is shaped by State cost containment interests. This overemphasis of food creates conflict in the management of diabetes because this disease requires glycemic control, which is directly associated with dietary intake.

May’s story.

May does not leave Rolling Hills very often. She suffers from a serious mental illness that causes extreme paranoia. She spends most of her time in her bedroom writing in her journals, and sitting on her bed looking at her various possessions, including stuffed animals, costume jewelry and greeting cards. She goes out only occasionally with her family when they come to visit. She also attends the big social events twice a year. May also has a diagnosis of diabetes, which she does not understand. This works against diabetes management because May lives for food.

During our interview, I had the privilege of being shown May’s 12 journals, which she has filled with her special memories. I discover while looking through the various pages that
May remembers all events and outings by what food was served, what restaurant was chosen, or what treats she purchased while she was out. Her journals include all the names of restaurants she has been to, the day trips she has been on, and the shopping trips she has taken. Under the names of the restaurants she has written the date she went to each, and the food selections she chose and enjoyed. Her journal entries also include her favourite recipes, and lists of food items she has bought over the years at grocery stores with the cost written beside each.

May tells me that she and others often put their money together to have pizza or Chinese food delivered. Also, May describes to me in detail what she ate at the summer picnic, which she attended almost a year ago with residents from the other homes. She repeats a few times, “I went to the picnic in July. We got hamburgers, hotdogs, and potato chips.” May exclaims, “The picnic is in July and the Christmas Party is in December, and we get Swiss Chalet at the Christmas Party.”

She then shows me all of her Easter, birthday, and Christmas cards she has kept over the years. She reads every card to me, and remembers the restaurant they went to for each of the celebrations. She states, “(sister’s name) took me out to The Dragon King Chinese Food Restaurant and we had chicken balls, pork fried rice, egg rolls…” During our conversation, May rhymes off the various food-related activities she participates in, and eagerly exclaims, “…I go shopping and I buy ice cream, Juicy Fruit gum, chocolate bars, and Hostess or Lay’s barbeque potato chips.” She also tells me, “I buy Orange Crush, Sprite and potato chips from here,” as she shows me the two vending machines, which are sitting just outside her bedroom (Interview with May).

May talks excitedly and writes all about her food related experiences. She spends her allowance and cash gifts on fast food and treats for herself and other residents in the home. The relevance of May’s story will become more apparent in subsequent sections.

**Food as pleasure.**

Food plays an important role in May’s and other women’s lives at Rolling Hills. The women look forward to their usual treats, like pop, chocolate bars, and chips, which are offered in the group home on scheduled evenings of the week. The women are also treated to such items as cake for everyone on birthdays, as they quite often do not get visitors to celebrate with them.
Chinese food take-out is provided every six weeks as a special meal. Holidays are also celebrated with bountiful meals, and they have parties on Canada Day, Christmas, and Halloween. The residents echo their appreciation of the work that Carol puts into food provision. They very much anticipate these offerings and are happy to indulge.

Funding bodies allot $125 per month for each resident’s discretionary use. This money pays for cigarettes for those who smoke. The home operator gives the money to each resident and must document the transaction to prove the resident received it and that the money is not spent on items Carol is responsible for purchasing. Observational notes that were taken during a trip to the mall show how the women spend their allowance.

Shopping at the mall includes a fast food lunch at Zellers or in the food court, and purchasing of snack items and meals to eat at the home. Rose, who has diabetes, explained to me,

*I have nothing to hide. I know I’m a diabetic, but I’m a good diabetic. I bought an Aero chocolate bar…I buy my chips, well Pringles…I go to Zellers for my treats, and I get my frozen ‘mac and cheese’ for lunch. I buy two, one for today and one I can substitute for another meal through the week.* (Interview with Rose)

Residents often purchase lunch and bring home treats and substitute meals from shopping trips.

Observational notes taken during a Social Night event revealed how food is organized at this venue, and how this, in turn, determines how residents spend their money. There is a snack bar where chips, chocolate bars, pop, and gum are the items for sale, along with hot food items, such as hot dogs, pizza, or chicken nuggets. Large family sized bags of potato chips are sold because they are cheaper for the staff to buy and therefore cheaper for the residents to purchase. Staff is not aware which residents have diabetes, and diabetes-friendly products are not sold. At one Social Night event, upon arriving, Anne meets up with her male friend and says, “Let’s get in there to get our chips and pop before they’re all gone.” Michelle, who has diabetes, buys three of the big bags of chips and two pop, which she consumes at the dance. All the women with diabetes either buy or have others purchase snack items for them while they are out.
Everyone involved with residents participates in these processes that effectively heighten the significance of food and encourage consumption of unhealthy items. The home operator purchases the food for meals and snacks, attempting to vary the menu and offer items that residents enjoy because, as she reports, “They have little else in their lives” (Interview with Carol). May’s story confirmed this perception: Food provides happiness in a life that has few other pleasures. The funding bodies participate in the process by focusing on finances in the policies over quality of life. Families also offer food as pleasure, and this is explored further in the following section.

Food Issues

Interviews with all participants resonated with certain issues around food, such as overeating and the tendency to cheat. The use of spending money on unhealthy food choices, hiding of food, family involvement in overeating, the use of snack machines, and side effects of psychiatric medications are some of the concerns raised in the interviews. The home operator and staff reported their frustration in not knowing how to curtail overindulgence in food by residents with diabetes. I demonstrate in this section that although these are valid concerns, the structures, processes, and budget restrictions around food, combined with the lack of quality of life initiatives, tend to promote the development and exacerbation of diabetes. Additionally, responsibility for diabetes is individuated, which creates further inequities for those who, within these constraints, develop the condition.

“I find sometimes I get bored through the day so I like to eat” (Interview with Violet). The residents talk about boredom as being one of the reasons for eating. The care providers acknowledge that the residents get bored, and also question the mental illness as playing a role in overeating.

*I’m not sure if it’s because...they never have change (in routine), but they umm want to eat more...I don’t know if that’s part of the mental illness side of it or not, because I noticed some of them when they’re bored even if they’re not diabetics they’re looking for something to do and it’s downing the sugar, or bags of chips.* (Interview with Phoenix)
Eating is something to do in an otherwise uneventful day. Further, the residents, including those with diabetes, enjoy indulging in fast foods and snacks when the opportunity presents itself, like when they are given spending money and when treats are offered. Having mental illness is also perceived as creating challenges, because some residents do not grasp the repercussions to overeating and making unhealthy snack choices. Others do understand they should make healthier snack choices, but sometimes choose the items that they prefer.

There is awareness amongst those overseeing care that opportunities for social participation are lacking, as described by the Domiciliary Hostel Worker, who stated, “There’s just not too much reward other than the three main meals, so that little trip to the convenience store to get something sweet or nice to eat just makes their day a little bit brighter” (Interview with Maria). She acknowledged that the residents have little to look forward to, and food may serve as a substitute for more rewarding experiences.

Families offer food as pleasure and to allay feelings of guilt or remorse for having placed their relative in a group home.

*Family members take them out and they know they’re diabetics but they wanna make them happy and feel guilty a lot of times that they’ve placed them in these settings. So when they take them out they want to spoil them and they don’t realize by buying them those things it’s not always to their benefit...Families feel sorry for them and feel they have enough to deal with, with their mental illness.*

*(Interview with Carol)*

Families offer food, often without regard for proper disease management. Generally, the meal or treats that are bought are those that the resident prefers, rather than what is considered healthy. This places health in tension with familial emotional complexities.

Mary stated, “I see my daughters every three weeks. Every three weeks they come here…We usually go out for a meal…(My favourite) is Swiss Chalet” (Interview with Mary). Mary associates her visits with her family with the sharing of a restaurant meal. Highlighted next by one resident is what she really desires, social interaction with her family and a sense of belonging and inclusion in the family unit.
But it doesn’t happen where (they)...bring you home for a week or something like that. That doesn’t happen anymore...or I don’t think so because it doesn’t happen in my case...Or visit me, like say, “Mom I’m coming to pick you up for two or three days”...I would love to see it but umm I have to accept the fact, and I do accept the fact, because when they do come up I have such a good time with them. (Interview with Margaret)

This resident was clear in what would provide happiness and fulfillment over food: time and togetherness with her family. Very few residents get the opportunity to stay with family and friends away from the group home and many do not get visitors often or at all.

The use of snack machines by people with diabetes is a further concern raised by participants. At Rolling Hills, the decision was made to install snack machines at the rural home, as a solution to the problem that the women cannot access a convenience store like the residents of urban group home settings.

We have a snack machine and a pop machine, which we have to have for the other clients because they have no access with no store out here and they’re at that machine all the time so do you take that machine out and punish the rest or not? And I elected not because it’s just not fair to the other people in the home. So then they now have access to these machines and they’re using them on a regular basis. (Interview with Carol)

Initially, Carol proposed to purchase products to fill the machines with healthy items at cost, but the administrators within the HSC Program denied this request due to potential conflict of interest. The concern was that she might profit from this venture, so an outside party has control of food choices. The machines contain high fat/caloric products for the residents to buy, which they do with their spending money. However, the residents with diabetes are advised to refrain from using them, even though they have money and the snack machines are on-site. Carol provides the option of using resident spending money to purchase healthy foods, like yogurt and cheese, but only two residents take advantage of this service (Carol).

The care providers acknowledged there are diabetes-related health risks associated with having access to the items in the snack machines because they cause elevations in blood glucose.
I have one diabetic that just came to me today and she knows there’s a few people ordering pizza tonight so a very ill girl that’s diabetic and she said that, “If she puts $20 dollars into pizza can the pizza man give her $10 in coin so she can use them in the snack machines?” So she’s going to sit there and probably she’s going to over the weekend have four or five cans of regular pop because she says that she can’t drink diet pop, it upsets her. So you know she’s going to have four or five Mars bars...It’s definitely a trust factor that there’s no control over. It’s a knot in our system. And you’re hoping that they’re going to honour that. Its mental health and some of them aren’t just gonna do that. (Interview with Susan)

In understanding the health risks, staff members frequently remind the residents with diabetes that they should not buy and consume the items from the snack machines, but diabetes-friendly items are not available (except for diet pop). The snack machines are challenges to disease management, and have become part of an exclusionary process, as they are considered off-limits to this group.

Furthermore, the majority of residents are prescribed atypical antipsychotics, which are known to cause metabolic changes and increased appetites. Those caring for this group find it extremely difficult to manage the residents’ constant complaints of hunger.

...I don’t think it’s the diabetes. I think it’s more the psych issues (that) causes these massive appetites...which obviously conflicts with what a diabetic diet needs and it becomes a real issue because they’re hungry and one actually thinks I’m trying to starve her...She weighs 180 pounds...but she really believes that I’m starving her to death... and you feel bad because...I believe that’s the way she feels. And she looks at you like you’re this monster when you can’t, you know, fill her up. (Interview with Carol)

Never being able to reach satiety presents problems, especially if the women cannot easily distract themselves with other activities due to lack of available options.

All of these processes intertwine to create an environment that perpetuates the development of diabetes. Atypical antipsychotic medications increase appetites, so the women feel hungry. Redirecting thoughts of food is a challenge due to lack of available opportunities
stemming from rationings. Food is used as a source of pleasure and also to allay feelings of guilt, and as such takes on an overemphasized importance. Thus, combined with the residents’ sedentary lifestyles, the development of diabetes seems inevitable given the circumstances.

**Monitoring the Residents with Diabetes**

Next, I explore the work of monitoring residents who have a diagnosis of diabetes. As part of social relations of accountability and risk management, residents, staff, and those overseeing care all engage in the work of monitoring the women with diabetes at Rolling Hills. Surveillance practices include monitoring glucose levels, physical symptoms, and dietary intake.

**Margaret: The work of monitoring.**

*I test my sugar at 7:30 a.m. and if it’s low...then (care provider) has to hold my pills and hold my insulin until I have my breakfast. And then we take my sugar again and if it’s up past 5.8 or 5.9, then I can go ahead with my pills and my insulin...At 10 o’clock it’s coffee time and we have coffee and I have a slice of toast...So, I have that and take my sugar again...after (a nap) we have lunch. Then I take my can of Glycerin (Glucerna)...I do my walk and then after lunch I drink half of it and then save the other half for break time in the afternoon so I’m getting something in my system at all times, every two hours...at 4 o’clock we take our sugar again and then pills...And then we have dinner and if my sugar goes down real low, then I have to keep track of it every ½ hour until it starts to go back up. I could be getting ready to go out and it will drop. (Interview with Margaret)*

Margaret’s life is organized around illness management. She is considered a “brittle diabetic,” one whose blood glucose levels may fluctuate frequently and sharply. Her safety is a concern, so she, staff, and other residents watch carefully for signs of acute complications. Her glucose levels are checked a minimum of five times per day, and she is also watched for physical signs of complications, such as mood changes, alertness, and skin colour, so treatment can be initiated in a timely fashion.

*With Margaret...if her blood is below 5 I hold her insulin until after she has breakfast and then by 9 o’clock I have her do her blood again and usually*
breakfast brings it back up and she gets her insulin then...out of a seven day span, two of those days it will be under (4) when she gets up in the morning... She’s eating every couple of hours...sometimes in the day her blood will dip for no reason and if it goes below 2 we call the ambulance and send her in...if she seems sleepy...in her chair sound asleep with her head down and I’ll know her blood’s low. (Interview with Phoenix)

This work of monitoring residents with diabetes is connected to both relations of accountability and risk management. Margaret’s blood glucose levels can fluctuate to the point where the initiation of treatment for hypoglycemia is necessary and emergency services must be called. The residents are required to self-manage, yet hypoglycemia limits the ability to self-treat because it is accompanied by reduced levels of awareness that can lead to unconsciousness, seizures, and potential death. As noted, the homes are not paid enough to hire regulated health care providers to manage acute medical conditions. This is meant to be a housing program and therefore they are unsupported in medical management. However, the operator is held responsible if, while in her care, a resident incident occurs. The home operator could also be held liable if a resident leaves the property in an unstable state. Residents with diabetes, in particular those who are unstable, are tested to determine physical status, and if treatment is required (for hypo/hyperglycemia, and/or placing of 911 call). Residents are also held back from outings if it is indicated by a low glucose reading that their safety may be in jeopardy. Thus glucose monitoring at this group home plays an integral role in both accountability and risk management processes.

Cheating: Monitoring behaviours.

At Rolling Hills, monitoring the women’s consumption of food is a major part of the extra work required to manage risk in people with diabetes. Although food plays a significant role in the lives of all the women at Rolling Hills, those with diabetes must control dietary intake as part of disease management, which creates conflict. Care providers described such behaviours as hiding food, buying snacks, and consuming them in seclusion to avoid monitoring, or eating others’ food during meals. Using interview data, I discuss the monitoring and detection of these behaviours, along with my analysis, which highlights how responsibility for diabetes management is further individuated in this process.
**Keeping an eye on them.**

* I have put them all at one table so we can keep a better eye on them. That’s really helped because before, you know, they’d grab off each other’s plates and they’ve got the understanding they can’t have sugar but they have the extra couple of sandwiches. They don’t get that they shouldn’t have the bigger portions, so we can kind of watch a lot better. I’ve also taught the other ladies so they are aware, “now she is diabetic” and they know not to give their leftovers to them...  

*(Interview with Carol)*

Residents with diabetes are watched closely during meals to curb overeating. Care providers and residents participate in monitoring the women with diabetes. The care providers have a routine they follow during meals.

*Your observations are: you’re serving out very quickly so each table has a table monitor (a resident in charge of taking food to their table), so you’re talking five minutes and everybody’s got their plate. So, it’s easy to wander...and that way you’re watching, you’re watching because there will be at some stage somebody who won’t eat their dinner that will want double dessert...*(Interview with Susan)*

The social organization of meals involves differentiation between the people with and without diabetes. Although the intent is to control overconsumption of food and sweets in the women with diabetes, the strategy does not extend to disease prevention and it ineffectively manages the illness. The majority of residents are at risk for developing diabetes, but adjustments to their diets are made only after a diagnosis is given. Further, the women with diabetes are grouped together during meals and monitored by care providers and by other residents. These women also watch as the rest of the residents get bigger portions and sweet desserts, which are both exclusionary processes. Mary, in describing her perceived position, stated, “I cannot have dessert that most people have. I have to have something that’s for diabetics, like fruit...Then if I do have dessert, I may just have just a sliver of their dessert to get a taste of it” *(Interview with Mary)*. Given the preceding analysis of a social organization that heightens the significance of food, in addition to medication side effects that preclude satiety, these strategies further inadvertently segregate and inferiorly position this group. They also offer no preventive measures for women who are at risk for developing diabetes.
Glucose readings to monitor behaviours.

Glucose monitoring is also used to determine the intake of foods that will elevate blood glucose levels, and to attempt change in resident behaviours.

I’ve gone in and said to a client, “Your blood sugar is really high what have you been into?” And they’ll say, “Nothing, nothing”...and as they’re saying it I’ll see the can of Coke they’re hiding behind their chair... So it’s kind of like you are dealing with little kids in many cases. They know they shouldn’t be. This isn’t the issue...I find the issue is that they don’t have the mentality to be able to say no.

(Interview with Carol)

When blood glucose levels are elevated, the resident is questioned in an attempt to change certain behaviours, like hiding and consuming inappropriate foods. Margaret is known by the home operator and care providers as one who often “cheats,” especially at night, sneaking and hoarding foods like Coke that cause elevated glucose levels. Margaret described an incident where she went shopping and upon return had an elevated blood glucose reading.

I come back, and it’s, “What’ve you been eating? You must’ve been eating something.” And I said, “I wasn’t,” you know? And that really gets me upset...of course all the girls (other residents) watch me like a hawk. So...it made me feel...very bad. (Interview with Margaret)

The care providers fear high glucose levels caused from consuming inappropriate foods will result in acute and long term complications. Like many within the general population of people with diabetes, the residents may not consider long term effects of elevated glucose levels (Dr. P). If there is a craving for food and it is available, the women may find it difficult to refrain, especially since elevated glucose levels over a short period of time do not cause overt physical symptoms of ill health. The measurement of blood glucose is a strategy to show residents that eating certain foods results in physiological change. However, rather than inspiring positive behaviour change, Margaret indicated this makes her conspicuous and she interprets this attention as punitive. One logical counter strategy is to continue to hide food and eat forbidden items while out of the home to avoid scrutiny. Finally, the devolution of monitoring work to other residents, although viewed positively by care providers because of the assistance rendered,
has the social outcome of inferiorly positioning the women with diabetes in relation to the rest of the group. As Margaret stated, being watched like a hawk by the other women makes her feel bad.

To summarize this section, monitoring is taken up at Rolling Hills as part of the social relations of risk management and accountability to manage illness. This is one of the few group homes in the program that accepts residents with a diagnosis of diabetes and accepts the responsibility of monitoring glucose levels and watching for physical safety without State support. Although the intent is to ensure the wellbeing of this group, some monitoring processes and practices around food serve to individuate responsibility for diabetes, rather than treating it as a contextually perpetuated condition. This finding is similar to what was seen in clinical practice, and in the governing text for diabetes care.

**Diabetes: Whose Problem Is It?**

Diabetes, as a problem, is individuated in the diabetes best practice guidelines, in clinical practice, and in group home care. As noted in Chapter 6, self-care is promoted in the diabetes practice guidelines, and responsibility for illness management is assigned to the person with the condition. In promoting the self-care ideology, health care experts draw the person with diabetes into complex self-management treatment regimens, use surveillance methods to monitor the condition, and if and when attempts fail, the person is held accountable. Within group home care, diabetes is also individuated, as the resident is required to be responsible for self-management. Further, the social and contextual circumstances that lead to the development of diabetes and those that impede illness management are either overlooked or not addressed in the diabetes guidelines, the group home policies, and in clinical practice. Additionally, certain surveillance and exclusionary processes taken up by health professionals and group home care providers inferiorly position and create health disparities for the afflicted individuals.

As we have seen, the resident with diabetes in the group home is required to assume responsibility for illness management. Cognitive and physical limitations, little control over meals and snacks, budgetary restrictions that limit proper food purchases, and lack of opportunities for full social participation are constraining forces that are overlooked in group home policies. Contextual conditions that perpetuate the development of diabetes and shape diabetes-related outcomes are also not addressed. In clinical practice, diabetes experts also
individuate the problem, and there is a lack of awareness of the contextual constraints faced by people in group home settings. These issues are not recognized when residents are diagnosed with diabetes, and they do not receive useful diabetes care as a result.

In the individuation of diabetes as a health problem, people are subjected to interlinking surveillance and exclusionary processes. As already highlighted, residents are denied access to group homes within the HSC Program if they cannot manage self-care activities. Alternatively, they must undertake self-care activities without support if accepted into one of the homes where the operator does not assume illness management responsibility. Also, similar to what was seen in the group home, in the clinical setting if glucose results are above normal the person with diabetes is questioned about their dietary intake. In order to avoid future scrutiny, the person with elevated readings will cancel follow-up appointments, forget to bring in the incriminating glucose meter, or record falsified normal numbers in the log book. These surveillance methods are not overly useful in generating behaviour change, and inadvertently create further inequities.

Next, a poignant quote by a field worker highlights how diabetes is individuated, and how textually mediated social relations that organize residents’ circumstances are at play. The resident of reference was in another group home within the HSC Program. She had severe diabetes and was known to cheat on her diet.

She was on insulin three times a day. You’d go into her room, there on her night table or dresser, and I’m not talking little chocolate bars, I’m talking the big ones. She’d have four or five of these with a case of pop hidden under her bed...I said, “Look, I have to report this. You can’t have food under your bed for one. Two you’re a diabetic.” She said, “But I need it.” I said, “I know you need it when your sugars are low, but you don’t need a big one”...Unfortunately she died of diabetic problems. She was warned and warned and warned by the doctor... (Interview with Laura)

This anecdote illustrates how, in individuating the problem and distributing responsibility to the person with mental illness, unsafe situations are created that lead to complications and death. The residents are entrusted into others’ care because they have a serious mental illness and require supervision. However, supervisors have limits on what they can do to handle the situations. In
this instance, the resident was not making healthy lifestyle choices, but the field worker did not have the option of distributing responsibility to the home operator, who is mandated to not take up diabetes practices. Nor, could she legally or ethically confiscate the resident’s property (pop and chocolate bars). The lack of communication and understanding of group home care also limited the ability to seek assistance from diabetes experts. Thus, like the resident’s doctor, she could only resort to warnings, persuasive efforts, and threats in attempting to change the resident’s behaviours. In this social organization of diabetes care the resident ultimately died.

Summary

To summarize this chapter, I have explained how women with diabetes live out the social relations of chronic disease management within the confines of group home care. The cornerstones of diabetes self-care involve regular exercise and dietary precautions, in addition to glucose monitoring and medication. However, these activities are difficult to learn and practice under ideal conditions. I have illuminated how they are practiced at the troublesome intersection of group home regulatory policies and diabetes evidence-based guidelines.

There are many barriers and constraints to attaining physical activity for group home residents. Funding is not provided for transportation to community programs and events, gym memberships, or for extra staff to facilitate or supervise exercise. At Rolling Hills, exercise is limited to walking inside or on the property, and some residents do not willingly engage. Field workers refer to discourse of “freedom of choice” to assign responsibility to residents who do not participate in this activity. Also, negative societal attitudes are given priority by field workers over promotion of exercise for health benefits. Constraints at the local site include care provider time restrictions, weather conditions, and resident physical limitations. Furthermore, the residents lack opportunities for full social participation in addition to vocational and educational prospects. This problem is most evident in rural group home settings, where access issues preclude community involvement.

Food-related budgetary restrictions create further tensions that undermine opportunities for diabetes prevention and control. The State mandates adherence to Canada’s Food Guide, but funding provision is extremely low at $1.91 per day for each resident, which makes alignment with nutritional recommendations impossible. Three meals plus snacks are offered daily to meet the group home care regulation. Although there is plenty of food and variety in the menu, the
diet is high in carbohydrates and fat, and certain foods are lacking to the extent recommended, including fruits and vegetables, milk, and fibre. Most of these food items are more expensive and are indisputably unattainable, given the extremely restrictive per diem amount. Diabetes food products are also expensive and although they are purchased at Rolling Hills, additional budget support is not offered. Nutritional education is poorly suited to residents because diabetes education teams do not visit group homes to better understand the unique circumstances. Adequate support is not offered to allow care providers and home operators to join residents at diabetes clinic appointments, so they can learn and share important information.

As a further issue, the use of atypical antipsychotic medications causes increased appetites, along with other metabolic changes, making it difficult to reach satiety, resulting in overeating and heightened risk for diabetes. To add to the complexity, in the absence of more fulfilling opportunities for social involvement, food takes on an intensified significance. Those overseeing care recognize that food is used as a substitute for more meaningful, fulfilling activities, and the use of food as pleasure is supported, until a medical diagnosis like diabetes is made. Management of the condition within the above constraints creates tension, as the disease requires dietary restrictions. Further, diabetes as a problem is individuated in its management, which leads to additional health disparities and inequities.

Overall, diabetes practice guidelines, the group home policies, and the lack of coordination and communication among the health care professionals and between the people responsible for the care of the mentally ill, all intertwine to position the residents into a life of low social participation, which features a lack of recreational, vocational, and educational opportunities. These conditions potentiate existing risk of medication-induced chronic illness. Once diabetes is diagnosed, its management is the responsibility of the resident, unless the home operator chooses to risk liability by offering unsupported assistance. In the next and final chapter I discuss these findings, along with recommendations for change and future research in this area of health.

As I worked on the final draft of this thesis I learned that in September 2011 the Domiciliary Program reviewed the cost of medications used by the residents. Letters were sent by the regional government to the home operators outlining several policy changes effective April 1, 2012 (Appendix I). There will be no coverage for over-the-counter medications, or
payment of dispensing fees, as well as limits to coverage of prescription drugs. The regional government suggested in the letter that residents and their supervisors request samples from the prescribing physician. Given that there are 400 Domiciliary Hostel beds in the region of reference (Interview with Maria), requesting samples is not an appropriate solution and it is a debasing position in which to place residents, who are already in the social margins. Residents are also instructed to apply for support through the Trillium Drug Program, even though most are not eligible because they already receive drug coverage under Ontario Drug Benefits (MOHLTC: A Guide to Understanding the Trillium Drug Program, 2008). This devolving of fiscal responsibility places the onus on the residents to pay out-of-pocket for necessary vitamins and supplements, among other medications, plus numerous, ongoing dispensing fees. Given the low social support payments and Personal Needs Allowances that they survive on, this group cannot afford to pay for medications. This unilateral decision by the regional government is yet another example of the interest in cost containment taking precedence over residents’ health and wellbeing.

The newest version of the Operating Guidelines for HSC (2011) was also released while I was finishing this thesis project. Policies were added that regulate systems of safety and accountability, but still do not promote health. Added regulations include air conditioning in at least one common area, a system for infection control must be in place, and operators must carry increased general liability insurance. Additional Acts to be followed include ‘The Safe Drinking Water Act (2002),’ ‘Smoke Free Ontario,’ and ‘The Personal Health and Information and Protection of Privacy Act (2004).’ There is a new emphasis on ‘recovery-based’ services and priority for licensing is given to operators who provide this type of program, and who offer single bedrooms to facilitate privacy (MOHLTC: Operating Guidelines for HSC, 2011). However, there is no written commitment to financial support for facilitation of recovery program initiatives, and if operators cannot afford to make home alterations to accommodate private bedrooms this new policy may affect placement opportunities. Funding provision was not increased, and all regulations will increase expenditures, and add more layers of monitoring. Further, repercussions for noncompliance are now clearly delineated in a new section, which indicates that if the conditions of the HSC license and agreement are not met, tenant removal and cessation of funding will ensue (MOHLTC: Operating Guidelines for HSC, 2011). Thus, the
residents will be relocated within the same program to suffer similar imposed restrictions and social inequities, and home operators will lose their livelihood.

Other changes highlight both the Ministry of Health and Long-Term Care’s stance and unwillingness to address the insufficient funding issue. First, the funding formula that pointed to the inadequacies and resultant health disparities was removed from the guidelines. Rather than addressing the imposed financial constraints, the State has rendered the problem ‘invisible.’ Furthermore, residents are now referred to as “tenants,” (MOHLTC: Operating Guidelines for HSC, 2011, p. 5) which points to the Ministry of Health and Long-Term Care’s position that this is merely a housing program. There continues to be no written focus on medical comorbidities, and medical management is not supported. There are further restrictions on dental services: Rechecks are mandated every 9 months as opposed to every 6 months, the funding amount for basic dental services was not increased, and the written financial commitment to pay 75% for crowns, bridges and root canals was removed. Field staff is also to monitor and minimize costs of medications and medical equipment (MOHLTC: Operating Guidelines for HSC, 2011). Cost containment continues to be a central State concern in group home care guidelines, while interests that would facilitate resident overall health and wellbeing are neglected.
Chapter 8
Discussion of the Findings, Implications, Limitations and Recommendations

In this concluding chapter, I discuss the findings of my exploration of the social organization of diabetes care in a rurally located Southern Ontario for-profit group home. This was the first study to examine the social forces that impact overall health and wellbeing in the vulnerable population of mentally ill adults with diabetes who reside in residential care facilities. With an interest in improving diabetes care provision, I discuss possibilities for sociopolitical change, implications for clinical practice, inclusion of the unique needs of this population in diabetes practice guidelines, and changes that might be implemented at group home sites. Finally, I present recommendations for future research in this area of health, which I follow with a discussion of the strengths and limitations of the study and concluding remarks.

Discussion of the Findings

Using institutional ethnography to guide this study, I discovered that the way in which group home care is organized creates and sustains social inequities and disparities in health. The overarching State interest in cost containment restricts the amount and type of care afforded the residents, resulting in poor dietary intake and lack of quality of life opportunities, among other inequalities. Further, group home policies regulate systems of safety, reporting, and financial accountability, but do not promote health and wellbeing. The lack of regulatory focus on illness prevention, health promotion, and comorbid conditions, while simultaneously paying extreme attention to such aspects of care as fire safety and finances, undermines health. The medical and psychiatric disconnect results in further health inequities for this group that is at an intersection, requiring both medical and mental health care. Furthermore, self-management of diabetes is prescribed, both in diabetes care provision and in group home care, which is challenging within these social contexts. The manner in which diabetes care provision is offered and the managed care found in clinical practice produces further health inequities and limits health care providers’ ability to assist this high risk group. Combined, these social relations create circumstances that perpetuate disease development and make illness management difficult, resulting in poor health outcomes.
The knowledge generated from this study builds on previous work that focused on diabetes and mental illness. In congruence with the existing body of literature reporting that mentally ill adults have low income (Wilton, 2004) and difficulty finding and maintaining employment (Canadian Mental Health Association and Centre for Addiction and Mental Health, 2010), I found the residents in this study received a low monthly social assistance payment, which was given to the home operator for room and board. Further, all of the residents in the group home were unemployed.

Coinciding with previous work on health behaviours of the seriously mentally ill (Knol et al., 2010; Xiong et al., 2010; Goldberg et al., 2007; Strassnig et al., 2005; Bartels, 2004; Sokal et al., 2004; Daumit et al., 2005; Holmberg & Kane, 1999), the women residents in this study also had sedentary lifestyles, obtaining on average 10 minutes per day of low-intensity exercise. This study explored levels and types of physical activity within the group home setting, which builds on the previous research that utilized self-report data (Xiong et al., 2010; Daumit et al., 2005) and small intervention studies (Teachout et al., 2011; Jerome et al., 2009; Knol et al., 2010; Vreeland, 2007; Ohlsen et al., 2005; McDevitt et al., 2005) to assess exercise. Similar to other researchers who investigated eating patterns in mentally ill adults (Xiong et al., 2010; Strassnig et al., 2005; Bartels, 2004; Holmberg & Kane, 1999), my analysis revealed that the residents consumed a diet high in carbohydrates and fat, and low in fruits, vegetables, and fibre. Furthermore, dairy products, as an essential food group were also found to be lacking in the residents’ diet. Coinciding with others’ findings (Goldberg et al., 2007; Daumit et al., 2005; Brown et al., 2010; Ohlsen et al., 2005; Bartels, 2004), I discovered a high rate of smoking among the residents: 18 out of 26 women, or 69%. Xiong et al., through the inclusion of group home operators, further found there is a need for support and consensus among all stakeholders, including residents, home operators, medical practitioners, and funding bodies to determine what constitutes a healthy diet and effective exercise program for residents.

The medical and psychiatric disconnect described by other researchers (Xiong et al., 2010; Galassi et al., 2006; Dombrovski & Rosenstock, 2004; Vreeland, 2007: Dembling et al., 1999; Dixon et al., 2004; Chafetz et al., 2006; Dickey et al., 2002) was also found to pose barriers to the health of mentally ill residents in this study. Furthermore, as reported by others (Ganguli & Strassnig, 2011; Vreeland, 2007; Henderson et al., 2000), this group’s risk for
diabetes is exacerbated through the use of atypical antipsychotic medications that are initiated by psychiatrists, who often do not screen for metabolic conditions. In this study, almost the entire group of residents was treated with atypical antipsychotic medications in accordance with best practice guidelines. Although the house physician screened annually for diabetes and other metabolic markers, no preventative measures were in place. The metabolic risks associated with the use of second generation antipsychotic agents have been known for at least a decade and no action has been taken within the programs such as initiating screening, implementing preventative measures, and facilitating awareness through education, to reduce these risks. The residents are fundamentally at high risk for diabetes due to genetic predisposition, which is compounded by treatment with atypical antipsychotic medications. Contextual conditions add complexity to the problem.

Similar to the body of qualitative literature that reported on the diabetes illness experience (Mercado-Martinez & Ramos-Herrera, 2002; Schoenberg et al., 1998; Mitchell & Lawton, 2000; Tang & Anderson, 1999; Koch et al., 1999; Hornsten et al., 2004; Rayman & Ellison, 2004; Anderson et al., 1991; Burke et al., 2006; Thorne et al., 2003; Koch et al., 2000; Samuel-Hodge et al., 2000), participants in this study reiterated that diabetes is a complex chronic condition to manage. The treatment of this illness is time-consuming, expensive, and can be overwhelming because disease management requires monitoring and lifestyle restructuring. For those suffering associated complications, added work is required such as extra medical appointments, more blood glucose monitoring, and watching for physical symptoms of distress. In congruence with the findings in the body of qualitative literature (Burke et al., 2006; Thorne et al., 2003; Tang & Anderson, 1999; Mitchell & Lawton, 2000; Anderson et al., 1991), I discovered that the diabetes experts did not take into consideration or effectively address contextual constraints faced by this group. However, by choosing a research methodology that went beyond the individual experience to explore the social (Smith, D., 2005), new knowledge was generated. In this study, I showed how sociopolitical forces shape the everyday lives of the residents in the group home in such a manner that poor diabetes-related care and outcomes are essentially inevitable.

The analysis of textual coordination also enabled the discovery that responsibility for safety and hygiene is distributed to home operators to ensure certain standards are met. People at
the local site and those overseeing care enter into “text-reader conversations” (Smith, D., 2005, p. 104) to carry out social relations of accountability and risk management in alignment with regulations that focus on fire prevention, proper food handling, safety, and home cleanliness. Annual license renewal is contingent on meeting the outlined criteria on group home care forms, and work at the local site was prioritized accordingly.

I found that the texts used by health providers in the diabetes clinic also organized work in a certain manner. Forms used to collect patient information did not facilitate the capturing of special needs and housing arrangements, and those used to collect statistics grouped the seriously mentally ill with the general population of people with diabetes. This finding was echoed by the Canadian Mental Health Association (2009) in the report titled, “Diabetes and Serious Mental Illness: Future Directions for Ontario, A Think Tank Report,” wherein it was noted that special populations like those with mental illness are not captured in the diabetes registry or in diabetes messaging. Assessment and evaluation forms are also problematized in others’ work (Campbell, 2001; Rankin, 2003). Campbell found that the application form for home care support, when activated, organized nurses’ decisions regarding the applicants’ eligibility to receive services. Rankin, who investigated the patient satisfaction survey, found that the form did not enable the capturing of nurse and patient experiences, thereby jeopardizing quality of care.

Texts, interpreted and enacted across local sites, have the ability to standardize, objectify, and decontextualize the problem (Smith, D., 2005). Health sciences research, upon which evidence-based recommendations are based, is used in the development of organizing texts, like the diabetes practice guidelines. As reported in Chapter 6, Mykhalovskiy and Weir (2004) point out that evidence-based medicine is an important knowledge relation. Health care providers across Canada use evidence-based recommendations in clinical decision making. However, the problem is decontextualized in guidelines and as such individual, contextual constraints that certain people face, like this group, are overlooked. As exemplified, evidence-based recommendations were inaccessible due to budget restrictions, lack of control over food choices, and limited access to medications, among other constraints. Mentally ill adults were also excluded from the list of special populations, and as such were not recognized as needing added attention in practice.
In the diabetes practice guidelines, evidence-based health science research is also used to claim authority on how diabetes is to be managed. The Chronic Care Model is promoted as the most cost-effective and efficient way to deal with the problem. Health providers in the practice setting carry out self-management education and assign responsibility to afflicted persons, as outlined in the recommendations, thereby drawing them into evidence-based decision making as an integral part of illness management. As reiterated by Mykhalovskiy and Weir (2004), “The proponents of evidence-based medicine and its derivatives are democratizers, eager to invite their addressees—patients, clients, students and others—into the cultures and regimes of evidence-based decision making” (p. 1067). The ideology of self-care removes responsibility for health from the State and assigns it to the individual. As was shown in this study, the residents were expected to assume responsibility for diabetes self-care practices, regardless of contextual constraints. However, residents could not exercise full agency over food, had transportation access issues, lacked opportunities for exercise, and had cognitive and physical limitations. This aligns with Anderson et al.’s (1991) work that explored diabetes care in a group of Chinese immigrant women. The researchers argued, by removing the personal from the sociopolitical, cultural, and economic context, illness management is reduced to individual capabilities. As in this study, health care professionals were brought under scrutiny for uncritically upholding the ideology, thereby sustaining it in practice. I showed how this increases barriers to adequate health care for the socially disadvantaged and places them further into the margins of society.

Smith, D. (2005) highlights that textually mediated relations organize activities across space and time. In this study, the coordinating effects of texts in diabetes care and in group home care were analyzed. In the Ontario mental health reform documents (Appendix D), it was discovered that the texts do not focus on comorbid conditions, which are becoming increasingly prevalent, nor do they focus on illness prevention or health promotion. Further, as was shown, there is an overarching interest in cost containment within the sociopolitical agenda. The deinstitutionalization movement, welfare reforms, and mental health reform were sociopolitical forces responsible for creating and sustaining social and health inequalities.

The interest in cost containment is seen not only in mental health, but is an integral component of the political agenda that drives Canada’s entire health care system. Deber (2003) reported that reductions to hospital budgets in the mid-1980s placed greater pressures on health
providers to increase efficiency of care to more patients. Deber wrote, “The first law of cost containment states that the easiest way to control costs is to shift them to someone else” (p. 22). As reported by Deber, restructuring within hospitals to save costs included reducing lengths of stay, increasing the percentage of day surgeries, and reducing the number of inpatient beds. A further related strategy used by the government to reduce health care expenses is to provide services in the community, rather than in more costly hospital settings, which was exemplified in the deinstitutionalization movement. Also, pharmaceuticals, nursing care, and physiotherapy costs, among other medical services, are assumed by public funding within the hospital (Deber, 2003), but are generally privately funded within the community.

In the course of this thesis project I also discovered that both diabetes care providers’ and field/social workers’ work is tied into the sociopolitical agenda to reduce costs. Field workers monitor and restrict expenditures for all dental services, medications, medical supplies, transportation, clothing, and hair care, among others. They also monitor administrative functions of the home operator to ensure funding dollars are spent appropriately. In diabetes care, clinical practice is organized within the confines of budgetary restrictions: The hospital is accountable to the primary funding body, the Local Health Integration Network, and subsequently to the Ministry of Health and Long-Term Care, for showing that investment dollars are linked with patient outcomes. A central interest of the governing body is ensuring the provision of cost-effective and efficient services to manage diabetes as a health problem. In the diabetes clinic of reference, this type of service provision was exemplified in the promotion of group sessions to accommodate many people in a time economical fashion. Time restrictions were also placed on patient appointments, which limited clinicians’ discretion to modify or intensify care for those with special needs.

This overlap of a managerial agenda on health care provision is critiqued in others’ work (Rankin & Campbell, 2006; Rankin, 2001; Diamond, 1992; Mykhalovskiy, 2001). Diamond (1992) noted that systems of accountability were used to decide the number of people required to complete intended tasks, and other staff and residents’ needs were not considered in the equation. This resulted in employees carrying heavy workloads and not being able to meet certain residents’ needs (Diamond, 1992), as was seen in this study. Rankin and Campbell (2006) explored nurses’ work to show how it is connected to the political agenda to reform health care
services in Canada. Nurses accept ‘innovation’ and ‘change’ as positive reasons for actively participating in the new managed care that serves the overall interest to reduce costs by increasing service efficiency (Rankin & Campbell, 2006). Mykhalovskiy (2001) explored how health services research coordinated medical and managerial practices and rationalities into extra-local ‘medico-administrative’ relations. Mykhalovskiy showed how health services research plays an active integral role in standardizing and reducing the amount of hospital time allotted to patients who have had heart attacks.

In this study I also analyzed the coordinating effects of texts that govern for-profit group home care, which are disseminated by both the provincial and regional funding bodies. I discovered that the State’s interest in cost containment is also embedded within these documents, which effectively distribute responsibility to providers to organize care for the mentally ill, albeit within extreme restrictions. In comparison to long term care facilities in Ontario, which also provide 24/7 care and supervision, financial support provided to group homes from the Ministry of Health and Long-Term Care is much lower for similar services. The fee for living in a nursing home is $53.23 per day or $1619.08 per month, which covers the cost of room and board. In addition, the Ministry of Health and Long-Term Care pays for all nursing and personal care, meals and snacks (including special diets), laundry services, housekeeping, medication administration, social programs, activities, assistance with activities of daily living, and personal hygiene (Nursing Home Ratings, 2012). As reported previously, the daily fee for living in a group home or residential care facility is $47.75 or $1450.00 per month, which is also meant to pay for room and board. However, the Ministry of Health and Long-Term Care, the Ministry of Community and Social Services, and the local government do not cover any of the nursing or personal care costs, laundry or housekeeping services, nor are linens or furnishings compensated, as in nursing homes. Instead, in group homes, all of these expenses must be paid out of the monthly per diem amount, which was shown in this study to have far reaching repercussions for the residents.

I found that the current funding limits the amount and type of care available for the residents by providing inadequate financial resources to meet the recommended staffing ratio and nutritional needs. As was shown, funding provision is much lower than the amount required in order to employ one staff member for every seven residents, and makes hiring of regulated health
professionals impossible. Additionally, food allotment totals $1.91 per resident per day, an amount that is far below what is required to meet stipulated nutritional recommendations. Medical escort services are also restricted and the extremely low funding provision makes it difficult to hire people for this role. Dental coverage is limited to basic services, and some medications and medical services are not paid for. The recent policy changes in the Domiciliary Program that devolve government responsibility for the cost of over-the-counter medications and dispensing fees further increases inequities in this already marginalized group.

Furthermore, there is no written financial commitment for quality of life initiatives such as vocational, educational, and recreational opportunities that would facilitate full social participation. Even if employment opportunities exist, transportation access issues make such prospects unavailable for people in rural group homes, further increasing social inequities. In the study, quality of life initiatives were limited to the in-home craft program, the scheduled weekly outings, volunteer household jobs, and individual hobbies. Between the daily routines, including meals and snack times, and morning bathing and house cleaning, many residents were often seen sitting in the common areas or in their bedrooms.

Reaume (2009) studied patient life in the Toronto Hospital for the Insane from 1870 to 1940 and his findings suggest that the patients had more quality of life opportunities than are approved by the funding bodies today. In addition to weekly movies, church, dance and bowling, and annual picnic, the patients were offered sleigh rides, physical training, card parties, croquet, cricket, baseball, and billiards (Reaume, 2009). As reported by Reaume, weekly concerts were also held where residents could showcase their talents. Recognizing that activities had a medicinal effect, community volunteers and church groups were invited during winter months to entertain patients through various drama performances, readings, and concerts (Reaume, 2009). In contrast, my analysis of group home life today found there is a lack of State attention to residents’ health disparities, especially their confinement and lack of diversion during winter months. Also noted by Reaume, in spite of documentation that church and weekly dances were the most anticipated events, the decision was made by the authorities in 1906 to abruptly stop Anglican services, which had been offered alongside other Protestant services for 50 years (Reaume, 2009). This mirrors the unilateral decision-making seen in this study, with the sudden closure of Social Night by the HSC Department.
My study resonates in many ways with Diamond’s (1992) work that pointed to the political, economic, and cultural forces that constrain quality of care for elderly people in nursing homes in the United States. Diamond’s (1992) ethnographic study with nursing assistants also explored caretaking as a business and found that nursing homes are organized to maximize profit. Similar to my findings, authority over if and what needs would be met were externally defined and controlled by regulations and policies. He also found that the staff to resident ratio was kept low to reduce costs, and there was rationing of services and items within nursing homes. The government of Ontario transfers a restricted amount of funding through the Ministry of Health and Long-Term Care and the Ministry of Community and Social Services to the HSC and Domiciliary Programs, which similarly results in rationed care.

Nursing attendants’ work was found by Diamond to be devalued, as is the work of those operating group homes. The attendants, primarily impoverished women of colour, were paid low wages, and much of their work remained invisible (Diamond, 1992). Similarly, the ‘hostess’ was viewed as a domestic caregiver, and as I showed, has always been paid a very low per diem amount to provide care 24 hours a day seven days per week. The nursing assistants in Diamond’s study brought with them caring skills learned within their own family units, like the experiential knowledge the care providers of group homes bring to their jobs. Although education was supported in Diamond’s study, the lessons taught were task oriented and served other interests, rather than the interests or needs of those for whom the care was being organized. The imposed care routines were not sensitive to particularities and were so distant from the actual resident needs that good caretaking was impossible, as discovered by Diamond.

The residents of the nursing homes were also known as being a ‘cost,’ similar to the residents of group homes and in particular those with diabetes. In Diamond’s (1992) study, the residents’ lives were routinized around medication and mealtimes, bathing schedules, and organized activities. They involved themselves in hobbies like reading, doing crosswords, or watching television, while “…many appeared to curl into their own worlds, sometimes nodding off” (Diamond, 1992, p. 96). Diamond noted that others found self-worth in various work activities like handing out food trays and cleaning them up afterwards, emptying wastebaskets, or watching out for other residents. Planned activities, like bingo, were organized on a restricted budget. These accounts are similar to my findings regarding structured and unstructured
activities. He also discovered that residents built relationships with each other and with staff, similar to those in the group home. I echo Diamond’s cry for sociopolitical change. As he poignantly pleads, we must listen to the residents and let them share in the shaping of their own lives, not letting profits take precedence over resident wellbeing.

Gender relations

Although Dorothy Smith began from a feminist perspective, she does not promote the reduction of women to a singular category: by naming ‘gender’ it becomes a discursive, abstract entity or phenomenon (1990). Rather, she argues that the multiple, often contradictory social relations that gender women’s particular local historical experiences must be attended to, not gender in the abstract or ‘total’ (Smith, D., 1990). The notion that all women are marginalized is also an erroneous assumption. For example, some women who do not have mental illness are far more equipped than others to mobilize resources in disease self-management. Social contexts, as argued by D. Smith (1990), are socially organized. Text-based discourses are instruments through which social marginalization can occur, as was shown in this study. The mentally ill, as a high risk group, are excluded in diabetes practice guidelines and there is no focus on social constraints, which leads to inequities in health care. Medical comorbidities are omitted in group home care guidelines and imposed regulations create health disparities. The lack of attention to health promotion and illness prevention, and embedded rationing in group home care texts, leads to further health and social inequities.

Lorber and Moore (2002), who explored the social construction of gender and illness, echoed that the biomedical profession emphasizes biology and physiology, and social and environmental aspects of illness are secondary concerns. “Social location produces patterns of health and illness behaviour, but equally important in shaping experiences as patients are the actions of professionals encountered in seeking help and the organizational and financial structures of health care systems” (Lorber & Moore, 2002, p. 9). As was found in this study, in health sciences research, upon which recommendations for practice are based, the person with the illness becomes the object of study and impeding social elements are neglected. The problem is individuated, becoming the responsibility of those afflicted, regardless of social circumstances, which are, at least in part, responsible for disease development.
Like gender, illness is socially constructed (Lorber & Moore, 2002). Social stigma is attached both to a diagnosis of diabetes and mental illness. Where mental illness is concerned, the person is often viewed as being socially different, incapable, or unpredictable. As noted in the pilot study, Anne was labeled an E.U., or an ‘Emotional Upset,’ by the nurse, who stated she was not comfortable providing education to people with mental illness. A person diagnosed with diabetes is stigmatized because this disease is reduced to individual capability: He or she is often viewed as lazy and lacking will power or motivation. Rather than treating this as a socially perpetuated illness, I have shown how diabetes as a problem came to be the residents’ responsibility, while outside forces that are creating disparities and social inequities are overlooked.

**Implications for Change**

*My utopian perspective.*

In the ideal world, people with mental illness would not suffer social segregation and inequalities or disparities in health. In this utopia their health would be privileged over such aspects of care as fire safety. Health promotion initiatives would take priority over mattress checks and roof inspections. The mentally ill would not be rendered homeless because they have an illness, but would be supported in their attempts to seek health. Better yet, illness would be prevented by ensuring access to vitamins, healthy food, exercise opportunities, and integrated health care. This group would have assistance in attaining education, and seeking and maintaining employment opportunities. They would have a sense of meaningful involvement in their communities, and access not only to the small things they wish for, like a walk in the park, but also to attend events or enjoy a weekend away if they desire. Their voices would not be silenced, but instead they would be actively involved in the shaping of their own lives. I can hope for this perfect world, but I also realize that there are limitations to what can be done so that the mentally ill can realize overall health and wellbeing. Therefore, I present my practical list of recommendations for change under the following subheadings; ‘implications for policy changes,’ ‘implications for health care providers,’ ‘implications for changes within the group home,’ and ‘implications for future research.’
**Implications for policy changes.**

The longstanding sociopolitical notion that ‘meeting the basic needs of the seriously mentally ill is enough’ must change so this population can realize a better quality of life. Government directives for mental health should incorporate health promotion and illness prevention as required policy directions. In addition to community supports like housing and mental health programs that are already requirements listed in government documents, linkages to medical practitioners, quality of life initiatives, health promotion programs, and educational and vocational opportunities are further essential elements to reduce health disparities and social inequities. **Recommendation:** Health promotion, illness prevention, medical care of comorbid conditions, and quality of life (recreational, vocational, and educational) opportunities, as integral components to health, must take priority in mental health policy directives.

In addition to mental health funding, the Ministry of Health and Long-Term Care provides financial support for diabetes treatment in Ontario. However, there is no connection made between diabetes and mental health care in respective policies and guidelines. A link between mental health and physical health is needed in policy directives. Tracking of related illnesses is required so relevant data is available to support practice changes for this group, including modified or intensified care. **Recommendation:** There is an urgent need for a linkage between mental health and diabetes in policy directives. Statistics must also be tracked in those that have both diabetes and mental illness in the provincial diabetes registry.

The texts that organize group home care (MOHLTC: Operating Guidelines for HSC, 2003; Lodging Houses By-law, 2005; Hostel Compliance Checklist, 2008; Residential Home Report, 2007) also require an intense focus on health promotion and illness prevention. This population is at high risk for chronic conditions like diabetes and the texts that coordinate group home care need to reflect this. Type 2 diabetes, which accounts for 90% of the cases, is preventable with lifestyle modifications and thus readily lends itself to a preventative approach. Health promotion strategies would also lead to improved outcomes for those already diagnosed with diabetes by, for example, facilitating improved control over glucose levels through exercise and weight loss. **Recommendation:** Group home guidelines and licensing documents must give priority to health promotion, illness prevention, and medical management of comorbid conditions in the mentally ill.
As reported, group home care guidelines contain regulations that are illogical and require amendments, or cannot be carried out in view of financial constraints. Although it is stipulated that nutritional recommendations in Health Canada’s “Eating Well with Canada’s Food Guide” (2007) be met, low funding provision makes alignment with the policy impossible. **Recommendation:** There is an urgent need for financial support so that nutritional recommendations can be met. Additional financial support is also required for more expensive diabetes-related food products.

A healthy, well balanced diet is essential for preventing such chronic illnesses as heart disease, osteoporosis, obesity, and diabetes. The majority of residents are at risk for metabolic conditions. I suggest that a heart healthy diet be incorporated (with modifications for those requiring special diets, like low potassium) into group home care in order to benefit all residents. Providing healthy food choices and similar portion controlled sizes to all residents would also eliminate exclusionary processes that were seen in this study. Options for variety should be included so that agency over food choices can be established. **Recommendation:** a) A heart healthy diet is recommended for all those living in group homes because of their high risk for developing chronic conditions such as diabetes. Further, b) options for variety must be included to facilitate resident agency over food choices.

I also discovered that it is the responsibility of the field workers to ensure residents have healthy food products and to consider weights, portion sizes, and resident eating practices (MOHLTC: Operating Guidelines for HSC, 2003). However, field workers are not trained to carry out these regulations, which would be better implemented by a registered dietitian. **Recommendation:** a) State support is required to facilitate resident, care provider, and home operator attainment of nutritional education that is sensitive to this population’s particularities by a registered dietitian. b) Amendments to group home guidelines to reflect this policy change are required.

Furthermore, the group homes are operated on a monthly food budget and thus nutritional advice needs to accommodate for this and ensure suggestions for change are not unattainable due to financial constraints. All participants voiced their desire for nutritional information to enable healthy eating, but recognized that typical diabetes education did not account for budgetary restrictions. Registered dietitians could work with the residents and home operators to organize
healthy eating within the budget allowance. Once knowledge is obtained, this can be shared on an ad hoc basis with family members who are taking their loved ones out for meals and buying treats. **Recommendation:** a) I recommend that counseling by a dietitian that is sensitive to group home and resident circumstances be provided on-site. However, as noted previously, it is imperative that the funding bodies provide additional financial support for food, and compensate for the added expense of diabetes products. b) Amendments to policies are required to reflect these initiatives.

The policy that stipulates three meals and snacks be available to residents daily leads to obesity. In diabetes care, the addition of healthy snacks is considered for those who are at increased risk for hypoglycemia, but is balanced against the potential for weight gain. In view of the high levels of fat and carbohydrates that are routinely consumed, enacting this regulation without consideration for individual needs creates health disparities. **Recommendation:** Amendments are required to the group home policy that stipulates three meals and snacks must be available to residents daily, to better fit individual requirements for dietary intake.

Regulations also stipulate that medications not be administered by unregulated care providers, but conversely, that staff be knowledgeable of medications, and that a medication management system be in place in the group homes. As was shown, there is much work involved in staying within the boundary of ‘assisting’ with medication administration, and inequities and health disparities are the outcome of these processes. In actuality, the care providers in the group homes are managing and administering medications. Additionally, at the local site the care providers supervised and helped with insulin injection for safety, and performed glucose monitoring with assistance from other residents. All of the participants in this study requested support for diabetes care provision, and care providers wanted formal training on treatment procedures and insurance coverage for liability risks. Currently, medical management (including medication administration, glucose monitoring, and insulin injection) by unregulated care providers is unsupported by the Ministry of Health and Long-Term Care, and the HSC Program is upheld as merely a housing program. The regulating bodies need to recognize that medical comorbidities exist in this population.

There was considerable deliberation on my part in formulating a possible solution to the dilemma of unregulated care providers not being able to administer medications. I know from
my experience as a group home operator that this regulation has created tensions since it was inserted into the revised guidelines in the 1990s. Although unregulated care providers are not to assume this responsibility, as stipulated in the group home care guidelines (MOHLTC: Operating Guidelines for HSC, 2003), home operators are not paid adequately to hire regulated care providers for this role. Additionally, both glucose monitoring and insulin injection are controlled acts to be carried out by regulated health professionals because they involve, “…performing a procedure on tissue below the dermis, below the surface of a mucous membrane…” and “…administering a substance by injection…” (Government of Ontario, Regulated Health Professions Act, section 27.1 and 27.2, 1991). Unregulated health providers are not accountable to an external body like the College of Nurses of Ontario, and therefore there is no system for ensuring service quality or that practice standards are met (CNO, Practice Guideline: Working with Unregulated Care Providers, 2011).

However, in order to accommodate for fiscal constraints and the move from hospital to community care, the College of Nurses of Ontario guidelines for medication administration were revised in 2008 so that registered nurses can now teach unregulated care providers to administer medications. The nurse must still remain responsible for the client plan of care, ongoing assessment of needs, medication effectiveness, and evaluation of client health status (CNO: Practice Standard, Medications, 2008). Therefore, a registered nurse can teach unregulated care providers to administrate medications if a process for ongoing assessment and evaluation is in place.

Further, glucose monitoring is a controlled act that must be delegated: As such, the CNO Practice Standards stipulate additional safeguards must be in place to ensure public protection (CNO: Authorizing Mechanisms, 2011). The nurse is accountable for assessing the individual’s knowledge and judgment to perform the controlled act safely, and that it is only performed on the intended client (CNO: Authorizing Mechanisms, 2011). The nurse can also set limits, for example, by delegating the act for a specific client and only while her or his condition is stable (CNO: Authorizing Mechanisms, 2011). Therefore, according to the College of Nurses of Ontario, glucose monitoring as a controlled act can be performed in the group homes by unregulated care providers if delegated by a registered nurse on a client to client basis.
Where insulin injection is concerned, the Regulated Health Professions Act (1991) contains an exception that allows unregulated care providers to perform controlled acts that are deemed routine activities of daily living (Section 29), which includes giving the same dosage of insulin every day to a client with well-controlled diabetes (CNO: Authorizing Mechanisms, 2011). If the insulin dosage or type requires frequent changing it is not considered a routine activity and cannot be delegated (CNO: Authorizing Mechanisms, 2011). Thus, under certain circumstances, unregulated care providers can perform insulin injection without being delegated by a registered nurse.

With the above knowledge, I pose the following potential solutions to this longstanding issue that requires resolution. Since registered nurses must oversee medication administration, delegate glucose monitoring, and perform ongoing assessment of residents’ physiologic status for insulin injection, as per the Regulated Health Professions Act 1991, their involvement in care provision is fundamental. Currently, the home operators and care providers fear repercussions to providing services for residents with diabetes, as was shown, with worries centering on resident safety and liability risks. **Recommendation:** The Ministry of Health and Long-Term Care, the Ministry of Community and Social Services, and the local government must recognize that medical management, including medication administration, insulin injection, and glucose monitoring, are integral components of providing care to the mentally ill, and must support processes to enable safe practice and protection of residents and staff in these settings. To do this, **a)** financial support is required so that home operators can hire regulated health professionals and obtain proper liability insurance to cover these practices as part of routine care, and **b)** policy changes are needed to reflect medical management and inclusion of registered nurses in the care of the residents in these settings.

Further, the restricted budget limits the amount of available human resources, which affects care provision. It was shown how competing regulatory interests leave little time for care providers to work with residents in their self-care attempts with glucose testing. Although many residents are able to learn and practice glucose monitoring, this is a time-consuming, complex task and some require varying degrees of assistance. It is imperative that the residents continue to be taught and take active roles in diabetes self-care activities. However, working with each resident while they perform various tasks like glucose testing and insulin injection requires extra
time and patience. **Recommendation:** Financial support is required to not only meet the recommended staffing ratio as outlined in group home policies, but to also accommodate for diabetes care provision, a chronic condition that requires added attention.

There are restrictions to funding for medical escort services. Having a care provider accompany the residents to their appointments is crucial, whether it is to help gather information provided by the health provider, or to explain pertinent circumstances. A care provider that has knowledge of the residents and the group home will also help to bridge the gap between mental and medical health care in discussing psychiatric, social, and medical particularities during treatment. **Recommendation:** The governing bodies must **a)** provide competitive funding for medical escort services, and **b)** make amendments to policy documents to reflect the necessity of this important component of care provision.

Exercise is a cornerstone of diabetes care and as was shown the majority of women residents are extremely sedentary, falling short of the recommended 150 minutes per week of moderate-to-vigorous intensity aerobic exercise (CDACPG, 2008). There are numerous barriers and constraints to this group’s attainment of physical activity, including care provider time restrictions, weather conditions, resident physical limitations, lack of interest in the form of activity offered, and lack of funding for transportation to community events or programs, and for staff to accompany residents. Although exercise is recommended in group home guidelines and responsibility is assigned to those in charge for seeking out quality of life initiatives and exercise opportunities, there is no State commitment to financial support. **Recommendation:** **a)** State financial support is required to facilitate engagement in exercise and quality of life initiatives that enable full social participation. **b)** Amendments to group home care policies are needed to reflect the State’s commitment to funding support for engagement in recreational, vocational, and educational opportunities as necessary requirements for overall health and wellbeing.

Thus, as highlighted, the findings warrant the urgent need for the Ministry of Health and Long-Term Care, the Ministry of Community and Social Services, and the local government to recognize that extensive financial constraints have led to disparities in health in an already marginalized population. Policies that direct mental health care must include health promotion, illness prevention, care of comorbid conditions, and quality of life opportunities as essential components to health and wellbeing. Regulations that govern group home care specifically must
also reflect these important elements of care. Additionally, as the agencies responsible for the HSC and Domiciliary Programs, the Ministries must provide proper financial support so nutritional recommendations can be met, safe and inclusive medical care can be offered, and the residents can enjoy full social participation.

Implications for health care providers.

Health care providers practice according to the neo-liberal discourse and self-care ideology that is promoted in government policy directives and in the diabetes practice guidelines. As recommended by Anderson et al. (1991), health care providers need to recognize social ideologies, and rather than uncritically sustaining them in practice, critique their role in creating inequities in health care. Other options or modifications to the self-management model must be considered for groups, who for various reasons are not able to carry out self-care activities to the extent required for success. Recommendation: Health providers must recognize that ‘self-care’ is not suitable for all people, facilitate the gathering of important contextual constraints in practice, and modify treatment modalities to suit particularities.

Health providers must also be cognizant of the managed care in which they participate, and start to question how ‘effective’ and ‘efficient’ services influence the patients they serve. The starting point to facilitating change is critiquing how things work, which includes looking at our own undertakings as care providers. Health professionals need to ask such questions as, “How is a certain text informing my practice and my patient’s service provision?” and “Which interests are being served and which are being excluded?” Changes that focus on the patient, who, according to the government of Ontario, is in the centre of the health care system, can transpire when questions such as these are addressed. Recommendation: Health providers must be aware of how cost containment strategies affect the patients we serve, and prioritize work practices so that health takes priority.

In this study, the disconnect between medical and psychiatric health services was found in both diabetes care and group home care. Within the group home, psychiatrists prescribed medications that are known to cause metabolic changes and proper screening processes were not in place. Recommendation: Risk assessment and screening processes must be incorporated into the practices of psychiatrists overseeing care of group home residents.
In diabetes best practice guidelines, which are developed by health providers, the link is not made between mental illness and diabetes, aside from the acknowledgement of genetic predisposition with schizophrenia. Because the mentally ill are not recognized as a special population in the clinical practice guidelines, diabetes health providers may be unaware of their added risk. Increased awareness of contextual conditions and particularities of this population is required so that health care that is sensitive to this group’s unique circumstances can be offered.

**Recommendation:**

a) The seriously mentally ill must be included in the diabetes guidelines as a high risk population that requires additional attention. b) Impeding social elements also need to be acknowledged in this text for health providers’ consideration in patient-provider encounters.

To do this, barriers and constraints to diabetes care that are captured through qualitative research methodologies should be utilized in the development of future best practice recommendations.

Diabetes education teams lack knowledge of group home circumstances and how best to offer care for the mentally ill. Building of partnerships between residents, group home care providers, and diabetes health professionals is required to increase awareness of barriers and constraints faced by this group. By learning and incorporating resident and group home contextual circumstances, the diabetes educators could better assist the residents in their illness management, and also develop strategies to prevent disease development. Furthermore, diabetes education and training must be tailored to individual capabilities to ensure residents maintain active roles in self-care activities that are supported by others. As a diabetes health provider, I am aware that funding dollars from the Ministry of Health and Long-Term Care have increased over the past few years in an attempt to address the diabetes epidemic. A stipulation for funding is that diabetes teams go into the community to provide services. **Recommendation:** I suggest that some of the funding dedicated to diabetes care in Ontario be used to facilitate a new initiative whereby diabetes teams enter group homes to assess particularities in order to plan and provide relevant, useful education on-site. Within this context, a collaborative approach is required, where experiential knowledge is given primacy to enable the exercising of resident agency to the fullest extent. Offering care in this manner will facilitate awareness of group home conditions, and will initiate relationship building and trust with residents and care providers.

There is also an urgent need for increased public awareness of this issue. The Canadian Diabetes Association, for example, could increase public knowledge and awareness by
designating the seriously mentally ill as a group with a very high incidence of diabetes with limited resources in their public messaging in such texts as those disseminated for diabetes health care providers, and on the CDA website. **Recommendation:** There is an urgent call for increased public awareness through Canadian Diabetes Association messaging strategies such as campaigns, the use of the CDA website (which is accessed by the public at large and by diabetes health professionals), and development of texts that would be available online, in CDA offices, and in clinical settings across Canada.

**Implications for changes within the group home.**

I have mapped out the social relations responsible for creating inequities and health disparities in a group of women with mental illness and diabetes. I have also shown how everyone involved, from the State to the residents at the local site, participate in these textually mediated social relations that are sustaining inequities in health. As a starting point, the people involved with resident care need to recognize how their everyday work practices are connected to the organizing institutions.

I showed how the field and social workers overseeing group home care enact policies that demand attention be paid to the monitoring, restricting, and limiting of resident services, items, and programs. They interpret and enact texts in their decision making regarding approval of certain services, medications, and items, and to deny those that are excluded from the list. Their enactment of licensing documents during formal and informal inspection processes results in a focus on certain aspects of care, and a lack of attendance to others. **Recommendation:** Field and social workers in charge of group home operations need to critically analyze how their work practices, like monitoring and restricting items and services, organize care in a way that creates resident inequities.

The people at the local site, including the residents, also participate in organizing social relations in their everyday activities. As was shown, residents, care providers, and the home operator all engage in budget work and rationing of food and sundries in order to maximize every funding dollar. The home operator also makes creative use of limited human resources in her attempts to provide care and align with criteria for licensing. Residents volunteer to assist with household work, and given the extreme regulatory expectations that are placed on the group home operators, if residents did not assume some responsibility it would be very difficult to get
all of the required daily work done. I showed that the residents are proud of their contributions to their home, and this work offers a sense of worth. However, it points to the lack of State support for resident engagement in employment opportunities outside the home. By participating in these processes, the people at the local site are unknowingly serving cost containment interests, thereby sustaining social inequities that perpetuate health disparities.

Even if home operators were aware that they participate in relations of cost containment, they are in a subordinate position: Receiving funding, future placements, and maintaining their licenses and livelihood are contingent on compliance. The residents are positioned subordinately to other members of society, to those in charge of the programs, and as shown, sometimes to other residents. As reiterated by the women residents who participated in this study, they do not feel it is their place to suggest changes. The home operators’ suggestions and requests are also often denied. This was exemplified when the home operator offered to fill the snack machines with healthier food choices and another operator offered to provide an alternative, more accessible method of transportation. Both proposals were denied by the State, purportedly in view of potential for conflict of interest. The home operators are also extremely aware of the repercussions to enacting certain regulations, like the policy that stipulates that medications not be administered by unregulated care providers, and the regulation that leads to obesity. Yet, home operators are subordinately positioned in an imbalanced relationship with the governing bodies, and as such their suggestions and requests for change are often not acknowledged.

**Recommendations:** I strongly recommend that the Ministry of Health and Long-Term Care, the Ministry of Community and Social Services, and the local government work with residents, care providers, and home operators to gain knowledge and appreciation of how regulations and rationing affect resident health. The governing agents must take steps to increase their own awareness of the repercussions to providing inadequate funding and neglecting health, while heavily regulating other aspects of care. Importantly, the governing agencies must recognize the imposed social locations in which residents and group home operators are positioned and work to reduce the relational inequalities.

**Implications for future research.**

This thesis research project breaks ground for further investigation of the complexities involved in providing diabetes care for residents of group homes. Important discoveries were
made by investigating the social organization of both group home care and diabetes care through the examination of work activities and by analyzing the coordinating effects of texts. Future inquiry is required into the Ministry of Health and Long-Term Care, the Ministry of Community and Social Services, and local government as a next step to determine how funding and policy decisions are made in order to affect important changes. Further potential areas for future investigation where diabetes care is concerned include, but are not limited to, qualitative work in other group homes within the same program for comparison purposes, community-based participatory research, and intervention and evaluation studies.

This research can be used as a backdrop in future comparison studies that examine diabetes care in other group homes in various locations across Ontario and other areas. As reported, the owners operate their group homes differently and important insight can be gained by investigating other homes within the program. Further knowledge can be generated by seeing differences and similarities in the diabetes care practices of, for example, males versus females. Future comparison studies are also needed between rural, suburban, and urban group home settings, using this study as a reference point for the rural homes in Ontario. Resident lifestyles may differ significantly in the homes located on farmland where the men work outside, or those in urban areas where residents have access to amenities.

Intervention studies are required to determine the efficacy of any future programs that may be designed and implemented. I recommend that demonstration studies accompany the implementation of new initiatives to evaluate their effectiveness and sustainability. This information can be utilized to implement similar programs in other group home settings if it is determined that they have a positive influence on diabetes care and outcomes. This knowledge can also be shared through publications to give health care providers direction on how to organize diabetes care provision to better suit this group’s needs. Intervention studies would be useful, for example, in determining the most suitable, feasible, and sustainable exercise program for this population. It is difficult to ascertain at this point what type of program would work best in this setting to motivate and keep the women engaged in routine exercise. Preliminary thoughts centre on keeping it fun, which would entail offering variety, and incentives for participating.

Participatory research could accompany health promotion and quality of life initiatives, implemented as part of an entire social change program to facilitate resident full social
participation. Community involvement and opportunities for vocational, educational, and recreational experiences are imperative for overall health and wellbeing. This type of research, conducted in conjunction with such initiatives, would assist with networking and partnership building with other community members. Everyone, including the residents, is involved and takes ownership and maintains control over the research process. Generating local knowledge regarding the effects of social change programs on their lives is crucial in creating successful, useful research. The Canadian Diabetes Association, along with other organizations like the Canadian Mental Health Association and the Schizophrenia Society of Canada, could support research in this area. Building partnerships through such research initiatives will facilitate important change in societal attitudes towards the mentally ill.

**Strengths and Limitations**

**Strengths of this study.**

By using this approach to conduct the research inquiry I was able to gather rich observations of how life is orchestrated in group home settings that are regulated by the Ministry of Health and Long-Term Care, the Ministry of Community and Social Services, and the local government. Observations also facilitated collection of empirical data to show how sustaining the social ideology of self-care results in health inequities. The initial step in creating social change is to illuminate the ruling social relations that are responsible for deepening the social and health inequities that this already marginally positioned, vulnerable group suffers.

**Limitations of this study.**

I entered into this research having multiple stances as a registered nurse, diabetes educator, previous group home operator, and a doctoral student, which turned out to be one of the greatest difficulties I faced throughout the study. My clinical focus at times limited my capacity to critically question some of my solutions to discovered issues. I have grappled with the “institutional capture” (Smith, D., 2005, p. 155) that propelled me to quick fixes, for example by suggesting inexpensive food-related adjustments, which would not address the social problem of inadequate financial support. However, with recognizing that the entirety of my study looks at institutional processes, I had to hone in on the overall social organization of group home care and what to make of these revelations.
A further limitation, this study investigated diabetes care practices in one group home. As noted, group homes are operated by different people and although standards of practice are in place, there are large variances. Some are kept within families, who own and operate the business and live on the premises. Others are owned by entrepreneurs who hire managers to live in and operate one of their several homes. Some home operators have medical backgrounds and others do not. Future research studies involving other homes within the HSC and Domiciliary Programs are required to gain important insight.

For this study, a group home was chosen that housed all female residents, which limited the ability to explore diabetes care practices carried out by male residents. Male residents may have very different diabetes illness experiences, varying in the way they carry out self-care activities, their eating patterns, and their levels and types of activity. Home operators of male residential facilities may make different food purchasing and menu planning decisions. Many of the homes house both males and females, which may also create variances in diabetes care practices. Future research is required that explores how diabetes care is organized in homes with male residents, and homes with both males and females.

I chose a rurally located group home for this study because many of these homes are located in rural settings across Ontario, as a result of how group home care evolved. Choosing a group home in a rural location enabled the exploration of transportation access issues and the effect on diabetes care and outcomes. Future research involving homes located in urban areas is required because this study highlighted the social inequities faced by residents in country settings. Comparison studies are needed to determine the extent of inequities and to work towards bridging the gaps.

**Concluding Remarks**

This research has made visible the institutional processes that are responsible for creating and sustaining inequities in health in a population of female mentally ill adults who reside in a for-profit group home in rural Ontario. Cost containment as a central State interest has been driving policy decision making for decades, as shown through such major sociopolitical forces as the deinstitutionalization movement, welfare reforms, and health care reform. Inadequate State financial support found in group home care since the inception of the HSC Program has led to deep rationing that limits the amount and type of care that can be afforded the residents.
Nutritional requirements and staffing ratios cannot be met, quality of life opportunities are not available, and medical management is not supported. Field workers, group home operators, and residents all engage, both knowingly and unknowingly, in the social relations of cost containment. Health care providers are also tied into the political agenda to reduce costs, and the managed care in which they engage leads to further disparities in health.

The medical and psychiatric divide creates further barriers to care for the mentally ill. Psychiatrists prescribe atypical antipsychotic medications to this population as part of best practice, thereby increasing their risk for metabolic conditions, but do not implement screening processes or preventative strategies. There is no linkage in policy directives between mental and physical health. Furthermore, the mentally ill are not recognized in the diabetes practice guidelines as a special population requiring additional attention. Support is also lacking for medical management within group home care.

Moreover, the way diabetes care is organized limits its utility for this group because the self-care ideology is promoted in diabetes best practice guidelines and health professionals carry out this method of care in practice. Contextual constraints are not recognized or addressed, and other methods of care are not offered. This creates and sustains further health inequalities for those who cannot carry out self-care practices to the extent required to prevent or delay associated complications. These intertwining social relations all combine to shape disease perpetuating conditions and inequities in health care that lead to poor outcomes.

Thus, there is an urgent need for the Ministry of Health and Long-Term Care, the Ministry of Community and Social Services, and the local government to recognize the repercussions to prioritizing cost containment interests over those that enable health and wellbeing. Low funding provision restricts the ability to hire the adequate number and complement of employees to carry out safe, inclusive care practices. Inadequate funding for basic food provision makes meeting nutritional recommendations impossible. State financial support for diabetes food products is lacking. Costs for over-the-counter medications and dispensing fees are not assumed by the Domiciliary Program. Restrictions are placed on the use of medical escort services. Although quality of life initiatives are promoted in group home policies, there is no written commitment for financial support. Costs are not covered for transportation from rural locations for recreational, educational, or vocational opportunities, or
community events outside the already approved out-of-home weekly activities. These cost containment strategies severely jeopardize the health and wellbeing of the residents who find themselves in these government funded programs. It behooves the government of Ontario to provide financial support in order to eliminate these social inequities.

The government agency responsible for developing for-profit group home guidelines is asked to revisit the regulations that give primacy to certain aspects of care, while omitting other important components of health like medical management of comorbid conditions, health promotion, and illness prevention. There is also a call for policy makers in both the areas of mental health and diabetes care to recognize that a linkage between physical and mental health is required. The connection needs to be made in policy directives to increase health care provider awareness, to build partnerships, and to facilitate required practice changes.

Health care providers must critically analyze social ideologies like self-care, so those that create health inequities are not sustained in practice. They must also be aware of and sensitive to constraining social elements that may be impeding health care and outcomes. Medical service providers must focus on not just the physiological aspects of health, but also sociological and contextual factors. Those responsible for developing texts like the diabetes guidelines need to consider qualitative research in its ability to inform decision making, in addition to randomized control trials where the patient is the object of study and sociological factors are overlooked.

Finally, the governing bodies, health professionals, and field workers need to build collaborative, power-balanced relationships with the residents, care providers, and home operators. The residents’ lives are shaped by outside social forces that not only push them further into the societal margins, but also create and sustain inequities in health. Through relationship building with those who live the everyday actualities of group home life, awareness and understanding of particularities and circumstances can be gained so that the above social changes can ensue. Only then will the residents be able to realize the health, wellbeing, and sense of equality that they deserve.
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Appendix A

Interview Guide: Questions and Prompts for Interview

This interview guide is meant to provide direction in all of the interviews, which will resemble focused conversations that are dialogic in nature. The aim of this institutional ethnography is to gain understanding of everyday experiences, with a particular focus on work activities, to gain insight into the organization of diabetes care for people with mental illness who live in group homes. The language, terminology and topic sequencing will vary according to informant preference and personal characteristics.

**Interview Protocol**

**Lead Statement/Question**

I am interested in learning about your work activities, what it is you actually do on a daily basis in relation to your work practices. Can we start with a general synopsis of ‘what your work involves’ so I can learn about your everyday experiences?

**Interview Questions**

*Throughout the interview clarification will be sought regarding specific tasks/work practices by using the following prompts as indicated:*

1) Please describe the sequence of your daily work activities.
2) Can you describe this particular task?
3) Why is this carried out in this manner?
4) What skills/knowledge are required for this work practice?
5) Can you explain this activity in more detail?
6) Can you describe your use of this form?
7) Why are you gathering this information?
8) Who uses this information? For what purposes?
9) Is this task a requirement? For whom specifically?
10) What challenges do you come across in your work?
11) Can you explain this in more detail? Can you provide examples?
12) What issues are of concern to you in your daily work practices?
13) How does your work connect with others’ work practices within the group home?
14) How does your work connect with others’ work practices outside the group home?
I’m interested in exploring your experiences as a field worker for the HSC Program. So, can we start with a synopsis of the HSC program, and what your role was within that program?

**Discussion related to the inception of the HSC Program:**
- How/why the program started?
- What were the major driving forces for group homes to be developed?
- How were potential home operators approached?
- How was it decided if a particular location and person was suitable to be/operate a group home?
- What were the requirements to become a group home operator?
- What were the requirements to keep a group home operating?
- Why are group homes situated in rural areas and specifically on farms?
- Why is it that they seem to be passed through generations of family members?
- How were the operating guidelines developed?
- What were criteria for licensing historically? How has this changed over time? Why has licensing criteria changed?
- How is it that the group homes are being taken up now as businesses (one owner purchasing many homes)?
- How does funding work?
- How does licensing work?
- How does this program connect with the Domiciliary Hostels Program?

**Your Role:**
- Your employer was the Centre for Addiction and Mental Health. Can you talk about how you came to be a field worker and what your role is?
- What are your daily work activities? When you enter the group homes, what is the focus of your work activities?
- What forms do you fill out regularly?
- What does the reporting process look like?
- Accountability: How many homes you are responsible for? How many homes are there and how many field workers? How are responsibilities defined?

**Admitting process for new residents:**
- Can you describe this work activity?
- What are criteria for admission?
- What paperwork is involved?
- How are financial matters managed?
- How is family involved?
How is the hospital involved?

**Psychiatric Wellbeing:**

What are the particular work activities in assessing for residents’ mental health?
Are there any continuous or routine checks?
How is mental wellbeing facilitated in the Program?
What was the process for having someone readmitted to hospital if required?
How has this changed over time?

**Medical Wellbeing:**

Was there any particular focus on medical wellbeing? If so please explain.
What are the particular work activities in assessing medical wellbeing?

**Funding Allotments:**

How does funding work?
How are policy decisions made in regards to funding entitlement (both per diem and personal needs allowance)?
Clothing, Supplies, Dentist, Special Requests, Appointments/Outings, Transportation

**Diabetes Care:**

Did you have any personal experience with diabetes care in the group homes?
Are there special guidelines or policies that the home operators follow regarding diabetes care?
What are the expected qualifications/specifications for care providers regarding diabetes care?
Are there expectations regarding ‘self-care’ for those living with diabetes in the group home?
Exercise: Are there guidelines in place? How is exercise attainment ensured?
Food: Are there food-related guidelines and expectations? How is ‘healthy’ eating determined?
How is medical care organized and ensured?
Are there medical care expectations? How is diabetes medical care supported?
How is a certain level of care ensured across various group homes where diabetes is concerned?
Are there special funding entitlements for people with diabetes?
Have residents voiced concerns about their attempts to carry out diabetes self-care activities?
Have home operators voiced concerns when trying to manage diabetes among residents?
I am wondering what happens when the person with diabetes needs placement? Is there ever a concern that they won’t be accepted because of their illness?
What if any barriers or constraints would you say there are to providing diabetes care to this population?
What recommendations would you suggest for improving both group home care and specifically diabetes care in this population?

**Domiciliary Hostels Worker**

Same ‘Interview Topic Discussion Guide’ focusing on the Domiciliary Program.
Appendix C
Observational Study Guide

Observational studies will be undertaken with people living and working within the context of the group home. Additionally, observational studies will be carried out on certain recreational trips outside of the group home. The purpose of the observational studies is to explore activities related to diabetes care as they occur within the natural social setting to gain insight actual experiences and activities as they unfold over time and place.

Observational Studies Within the Group Home

Types of observational studies to be included are as follows;

- Meal planning, food preparation and mealtime activities.
- Daily routine ‘tasks’ of care providers and people residing in the group home.
- Patterns of physical activity in which the people living in the group home engage.
- Recreational activities within the group home.
- Diabetes ‘work’ related activities, such as patterns of glucose (sugar) monitoring and types/patterns of physical activity, timing of meals, and structuring of medical appointments.

Observational Studies Outside the Group Home

Types of observational studies to be included are as follows;

- Mall shopping trips.
- Grocery shopping trips with homeowner and individuals living with diabetes.
- Bowling and other recreational outings geared towards obtaining physical activity.

Researcher’s Role

The researcher’s role throughout the observational studies will be that of a ‘participant observer,’ whereby she will be invited to participate in activities/experiences as they unfold. Researcher participation during the observational studies is meant to reduce ambivalence related to the researcher’s presence and to facilitate a deeper understanding of what every day experiences/activities mean to the individuals involved. The researcher will make clear to all participants prior to and during the observational studies that her role within the setting is that of a researcher. Additionally, all people involved will be made aware of the voluntary nature of their participation, and that they may choose to not participate at any time. It will also be made clear to participants that they may choose to ask the researcher to stop observing at any point during the observational studies without question. Fieldnotes will be recorded by the researcher both during and after each observational study on such aspects as the physical environment, the people in their various interactions, and social situations, dialogues that take place, daily process of activities, and the researcher’s personal reflections.
Appendix D

Government of Ontario Mental Health Reform Policy Documents

1983: Towards a Blueprint for Change: A Mental Health Policy and Program Perspective [Heseltine Report]. A separation of treatment and accommodation was recommended within a comprehensive, balanced mental health care system (MOHLTC, Making it Happen: Implementation Plan for Mental Health Reform, 1999).

1988: Building Community Support for People [Graham Report]. A long-range plan with principles and objectives for the development and implementation of an organized, comprehensive community mental health system was proposed (MOHLTC, Making it Happen: Implementation Plan for Mental Health Reform, 1999). The mentally ill were identified as a priority and in the plan there was a call for consumer and family involvement in care planning (MOHLTC, Making it Happen: Implementation Plan for Mental Health Reform, 1999).

1993: Putting People First: The Reform of Mental Health Services in Ontario. This policy framework endorsed the Graham Report's vision of a community mental health system and outlined a 10 year reform strategy. The mentally ill were again identified as a priority. Measurable targets and timelines for change, including specific plans to shift resources from institution to community, optimum bed ratios, hospitalization rates, and services ratios were outlined (MOHTLC, Making it Happen: Implementation Plan for Mental Health Reform, 1999).

1998: The Honorable Elizabeth Witmer, Minister of Health, requested that Dan Newman, Parliamentary Assistant to the Minister of Health, lead a consultative review of progress on Ontario’s mental health reform (MOHLTC, Making it Happen: Implementation Plan for Mental Health Reform, 1999). A report titled, “2000 and Beyond: Strengthening Ontario’s Mental Health System” (MOHLTC, 2002) was the outcome of a five week review, in which an implementation for change strategy was recommended.
1999: **Making it Happen: Implementation Plan for Mental Health Reform.** Developed in response to the call for an implementation strategy, the Ministry’s plan to continue with restructuring of the mental health care system over a three year period with a focus on community alternatives to care was outlined (MOHLTC: The Time is Now, 2002).

1999: **Making it Happen: Operational Framework for the Delivery of Mental Health Services and Supports.** This companion document to the Implementation Plan for Mental Health Reform was developed for providers and planners of mental health care services. This framework outlined more detailed directions on the organization and delivery of services for people with mental illness (MOHLTC: The Time is Now, 2002).

2000: **Mental Health: Making it Work: Policy Framework for Employment Supports for People with Serious Mental Illness.** Development and implementation of an enhanced system of employment supports for people with mental illness was recommended (MOHLTC: Making it Work: Policy framework for employment supports for people with serious mental illness, 2000).

2000: **Mental Health Act and Health Care Consent Act amendments: December 1, 2000, Bill 68 [formerly Brian’s Law].** Community Treatment Orders were introduced, which were meant to enable treatment of the mentally ill in the community, thereby reducing use of inpatient services.

2002: **The Time is Now: Themes and Recommendations for Mental Health Reform in Ontario.** Final Report of the Provincial Forum of Mental Health Implementation Task Force Chairs. Direction was offered for implementation of the principles outlined in, “Making it Happen: Implementation Plan for Mental Health Reform” (1999) and “Making it Happen: Operational Framework for the Delivery of Mental Health Services and Supports” (1999). The ‘recovery philosophy,’ whereby, “…people living with mental illness can take control of their lives, create new goals and aspirations, and engage in society as productive citizens” was highlighted as being integral to a reformed mental health system (MOHLTC: The Time is Now, 2002, p. 10 ). Recommendations included a) adopting a recovery-based philosophy, b) having the consumer at the centre of the system, c) creating linkages with other support services, d) building an accessible system
with equitable funding and clearly defined roles and responsibilities, e) implementing regional decision making to improve local delivery systems, f) developing greater system of accountability, g) supporting more research in mental health, h) building peer support into the mental health system, i) ensuring safe and affordable housing, j) increasing support for families, k) early intervention and treatment, l) enhancing employment and income support programs, among others (MOHLTC: The Time is Now, 2002). Policy development for populations with special needs such as those with a dual diagnosis, forensics, concurrent disorders, diverse cultures, Aboriginal People, and children and seniors were further recommendations (MOHLTC: The Time is Now, 2002).

2004: **Mental Health Accountability Framework (MOHLTC).** “This document is intended to be a ‘living’ document that sets the stage for increased accountability on a system-wide basis. It is to be reviewed and refined as performance measures are developed and implemented and as government and the MOHLTC consider the next steps in the mental health reform process” (MOHLTC: Accountability Framework, 2004, p. 5). Accountability, according to the Ministry of Health, is key to ensuring services and supports are delivered, and funding is used appropriately (2004). The Ministry of Health and Long-Term Care stipulations for transfer payment agencies and service providers were outlined: providers are accountable to the Ministry for delivering cost-effective, efficient services, setting performance expectations, and achieving measured outcomes (MOHLTC: Accountability Framework, 2004).

2004: Under the umbrella, ‘Program Policy Framework and Service Standards for Mental Health Services and Supports,’ the following documents that defined standards for service provision in each of these areas were developed. These policies were formulated to ensure accountability and cost effective services and follow the principles outlined in the overarching policy documents (MOHLTC: Program Policy Framework, 2009).

2004: **Program Policy Framework for Early Intervention in Psychosis.**

2005: **Crisis Response Service Standards for Mental Health Services and Support.**

2005: **Intensive Case Management Standards for Mental Health Services and Support.**

2005: **Ontario Program Standards for ACT Teams.**
2006: *A Program for Mental Health Diversion/Court Support Services.*

2008: **MOHLTC and Ministry of Community and Social Services. Joint Policy Guideline for the Provision of Community Mental Health and Developmental Services for Adults with a Dual Diagnosis.** A framework for planning, coordinating and delivery of mental health services for adults with a dual diagnosis was outlined.

2009: **MOHLTC: Every Door is the Right Door: Towards a 10 year Mental Health and Addictions Strategy.** A discussion paper to provide information to the Minister of Health and Long-Term Care on a potential 10 year strategic plan for mental health and addictions, including sequencing priorities, identifying where to start and who to involve, and establishing performance targets in order to measure progress.

2011: **MOHLTC: Open Minds, Healthy Minds: Ontario’s Comprehensive Mental Health and Addictions Strategy.** A framework to transform the mental health system. Guiding goals outlined included improved mental health and wellbeing for Ontarians, creating healthy, resilient inclusive communities, identifying mental health and addictions problems early and intervene, and providing timely, high quality, integrated, person-directed, health and other human services.
Appendix E

Lodging Houses By-law

THE REGIONAL MUNICIPALITY OF [Redacted]

BILL NO. 63

BY-LAW NO. L1-0012-2005-061

A by-law to provide for the issuance of licences
for lodging houses

WHEREAS section 165(4) of the Municipal Act, 2001, S.O. 2001, c. 25 (the "Municipal Act") authorizes The Regional Municipality of [Redacted] to license, regulate and govern lodging houses;

AND WHEREAS a public meeting was held on April 15th, 2005, at which time interested members of the public were given the opportunity to make representations with respect to the licensing of lodging houses;

NOW THEREFORE, the Council of The Regional Municipality of [Redacted] hereby enacts as follows:

1. PURPOSES OF THIS BY-LAW

1.1 This by-law and the licensing powers authorized herein are for one or more of the following purposes:

a) health and safety,

b) nuisance control, and

c) consumer protection.

2. DEFINITIONS

2.1 In this by-law:

a) "applicable law" means any Federal, provincial, municipal or local laws, statutes, regulations and by-laws in respect of or governing the matters in this by-law;

b) "applicant" means the person making an application for a licence or renewal of a licence under this by-law;
c) "authority having jurisdiction" means the ministry, organization, office or individual responsible for ensuring compliance with applicable law, and includes the Chief Building Officer, the Fire Chief, the Local Clerk, and the Medical Officer of Health;

d) "Chief Building Officer" means the person in the position of Chief Building Officer or equivalent thereto and his or her delegate of the local municipality in which the lodging house is located, who is a building official as defined under the Building Code Act, 1992, S.O. 1992, c. 23, as amended;

e) "Commissioner" means the Commissioner of Community Services and Housing of the Regional Municipality of [Redacted].

f) "Council" means the Council of the Regional Municipality of [Redacted];

g) "enforcement officer" means any person appointed by the Council of the Regional Municipality of [Redacted] as a Municipal By-law Enforcement Officer;

h) "Fire Chief" means the person in the position of Fire Chief or equivalent thereto and his or her delegate of the local municipality in which the lodging house is located, who is a fire chief as defined under the Fire Protection and Prevention Act, 1997, S.O. 1997, c. 4, as amended;

i) "licence" means a licence issued under this by-law and includes, unless the context otherwise requires, a provisional licence;

j) "licensee" means any person licensed pursuant to this by-law to operate a lodging house;

k) "Licence Committee" means the Committee of Community Services and Housing of the Regional Municipality of [Redacted] or such other committee as Council designates;

l) "Local Clerk" means the person in the position of Clerk and his or her delegate of the local municipality in which the lodging house is located;

m) "local municipality" means any lower-tier municipality as defined in the Municipal Act that forms part of the Regional Municipality of [Redacted];

n) "lodging house" means a nursing home and any house or other building or portion of it in which four (4) or more persons are lodged for hire but does not include a hotel, hospital, nursing home, home for the young or the aged or institution if it is licensed, approved or supervised under an Act, other than the Municipal Act;
3. APPLICATION

3.1 This by-law shall apply to any lodging house located within the Regional Municipality of [insert name].

4. INTERPRETATION

4.1 Schedules “A” and “B” shall form part of this by-law.

4.2 Where the time for doing any act or taking any proceeding expires on a Saturday, Sunday or a statutory or public holiday, the act or proceeding may be done on the next business day.

4.3 If any clause, paragraph, section, or article or part thereof of this by-law be declared by any court of law to be bad, illegal or ultra vires, such clause, paragraph, section or article or part thereof shall be deemed to be severable and all parts hereof are declared to be separate and independent and enacted as such.

4.4 A reference to a clause, paragraph, section or article shall refer to the applicable clause, paragraph, section or article in this by-law unless otherwise stated.

4.5 Where any person is authorized to take any action pursuant to this by-law, such action may be taken by that person’s authorized designate.
5. DELEGATION OF POWERS TO LICENCE COMMITTEE

5.1 Council delegates to the Licence Committee the responsibility to hold a hearing or give interested parties an opportunity to be heard in place of Council with respect to the consideration of the following licensing matters:

a) the Commissioner's recommendation to the Licence Committee that the Region has grounds to refuse to issue the licence,

b) the Commissioner's recommendation to the Licence Committee that the Region has grounds to revoke or suspend the licence,

c) the imposition of special conditions on a licensee that have not been imposed on all other licensees in order to obtain, continue to hold or renew a licence, and

d) the imposition of conditions including special conditions, as a requirement of continuing to hold a licence at any time during the term of the licence, being licensing powers under clause 150(3)(b), (f) or (g) of the Municipal Act.

5.2 The Licence Committee shall provide its recommendations to Council after which Council may make the decision in accordance with the provisions of section 252 of the Municipal Act.

5.3 Council delegates to the Regional Clerk the responsibility of coordinating dates with the Commissioner for the holding of hearings by the Licence Committee pursuant to this by-law.

6. POWERS OF COMMISSIONER

6.1 The Commissioner is authorized to administer the provisions of this by-law on behalf of the Region, including enforcement, together with such other enforcement officers as may be necessary.

7. INSPECTION POWERS

7.1 The Commissioner is authorized to inspect, at any reasonable time, the premises in respect of which a licence has been issued, to ensure compliance with the provisions of this by-law, and may inspect any books, records or other documents relating to the lodging house.

7.2 No person shall obstruct, hinder or otherwise interfere with any inspections conducted pursuant to this by-law.

7.3 The signature of the applicant on the application shall be deemed to be permission for an authority having jurisdiction to enter the premises named on the application at any reasonable time in order to carry out necessary inspections.
8. LICENCE REQUIRED

8.1 No person shall operate a lodging house until he or she has procured a licence to do so.

8.2 Where a licence is issued subject to any condition, no person shall operate a lodging house except in accordance with the condition.

8.3 No person shall operate a lodging house in violation of this by-law or any applicable law.

9. APPLICATIONS FOR ISSUANCE OF LICENCE

Applications for Licence:

9.1 The following two (2) types of applications for the issuance of a licence may be made:
   a) an original licence, and
   b) the renewal of a licence.

9.2 In respect of an application for an original licence:
   a) the application shall include the following information:
      i) the proposed name and the municipal address of the lodging house;
      ii) the name, address and telephone number of the applicant, and the
          manager, if the applicant does not reside on the premises or is not
          actively in charge;
      iii) where the lodging house is to be operated by a corporation, the names
           and addresses of its officers and directors;
      iv) where the lodging house is to be operated by a partnership or a
          proprietorship, the names and addresses of its partners or proprietor,
          respectively;
      v) the name, address and telephone number of the registered owner of the
         property upon which the lodging house is situated;
      vi) the proposed number of residents to be lodged and the number of
          sleeping rooms available for residents;
      vii) the names of staff members; and
      viii) a declaration of the applicant confirming the accuracy of the application
           and the authenticity of any documentation provided with the application.
b) the application shall be accompanied by the following documentation:

i) evidence that the lodging house has general liability insurance coverage of not less than $5,000,000 per occurrence on the Region’s standard certificate of insurance form or other certificate of insurance form acceptable to the Region’s Insurance and Risk Manager;

ii) if a corporation, its incorporation documents, and annual return under the Corporations Information Act, R.S.O. 1990, c. C. 39, and business name registration documents, if applicable;

iii) if a partnership or proprietorship, its registration documents;

iv) Canadian Police Clearance Certificates for all staff that will have direct contact with residents; and

v) a floor plan of the premises, including dimensions and the proposed use of each room.

c) the applicant shall pay, by certified cheque or money order, the non-refundable prescribed fee as set out in Schedule “A” to this by-law.

9.3 In respect of an application for a renewal of a licence:

a) the application shall include the information set out in paragraph a) of section 9.2.

b) the application shall be accompanied by the documentation set out in clause i) of paragraph b) of section 9.2, and if any documentation referred to in clauses ii) through v) inclusive of paragraph b) of section 9.2 has changed, furnish such updated documentation, save and except that even if the staff having direct contact with residents has not changed, the applicant shall obtain a Canadian Police Clearance Certificate after every three (3) years of such person’s employment with the applicant.

c) the applicant shall pay, by certified cheque or money order, the non-refundable prescribed fee as set out in Schedule “A” to this by-law.

d) the application shall be made no later than sixty (60) days before the date on which the licence will expire.

9.4 The Commissioner shall, upon receipt of an application referred to in either section 9.2 or section 9.3, make or cause to be made all inspections to determine whether issuing the licence applied for would be in compliance with applicable law. In this regard but without limiting the generality of the foregoing, the Commissioner shall request:

a) a letter from the Chief Building Officer stating that, in his or her opinion, the premises are in compliance with the applicable provisions of the Ontario
Building Code, and that the on-site sewage system will accommodate the number of residents set out in the application for a licence;

b) a letter from the Fire Chief stating that, upon due inquiry, there are no outstanding work orders or deficiencies against the premises with respect to the applicable provisions of the Ontario Fire Code;

c) a letter from the Local Clerk stating that, in his or her opinion, the premises are zoned to permit the operation of the lodging house and its operation would not contravene any by-law of the local municipality; and

d) a letter from the Medical Officer of Health stating that, following an inspection of the lodging house, in his or her opinion, there is no reason, from a public health perspective, that a licence should not be issued to the applicant.

Issuance of Licence:

9.5 The Commissioner shall issue a licence, where all of the following conditions have been met:

a) the applicant has complied with the requirements set out in section 9.2 or section 9.3, as the case may be;

b) the approvals of the authorities having jurisdiction set out in section 9.4 have been obtained;

c) the inspections do not indicate non-compliance with any applicable law; and

d) the Commissioner determines that there are no grounds as described in sections 10.1, 10.2 and 10.3 for the Region to refuse to issue a licence.

Provisional Licence:

9.6 Despite section 19.1, where the applicant requires additional time to satisfy the terms or conditions required by an authority having jurisdiction as a condition of granting its approval, the Commissioner may issue a provisional licence provided that the authority having jurisdiction consents in writing to the issue of a provisional licence subject to such terms or conditions being fulfilled by the applicant prior to the issue of a licence.

9.7 Where a provisional licence is issued under section 9.6, the provisional licence shall set out:

a) the period of time for which it is valid;

b) the provisions of any applicable law which the lodging house contravenes; and
c) a statement that the applicant is required to bring the lodging house into compliance with the applicable law within the period of time set out in clause a) herein.

9.8 Where a provisional licence is issued, the Commissioner shall cause an inspection to be made of the lodging house by an authority having jurisdiction to ensure compliance with this by-law, and if it has been brought into compliance, the Commissioner may issue a licence.

10. REFUSAL TO ISSUE LICENCE

10.1 For the purposes of section 9.5, the Commissioner may determine that there are grounds for the Region to refuse to issue a licence, where:

a) the past conduct of the applicant or any employee of the applicant or, where the applicant is a corporation, its officers, directors or employees, or where the applicant is a partnership or proprietorship, its partners or proprietor, respectively or employees, affords reasonable grounds for belief that the applicant will not operate the lodging house in accordance with applicable law, proper management, or with honesty and integrity.

b) there are outstanding complaints with respect to the lodging house or objections to the application have been received by the Commissioner, which complaints or objections are not considered by the Commissioner as being frivolous or vexatious.

10.2 In considering the issue of proper management under section 10.1, the Commissioner shall have regard to the following:

a) maintenance of the lodging house in a safe, clean and sanitary condition;

b) any conduct on the part of the applicant that would endanger the health and safety of residents or members of the public; and

c) the applicant’s practices and best efforts to prevent illegal drug and narcotic or prostitution related criminal activities or any other criminal activities by residents or visitors on the premises.

10.3 In considering the issue of honesty and integrity under section 10.1, the Commissioner shall have regard, among other matters, to the following:

a) any convictions, orders, rulings or judgments made by any authority having jurisdiction against the applicant related to the operation of the lodging house; and

b) any false or misleading information provided by the applicant in the application.
10.4 Where the Commissioner determines that there are grounds for the Region to refuse to issue a licence, the Commissioner shall give written notice thereof to the applicant, such notice to include a statement,

a) that a hearing before the Licence Committee will be scheduled to review the Commissioner's determination that there are grounds for the Region to refuse to issue a licence,

b) as to the time, date and place of the hearing, which shall be at least fourteen (14) days from the date the applicant received notice from the Commissioner,

c) setting out the facts upon which the Commissioner has determined that there are grounds for the Region to refuse to issue a licence,

d) that the hearing will be a public hearing unless otherwise decided by the Licence Committee under section 12.5, and

e) that, if the applicant does not attend the hearing, the Licence Committee may proceed in the absence of the applicant and the applicant will not be entitled to any further notice of the proceeding.

11. REVOCATION OR SUSPENSION OF LICENCE

11.1 Where the Commissioner is of the opinion that the licensee has contravened a provision of this by-law, the Commissioner may give written notice to the licensee setting out the licensee's contravention. The notice shall require the licensee to take remedial action to remedy the contravention within twenty (20) days or such shorter period in the Commissioner's sole discretion, or, where the contravention is not capable of being rectified within such period, take such diligent steps within such period, in the opinion of the Commissioner, to remedy the contravention. The notice may, but need not specify the remedial steps that the Region requires of the licensee to rectify the contravention.

11.2 If the licensee fails to remedy a contravention of this by-law despite being given the opportunity to do so in accordance with section 11.1, the Commissioner shall give the licence notice that a hearing will be scheduled before the Licence Committee to determine whether the Region has grounds to revoke or suspend the licence and to make a recommendation to Council therefor and the provisions of article 12 apply with necessary modifications.

11.3 Despite any other provision of this by-law, the Commissioner may report to the Licence Committee any breaches by the licensee of this by-law with a request to consider the status of the licensee and make recommendations to Council.
12. HEARING

12.1 The Licence Committee shall hold the hearing at the time, on the date and at the place set out in the notice by the Commissioner to the applicant or licensee.

12.2 The applicant or licensee may be represented at the hearing by counsel, and the applicant or licensee or its counsel shall have the right to adduce evidence, submit argument in support of its application and cross-examine witnesses adverse in interest.

12.3 The Region shall be represented at the hearing by the Commissioner, who is entitled to adduce evidence and submit arguments in reply to evidence and argument on behalf of the applicant or licensee.

12.4 At the hearing, the onus shall be upon the applicant or licensee to show cause why,

   a) the licence should be issued, or
   b) the licence should not be suspended or revoked, or
   c) conditions should not be imposed on the licence.

12.5 All hearings shall be public hearings unless the applicant or licensee requests that the hearing be held in camera and the Licence Committee may approve the request by a simple majority in accordance with the Statutory Powers Procedure Act.

13. COUNCIL DECISION

13.1 After holding a hearing, the Licence Committee shall provide its recommendation to Council whether to:

   a) issue a licence, including issuing a licence subject to terms or conditions, or
   b) suspend or revoke a licence,

after which Council may make the decision.

13.2 Where the matter before the Licence Committee concerns any grounds to refuse to issue a licence referred to in section 10.1, in deciding whether to make a recommendation to Council to issue a licence, the Licence Committee shall take into account any record of previous contravention or conviction against the applicant under applicable law and any record and disposition of complaints against the applicant by:

   a) an authority having jurisdiction;
   b) residents of the lodging house or other residential dwellings owned by the applicant;
c) persons residing in the vicinity of the lodging house; and

d) any other person who has knowledge of the manner in which the applicant operated lodging houses or permitted them to be operated.

For greater certainty, the Licence Committee may consider the above-mentioned record of contraventions, convictions or complaints, as well as those factors set out in sections 10.2 and 10.3, in deciding whether to make a recommendation to Council to revoke or suspend a licence.

13.3 The Commissioner shall provide written notice to the applicant or licensee of Council’s decision.

13.4 If the decision rendered by Council under section 13.1 is to grant the applicant or licensee the licence applied for, the licence shall be issued.

13.5 If the decision rendered by Council under section 13.1 is to suspend or revoke the licence, the licensee shall within forty-eight (48) hours after receiving written notice, return the licence certificate to the Commissioner, failing which the Commissioner shall have access to the premises in respect of such licence for the purpose of receiving or taking the licence certificate.

14. ISSUANCE OF LICENCE

14.1 If the provisions of this by-law are complied with and the issuance of the licence has been approved, the Commissioner may issue the licence and send it by ordinary mail to the applicant at the address shown on the application.

14.2 Every person obtaining a licence under this by-law shall ensure that the licence is posted in a conspicuous place in the lodging house, so as to be visible to the public.

14.3 No person shall enjoy a vested right in the continuance of a licence and upon the issuance, suspension or revocation thereof, the value of a licence shall be the property of the Region.

15. LICENCE PERIOD

15.1 A licence issued under this by-law, save and except for a provisional licence, shall be valid for one (1) year from its date of issue, or where a provisional licence has been issued to a licensee, the licence for such licensee shall expire one (1) year from the date of issue of the provisional licence.

15.2 A provisional licence shall be valid for a period not exceeding four (4) months from its date of issue. An applicant may be issued more than one and/or consecutive provisional licences so long as the aggregate period of such provisional licences is not greater than twelve (12) months.
16. TRANSFERS

16.1. No licence may be transferred without the consent in writing of the Commissioner.

16.2. A licence expires when the ownership of a lodging house changes, and a change in ownership includes:

a) the conveyance of the ownership on the title to the property on which the lodging house is situated, or

b) any arrangement by which the beneficial ownership is transferred, or

c) where the ownership is held by a corporation, the transfer of the ownership of shares which results in a change in the control of the corporation, or


d) where the ownership is held by a partnership or proprietorship, a change in the partners or proprietors respectively, which results in a change in the voting control of the partnership or proprietorship.

17. INSURANCE

17.1 The licensee shall maintain in full force and effect any policy of insurance required under this by-law for the period for which the licence is in effect.

18. NOTIFICATION ON HAPPENING OF CERTAIN EVENTS

18.1 Within ten (10) days of the happening of the following events, a licensee shall provide to the Commissioner in writing:

a) if any information or documentation set out in paragraphs a) or b) of section 9.2 has changed, such updated information or documentation.

b) prior to any construction, renovation, alteration or addition to the lodging house, the particulars of such work and evidence satisfactory to the Commissioner that all applicable permits and approvals to the work have been obtained by the licensee.

19. COMPLIANCE WITH LAWS, ETC.

19.1 The licensee shall comply with all applicable laws.

19.2 The licensee shall comply with the guidelines set out in Schedule “B” of this by-law.

19.3 Where the licensee has entered into a domiciliary hostel agreement with the Region for a fee subsidy of residents of the lodging house, the licensee shall comply with the provisions of such agreement.
20. SERVICE OF NOTICES

20.1. Subject to section 18 of the Statutory Powers Procedure Act, any notice or document required or permitted to be served by the Commissioner on the applicant or licensee may be delivered personally to the applicant or licensee or sent by registered mail to the address shown on the application or last on file with the Region.

20.2. Where a notice or document is served by mail, it is deemed to have been received on the fifth day after the date of mailing.

21. ENFORCEMENT

21.1 Every person, other than a corporation, who contravenes any provision of this by-law, and every director or officer of a corporation who concurs in such contravention by the corporation, is guilty of an offence, and on conviction is liable to a fine of not more than $25,000.

21.2 Every corporation that contravenes any provision of this by-law is guilty of an offence and on conviction is liable to a fine of not more than $25,000.

22. REPEAL

22.1 By-law no. LI-0009-2000-071, as amended, is hereby repealed.

22.2 Despite the repeal of By-law no. LI-0009-2000-071, licences issued under that by-law shall remain in effect until their expiry date.

23. SHORT TITLE

23.1 This by-law may be referred to as the "Lodging Houses By-law".

ENACTED AND PASSED this 1st day of June, 2005.

______________________________  ________________________________
Regional Clerk                                     Regional Chair

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### SCHEDULE “A”

**Fees**

<table>
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<th>Column 1</th>
<th>Column 2</th>
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<tr>
<td>Lodging house licence*</td>
<td>$175.00</td>
</tr>
</tbody>
</table>

*Note: Where a provisional licence has been issued there is no additional fee where licensee is issued a licence for the balance of the 12 month period.
SCHEDULE “B”

Guidelines to Lodging Houses By-law

The licensee shall comply with the following guidelines regarding the lodging house for which a licence has been issued under this by-law:

A. SAFETY AND SECURITY

1. The licensee shall take all reasonable health and safety measures to prevent damage to the residents' property or injury to persons. In this regard, the licensee shall conduct or cause to be conducted the following and upon request, provide documentary evidence of same to the Region:
   a) heating equipment and chimney inspections not less than once per year;
   b) pest control inspection not less than once per year; and
   c) roof inspection at five (5) year intervals.

2. The licensee shall have a fire safety plan that conforms with the requirements of the Fire Chief and the Ontario Fire Code which shall include but not be limited to:
   a) inspections of all fire extinguishers and standpipe equipment on a monthly basis;
   b) fire drills conducted with the residents under staff supervision on a monthly basis;
   c) a designated place of shelter in the event that the lodging house must be evacuated due to an emergency.

3. The licensee shall have a preventative maintenance plan for the lodging house regarding health and safety measures.

4. The licensee shall maintain the premises in a sanitary and hygienic condition, to the satisfaction of the Medical Officer of Health.

B. PREMISES

PREMISES GENERALLY:

5. Furniture or other physical property, and fixtures provided to residents for their use must be clean, and in good working order and repair.
6. Interior floors, carpeting, doors, and walls should be clean and in good repair.

7. Windows must be in good working order. Any window opening directly to the outside air must be equipped with a screen.

8. The exterior of the building, windows, stairs, porches, eave troughs, walkways, roadways, and gardens, should be clean and in good repair. The licensee shall ensure that parking areas, sidewalks, entrances, exits and roadways at the premises will be cleared of snow and ice to a standard of a reasonably prudent landlord to ensure safe site conditions.

9. The premises shall be ventilated by natural or mechanical means satisfactory to the Medical Officer of Health.

10. The licensee shall provide an adequate supply of hot running water which does not exceed a temperature of 48 degrees Celsius to residents at all times.

11. The licensee shall ensure that the premises, both interior and exterior, shall be illuminated in accordance with the illumination standards contained in the Ontario Building Code. Lighting fixtures and lamps shall be equipped with proper coverings.

12. Subject to applicable laws, the licensee shall:
   a) provide handrails on at least one (1) side of any stairway and, where the width of the stairway requires, on both sides;
   b) provide a structurally sound balustrade or guard rail in good repair on all open sides of a stairway, landing, raised porch or balcony, or roof to which access is provided;
   c) provide stair treads covered with an acceptable non-skid and fire-retardant material; and
   d) where the licensee accommodates residents who are wheelchair dependant, ensure that the premises are wheelchair accessible for such residents.

13. The licensee shall maintain the premises in a clean, safe and sanitary condition, and without limiting the generality of the foregoing shall, subject to applicable laws:
   a) keep the building weather-proof and free from dampness;
   b) maintain a minimum temperature of 21 degrees Celsius (69.8 degrees Fahrenheit) in the premises at all times;
   c) keep all heating equipment in good repair;
d) ensure that no cooking or heating appliance of any kind other than those specifically designed for their intended use, and approved by the Canadian Standards Association, is installed or maintained in any room;

e) remove from the premises all garbage, rubbish, and flammable material or other debris promptly;

f) ensure that garbage receptacles are fitted with tight-fitting lids; and

g) ensure that the premises are kept free of vermin, insects or other pests.

14. The licensee shall ensure that food service facilities on the premises comply with Regulation 562, as amended, (Food Premises) under the Health Protection and Promotion Act, R.S.O. 1990, c. H. 7, as amended.

15. The premises should be smoke free as far as practicable in accordance with applicable by-laws governing smoking.

16. The licensee shall admit residents only up to the licensed capacity of the lodging house save and except for emergency situations. The licensee shall use its best efforts to obtain the Commissioner’s prior written consent to exceed the licensed capacity. Despite the previous sentence if the emergency is such that the Commissioner’s immediate consent cannot be obtained, the licensee shall notify the Commissioner within forty-eight (48) hours of the occurrence of the emergency. Once the emergency has ended, the licensee shall take steps to ensure that the number of residents is reduced as quickly as is possible so that the licensed capacity is not exceeded.

BEDROOMS:

17. There shall be no more than four (4) residents per bedroom.

18. Each resident shall be furnished with a bed together with mattress, a chair, a dresser, a built-in closet or wardrobe, a waste basket, and a towel rack unless one is provided in the bathroom. Each resident shall be provided with an adequate supply of towels and bed linens, which will consist of, at a minimum,

a) one set of towels including a bath and face cloth;

b) one set of bed linens including sheets and a pillowcase;

c) one pillow; and

d) two blankets, or alternatively, one blanket and one comforter.
19. Residents' beds must be placed so that no part of the bed is closer than seventy-six (76) centimetres (30 inches) to another bed.

20. The licensee shall permit each resident to place, at his or her own expense, a lock of a type approved by the operator, on at least one (1) drawer of the dresser or closet in the resident's room.

21. No room in the premises shall be used as a bedroom for residents unless:
   a) the room contains a window opening directly to the outside air which:
      i) is not less than ten per cent (10%) in size of the total floor area of the room; and
      ii) can be opened to the extent of not less than five percent (5%) of the total floor area of the room.
   b) the room is ventilated by mechanical means satisfactory to the Medical Officer of Health.

22. Bedroom windows shall be equipped with appropriate window coverings such as shades, blinds or curtains to ensure privacy.

23. Subject to the Ontario Fire Code, bedroom doors should be equipped with a lock that locks from the inside only. An access key should be retained by the licensee for emergency purposes or for cleaning purposes.

24. Bedroom floors and walls should be in good repair.

25. The licensee shall not permit any resident to occupy for sleeping purposes:
   a) any space in the premises that is used as a lobby, hallway, closet, common seating area, dining area, bathroom, stairway, cellar, furnace or utility room; or
   b) any room having a floor space of less than 2.57 square metres (60 square feet) and less than 16.99 cubic metres of air space for each resident.

WASHROOMS:

26. The licensee shall provide not less than:
   a) one (1) bathtub or shower for every twelve (12) residents;
   b) one (1) sink for every six (6) residents;
   c) one (1) toilet for every six (6) residents;
d) handrails and grab bars beside each toilet and bathtub; and

e) a non-skid mat in each bathtub.

27. Each washroom or shower room shall be provided with a door and a lock which is of a type that can be easily released from the outside in case of an emergency.

28. Washrooms and shower rooms shall be equipped with an adequate supply of common toiletries including toilet paper, liquid soap and hand towels.

29. Washrooms shall be equipped with waste baskets of durable construction that can be easily cleaned and that can hold used disposable towels and waste materials.

30. The licensee shall post a weekly schedule regarding residents' laundry days and residents' bath schedules.

COMMON SEATING AREAS:

31. The licensee shall provide a common seating area for residents which can be used by residents on a twenty-four (24) hour basis. As well, the licensee should make this area available on request for special events. Depending upon the configuration of this area, its size, or the number of residents of the lodging house, where possible, the seating in this common area should be able to accommodate all of the residents at one time.

32. The licensee shall provide a minimum of one (1) television for residents' use in the common seating area. Depending upon the configuration of this area, its size, or the number of residents of the lodging house, where possible, the licensee shall endeavour to provide more than one (1) television in the common seating area.

33. The licensee shall provide a dining area suitable for eating. Depending upon the configuration of the dining area, its size, or the number of residents of the lodging house, where possible, the seating should be able to accommodate all of the residents in two sittings.

34. The licensee shall provide an outdoor seating area for residents which can be used during daylight hours.

C. SERIOUS INCIDENT REPORT

35. Where the licensee receives funding pursuant to a domiciliary hostel agreement with the Region for residents, the licensee shall comply with the provisions of that agreement respecting a serious incident involving a resident. Where the licensee does
not have a domiciliary hostel agreement in effect with the Region, the licensee shall file with the Region a report (the “Serious Incident Report”) in a form acceptable to the Commissioner, subject to guideline 36 below, to be completed and signed by the licensee’s staff member(s) responsible for the supervision of the resident involved in the serious incident, or staff member(s) having direct knowledge of the incident, within twenty-four (24) hours of learning about the incident, and in any event, not later than the next business day after learning of the incident. In cases where the licensee is also licensed under the *Homes for Special Care Act*, the licensee shall provide a copy of any report concerning a serious incident involving a resident funded under that Act. The Serious Incident Report must be filed for any serious incident involving a resident which may include but not be limited to the following:

a) the resident’s death;
b) the resident’s whereabouts are unknown for a period of twenty-four (24) hours or more;
c) the police are called or the police investigate a complaint at the lodging house;
d) there is a serious injury to the resident;
e) the resident is at serious risk;
f) a disaster at the lodging house occurs, eg. fire, flood, and the like;
g) a resident has made a complaint against a staff member of the licensee involving allegations of abuse or mistreatment of any resident;
h) there is a complaint concerning the operational, physical or safety standards of the lodging house that is considered by the licensee to be of a serious nature, including any report of adverse water quality;
i) the misconduct of a resident which may involve drug or alcohol abuse.

36. Guideline 35 above, does not compel nor shall it be deemed to compel a licensee to disclose to the Region any personal information, as that term is defined under the *Municipal Freedom of Information and Protection of Privacy Act*, R.S.O. 1990, c. M.56, pertaining to residents of the lodging house.
Appendix F
House Rules

HOUSE RULES

1) CLIENT MUST HAVE AND DISPLAY RESPECT FOR THEIR HOME, PEERS, STAFF AND SELF.

2) NO SMOKING IN THE HOME AT ANY TIME. DESIGNATED AREAS ONLY.

3) MEDICATIONS KEPT IN LOCKED CABINET AND SUPERVISED BY STAFF.

4) THE CLIENT HAS THE CHOICE OF TAKING MEDICATIONS PRESCRIBED BY THEIR FAMILY PHYSICIAN AND/OR THEIR PSYCHIATRIST. UPON REFUSAL, THEY MUST MAKE OTHER LIVING ARRANGEMENTS AND LEAVE THE HOME. THIS RULE IS FOR THE SAFETY, PROTECTION AND COMFORT OF ALL CLIENTS AND STAFF.

5) CLIENTS MUST MAINTAIN GOOD PERSONAL HYGIENE AND GROOMING, e.g. THE HOME SUGGESTS THAT THERE BE A MINIMUM OF 2 BATHS WEEKLY AND MINIMUM OF ONE SHAMPOO WEEKLY.

6) CLIENT MUST KEEP ROOM, CLOSET AND DRAWERS TIDY AND PLACE DIRTY CLOTHES IN LAUNDRY HAMPER (NOT BACK IN DRAWERS, UNDER BEDS, CLOSETS etc.)

7) NO BORROWING MONEY FROM PEERS OR LOANING MONEY TO PEERS UNLESS YOU TAKE FULL RESPONSIBILITY FOR ANY LOSSES WITH A SMILE. PLEASE DO NOT ASK STAFF TO COLLECT YOUR DEBTS.

8) PLEASE RESTRICT PHONE CALLS TO 15 MINUTES EXCEPT IN AN EMERGENCY SITUATION OR EXCEPTIONAL CASES AS THE PHONE IS FOR THE USE OF ALL INCLUDING BUSINESS, IT IS ONLY FAIR TO YOUR PEERS AND STAFF AS THEY MAY MISS THEIR CALL FROM FAMILY OR FRIENDS.

9) PLEASE ENCOURAGE PERSONAL PHONE CALLS FROM FAMILY AND FRIENDS BETWEEN THE HOURS OF 1PM TO 9PM EXCEPT FOR EMERGENCIES AS PHONE IS USED FOR BUSINESS. AFTER 9PM STAFF HAS QUIET TIME AND MANY CLIENTS ARE RETIRING FOR THE NIGHT. YOU MAY CALL OUT AFTER 9PM IF YOU NEED TO.

10) IF IT IS NECESSARY FOR YOU TO BE ABSENT AT MEAL TIMES, PLEASE NOTIFY STAFF PRIOR TO LEAVING AND IF CLIENT WISHES, THEIR MEAL WILL BE KEPT FOR THEM.

12) PHYSICAL AND/OR VERBAL ABUSE WILL NOT BE TOLERATED FOR ANY REASON. FAILURE TO ABIDE BY THIS HOUSE RULE CAN RESULT IN EJECTION FROM THE HOME AND/OR LEGAL ACTION.

RESPECT THE HOME - IT IS YOURS AND WE SINCERELY HOPE YOU ENJOY IT AND FEEL A PART OF OUR LARGE FAMILY.

I HAVE READ AND/OR UNDERSTAND THE HOUSE RULES STATED ABOVE.

______________________________
Signature and Date

______________________________
Witness and Date
**Appendix G**

**Homes for Special Care Cost Sheets**

### COMMERCIAL INVOICE GUIDELINES

**A** – Apparel: All HSC residents are responsible for all costs incurred on their behalf when under the HSC program.

<table>
<thead>
<tr>
<th>Item</th>
<th>Type</th>
<th>Approval</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>APPAREL</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clothing</td>
<td>A</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Footwear</td>
<td>A</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Orthopedic</td>
<td>A</td>
<td>Yes</td>
<td>$600.00 annual apparel limit</td>
</tr>
<tr>
<td><strong>CLOTHING</strong></td>
<td></td>
<td></td>
<td>*Non-prescribed.</td>
</tr>
<tr>
<td><strong>BATTERIES</strong></td>
<td>C</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Hearing Aid</td>
<td>O</td>
<td>Yes</td>
<td>As part of planned/supervised social/recreation activity.</td>
</tr>
<tr>
<td><strong>CLOTHING</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>COSMETICS</strong></td>
<td>O</td>
<td>Yes</td>
<td>As part of planned/supervised social/recreation activity.</td>
</tr>
<tr>
<td>See: Personal Hygiene</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>CRAFTS/CERAMICS</strong></td>
<td>O</td>
<td>Yes</td>
<td>As part of planned/supervised social/recreation activity.</td>
</tr>
<tr>
<td><strong>DENTAL</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anesthetic</td>
<td>H</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Emergency</td>
<td>H</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Examination</td>
<td>H</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Labeling</td>
<td>H</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Treatment</td>
<td>H</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td><strong>DRUGS/PRESCRIPTION</strong></td>
<td>O</td>
<td>Yes</td>
<td>Drugs not covered by Ontario Drug Formulary</td>
</tr>
<tr>
<td><strong>DRY CLEANING</strong></td>
<td>O</td>
<td>Yes</td>
<td>$60.00 annual limit</td>
</tr>
<tr>
<td><strong>EDUCATION</strong></td>
<td>O</td>
<td>Yes</td>
<td>As part of planned/supervised educational activity.</td>
</tr>
<tr>
<td>Vocational education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>MEDICAL ESCORTS</strong></td>
<td>O</td>
<td>Yes</td>
<td>Invoice &amp; Prescribed Form to Regional Coordinator. (5 km. Change plus $7.00 per hour) For Medical Purposes ONLY monitored by Field Staff.</td>
</tr>
<tr>
<td>KM for escorts</td>
<td>K</td>
<td>Yes</td>
<td></td>
</tr>
</tbody>
</table>

---

### HSC Operating Guidelines

<table>
<thead>
<tr>
<th>Item</th>
<th>Type</th>
<th>Approval</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FAMILY PLANNING DEVICE</strong></td>
<td>C</td>
<td>Yes</td>
<td>Authorization/prescription from physician or organization such as V.O.N. must be kept on file in local HSC office.</td>
</tr>
<tr>
<td><strong>FOOT CARE</strong></td>
<td>C</td>
<td>Yes</td>
<td>As prescribed for residents — authorization from a physician must be kept on file in local HSC office.</td>
</tr>
<tr>
<td><strong>FUNERAL &amp; BURIAL COSTS</strong></td>
<td>G</td>
<td>Yes</td>
<td>Authorization/prescription from physician or organization such as V.O.N. must be kept on file in local HSC office.</td>
</tr>
<tr>
<td><strong>HAIR DRESSING</strong></td>
<td>C</td>
<td>Yes</td>
<td>HSC Field Staff to closely monitor.</td>
</tr>
<tr>
<td><strong>HEARING AIDS &amp; BATTERIES</strong></td>
<td>C</td>
<td>Yes</td>
<td>As prescribed for residents.</td>
</tr>
<tr>
<td><strong>MEDICAL ALERT BRACELET</strong></td>
<td>C</td>
<td>Yes</td>
<td>As prescribed for residents.</td>
</tr>
<tr>
<td><strong>MEDICAL ASSESSMENTS</strong></td>
<td>O</td>
<td>Yes</td>
<td>As prescribed for residents.</td>
</tr>
<tr>
<td><strong>MEDICAL SUPPLIES</strong></td>
<td>C</td>
<td>Yes</td>
<td>As prescribed for residents.</td>
</tr>
<tr>
<td>Colostomy supplies</td>
<td>Dresings &amp;</td>
<td>O</td>
<td>Yes</td>
</tr>
<tr>
<td>Colostomy supplies, syringes*</td>
<td>Incontinent supplies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walking Aids:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Purchase/Rental of</td>
<td>Walker/Walking stick</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>MOVIES</strong></td>
<td>C</td>
<td>Yes</td>
<td>As prescribed for residents.</td>
</tr>
<tr>
<td>See: Recreation</td>
<td>O</td>
<td>Yes</td>
<td>As prescribed for residents.</td>
</tr>
<tr>
<td><strong>OPTICAL SERVICES/GASSES</strong></td>
<td>C</td>
<td>Yes</td>
<td>As prescribed for residents.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### HSC Operating Guidelines

**ORTHOPTIC APPLIANCES**
- C (Yes)
  - HSC Field Staff
  - Regional Coordinator
  - Comments: Portion of cost not covered by Assistive Devices Program

**PERSONAL HYGIENE/ GROOMING CULTURAL**
- C (Yes)
  - HSC Field Staff
  - Regional Coordinator
  - Comments: HSC Field Staff to monitor

**PERIODONTAL**
- C (Yes)
  - HSC Field Staff
  - Regional Coordinator
  - Comments: Requests for funding of products/supplies not listed must be reviewed by the Field Staff and submitted with recommendations for approval to the Regional Coordinators.

**SHAMPOO/CONDITIONER**
- C (Yes)
  - HSC Field Staff
  - Regional Coordinator
  - Comments: Portion of cost not covered by Assistive Devices Program.

**SPECIAL SEATING**
- C (Yes)
  - HSC Field Staff
  - Regional Coordinator
  - Comments: Application to be made to Assistive Devices Program funding prior to contacting Regional Coordinator.

### HSC Operating Guidelines

**TRANSPORTATION**
- Bus (K)
- Cab (K)
- Taxi (K)
  - HSC Field Staff
  - Regional Coordinator
  - Comments: In accordance with Operating Guidelines

**UMBRELLA**
- See Apparel

**VIDEO**
- See Recreation

**WALKING AIDS**
- See Medical Supplies

**WATCH REPAIR**
- C (Yes)
  - HSC Field Staff
  - Regional Coordinator
  - Comments: Portion of cost not covered by Assistive Devices Program

**WHEELCHAIR**
- Purchase (K)
- Repair (K)
  - HSC Field Staff
  - Regional Coordinator
  - Comments: Annual Program Funding Request required. Should include transportation costs incurred.
Appendix H

Menu at Rolling Hills

### WEEK ONE – LUNCH MENU

<table>
<thead>
<tr>
<th>DAY</th>
<th>MEAL DESCRIPTION</th>
<th>PORTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>MONDAY</td>
<td>CREAM of CHICKEN SOUP Cracker &amp; Cheese, Bread Pudding, Tea</td>
<td>8oz - 3Tins</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4oz Separate amount for diabetics/aspertame</td>
</tr>
<tr>
<td>TUESDAY</td>
<td>SLICED COLD MEAT SANDWICH Baked Good, Tea</td>
<td>1 ea.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 oz.</td>
</tr>
<tr>
<td>WEDNESDAY</td>
<td>1 1/2 GRILLED CHEESE SANDWICH Homemade Cake, Tea</td>
<td>2 oz.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 oz Diabetic No Icing</td>
</tr>
<tr>
<td></td>
<td></td>
<td>with diet puffing</td>
</tr>
<tr>
<td>THURSDAY</td>
<td>CREAM OF BROCCOLI SOUP Tea Biscuit, Homemade Tart, Tea</td>
<td>8oz</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 ea.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2oz Diabetic Mini Tart</td>
</tr>
<tr>
<td>FRIDAY</td>
<td>PANCAKES + SYRUP Homemade Oatmeal Muffin, Tea</td>
<td>2 Large each</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 Med. Diabetic 1 Mini</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SATURDAY</td>
<td>HOT DOGS + BUNS Tossed Salad, Jello, Tea</td>
<td>2ea</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6oz</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3oz Diabetic small portion</td>
</tr>
<tr>
<td>SUNDAY</td>
<td>TUNA SANDWICHES Pudding, Tea</td>
<td>3 oz - 1 1/2ea</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3 oz Diabetic Pudding</td>
</tr>
</tbody>
</table>

**NOTE:** Sandwiches for ALL – use 4 large tins or 6 small.
### WEEK ONE – SUPPER MENU

<table>
<thead>
<tr>
<th>MONDAY:</th>
<th>BAKED CHICKEN 4oz</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Steamed Rice 6oz</td>
</tr>
<tr>
<td></td>
<td>Vegetable - Mixed 4oz</td>
</tr>
<tr>
<td></td>
<td>Ice Cream 3oz Diabetic Ice Cream</td>
</tr>
<tr>
<td></td>
<td>Tea</td>
</tr>
<tr>
<td>TUESDAY:</td>
<td>FRIED BOLOGNA 3oz</td>
</tr>
<tr>
<td></td>
<td>Baked Potato Wedges 6oz</td>
</tr>
<tr>
<td></td>
<td>Vegetable - Green Beans 4oz</td>
</tr>
<tr>
<td></td>
<td>Banana 1 Med. Diabetic’s 1/2</td>
</tr>
<tr>
<td></td>
<td>Tea</td>
</tr>
<tr>
<td>WEDNESDAY:</td>
<td>ROAST BEEF 3oz</td>
</tr>
<tr>
<td></td>
<td>Mashed Potato 6oz</td>
</tr>
<tr>
<td></td>
<td>Vegetable - Diced Carrots 4oz</td>
</tr>
<tr>
<td></td>
<td>Apples 1 Med.</td>
</tr>
<tr>
<td></td>
<td>Tea</td>
</tr>
<tr>
<td>THURSDAY:</td>
<td>WEINERS &amp; BEANS 8oz Dinner Roll</td>
</tr>
<tr>
<td></td>
<td>(Salad Plate – June to Sept.)</td>
</tr>
<tr>
<td></td>
<td>Tossed Salad 6oz</td>
</tr>
<tr>
<td></td>
<td>Baked Goods 2oz Diabetic Alternative</td>
</tr>
<tr>
<td></td>
<td>Tea</td>
</tr>
<tr>
<td>FRIDAY:</td>
<td>FISH STICK 3oz</td>
</tr>
<tr>
<td></td>
<td>French Fries 6oz</td>
</tr>
<tr>
<td></td>
<td>Vegetable - Corn 4oz</td>
</tr>
<tr>
<td></td>
<td>Ice Cream 3oz Diabetic Ice Cream</td>
</tr>
<tr>
<td></td>
<td>Tea</td>
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<tr>
<td>SATURDAY:</td>
<td>CANNED HAM SANDWICHES 1 ½ ea.</td>
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<tr>
<td></td>
<td>Pickles 3</td>
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<tr>
<td></td>
<td>Baked Goods 2oz Diet Alternative</td>
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<td>Tea</td>
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<tr>
<td>SUNDAY:</td>
<td>MEAT PIE 1 3 Chicken/13 Beef 4oz</td>
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<td>Potato Salad 6oz</td>
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<tr>
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<td>Vegetable - Mixed 4oz</td>
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<tr>
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<td>Pie Wedge 2oz Diabetic Alternative</td>
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<td>Tea</td>
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</tbody>
</table>
WEEK TWO - LUNCH MENU

MONDAY:  
TOMATO SOUP  
Crackers and Peanut Butter  
Rice Pudding  
Tea  
8oz 3 Tins  
2 Pkgs. & 2 Peanut Butter  
4oz Sepolate Amount Cooked  
with Aspartame for diabetics

TUESDAY:  
SLICED COLD MEAT SANDWICH  
Baked Goods  
Tea  
1ea 2oz  
2oz

WEDNESDAY:  
GRILLED CHEESE SANDWICHES  
Homemade Cake  
Tea  
2oz - 1 ½ ea.  
3oz Diabetics No Icing

THURSDAY:  
BEEF VEGETABLE SOUP  
Tea Biscuit  
Homemade Tart  
Tea  
8oz  
2oz  
2oz. Diabetics Mini/ Tart/Pudding

FRIDAY:  
BACON  
Fried Eggs  
Toast  
Raisin Bran Muffin  
Tea  
2 Strips (Side)  
2 Grade A Large  
2  
3oz Diabetic 1 Mini

SATURDAY:  
HAMBURGER & BUN  
Macaroni Salad  
Jello  
Tea  
8oz ea.  
6oz  
3oz Diabetics Small Portion

SUNDAY:  
SALMON SANDWICHES  
Pudding  
Tea  
3oz - 1 ½ ea.  
3oz Diabetic Pudding

NOTE: Sandwiches for ALL - use 4 large tins or 6 small
WEEK TWO - SUPPER MENU

MONDAY: SWISS STEAK 4oz
Mashed Potato 6oz
Veg - Green Beans 4oz
Ice Cream 3oz Diabetic Ice Cream
Tea

TUESDAY: SAUSAGE LINKS - 3 2oz
Steamed Rice 6oz
Vegetable - Corn 4oz
Banana 1 Med. Diabetic’s 1/2
Tea

WEDNESDAY: ROAST BEEF 3oz
Roasted Potatoes 4oz
Vegetable - Diced Carrots 4oz
Oranges 1 Med.
Tea

THURSDAY: MACARONI & CHEESE 8oz Dinner Roll
(June to Sept. Salad Plate)
Tossed Salad 4oz
Baked Goods 2oz Diabetic Alternative
Tea

FRIDAY: CHICKEN FINGERS 1-3oz pc
French Fries 4oz
Vegetable - Green Peas 4oz
Ice Cream 3oz Diabetic Ice Cream
Tea

SATURDAY: CANNED CHICKEN SANDWICH 1 ½ ea - 4oz
Baked Goods 2oz Diabetic Alternative
Tea

SUNDAY: SPAGETTI & MEAT SAUCE 8oz 1 Dinner Roll
Tossed Salad 3oz ea.
Pie Wedge 2oz Diabetic Alternative
Tea
WEEK #3 - LUNCH MENU

MONDAY:  CHICKEN NOODLE SOUP  8oz – 3 Tins  
          Crackers & Cheese           3  
          Bread Pudding              3 oz  
          Tea                       made with aspartame

TUESDAY:  COLD MEAT SANDWICH     3 oz 1 ea.  
          Baked Goods                2 oz  
          Tea

WEDNESDAY:  GRILLED CHEESE      2 oz – 1 ½ ea.  
             Homemade Cake            2 oz  
             Tea                      Diabetics No Icing

THURSDAY:  CREAM of POTATO SOUP 8oz  
            Tea Biscuits              1 ea.  
            Homemade Tart            2 oz  
            Tea                      Diabetics mini tart pudding

FRIDAY:    FRENCH TOAST & SYRUP  2 ea.  
            Oatmeal Muffin            1 med.  
            Tea                      Diabetics Mini Muffin

SATURDAY:  HOT DOGS & BUNS      2 ea.  
            Tossed Salad              6 oz  
            Jello                    3 oz  
            Tea                     Diabetics Small Portion

SUNDAY:    CANNED HAM SANDWICHES 1 1/2 ea. 2 oz  
           Pudding                   2 oz  
           Tea

NOTE: Sandwiches for ALL – use 4 large tins or 6 small
WEEK #3 - SUPPER MENU

MONDAY: MEAT LOAF 4 oz  
Steam Rice 6 oz  
Mixed Veggies 3 oz  
Ice Cream 3 oz Diabetic Ice Cream  
Tea

TUESDAY: LIVER & ONIONS 4 oz  
Baked Potato 4 oz  
Corn Niblets 3 oz  
Banana 1 Med. Diabetic’s 1/2  
Tea

WEDNESDAY: ROAST BEEF 4 oz  
Mashed Potato 6 oz  
Diced Carrots 3 oz  
Apples 1 Med.  
Tea

THURSDAY: CHICKEN CASSEROLE 8 oz 1 Dinner Roll ea.  
(June to Sept. Salad Plate)  
Tossed Salad 4 oz  
Baked Goods 2 oz Diabetic Alternative  
Tea

FRIDAY: FISH STICK 2 oz  
French Fries 6 oz  
Green Peas 3 oz  
Ice Cream 3 oz Diabetic Ice Cream  
Tea

SATURDAY: CHEESE SANDWICHES 1 1/2 ea. with Lettuce  
Pickles 3 ea.  
Baked Goods 2 oz Diabetic Alternative  
Tea

SUNDAY: MEAT PIE 13 Beef & 13 Chicken 3 oz  
Potato Salad 2 oz  
Veg. Green Beans 3 oz  
Pie Wedge 3 oz Diabetic Alternative  
Tea
Appendix I

Letter from Regional Government

February 10, 2012

Dear [Name],

I would like to take this opportunity to wish you all a healthy and happy 2012.

At our last Domiciliary Hostel Operators' meeting in September 2011, one of the agenda items was the extremely high cost of medication for our Domiciliary Hostel Residents. As you will recall, we notified Operators at that time of a change to the reimbursement of medication practice.

As of April 1, 2012, the following changes to our current practice will be in effect. This will give Operators and pharmacies two months to transition to the new procedure.

Over the Counter Medication

- Over the counter medication (OTC) will no longer be approved by [Entity] even if prescribed by a physician. This includes vitamins, minerals, Tylenol, Armasol etc.
- Extenuating (life threatening) circumstances will be assessed on a case by case basis

Medication Not Covered Under the Ontario Drug Benefit (ODB)

Residents who are in receipt of Ontario Works, Ontario Disability Support Program and Seniors Pensions have most medications covered through the Ontario Drug Benefit (ODB). For medications that are not covered by ODB, the following applies.

- Speak to the prescribing doctor to see if they can change to another medication that is covered by ODB or determine if a generic brand is available as an alternative.
- Assess if Section 16 (individual clinical review) is an option. The approval process may take 4 to 6 weeks, during this time [Entity] will pay associated medication costs until the Ministry of Health funding is approved. If the resident is denied funding, then the denial letter is to be provided to [Entity]. Extenuating circumstances will be assessed on a case by case basis.
Determine whether the physician can provide samples to the client. This may include either the pharmacist or the home operator engaging in a quick conversation with the doctor. It is the responsibility of the pharmacist to inform the operator that the medication is not covered so other means can be explored.

**Trillium Drug Program**

- Clients must apply for Trillium funding. This can be in collaboration with the home operator, the client’s family and/or the staff worker. Again, the pharmacist must notify the operator or staff that the medication is not covered so that this step can be initiated. It will be assessed whether or not the deductible will be paid by pending proper documentation.

**Co-Payment Fees**

- All seniors must complete their yearly income taxes as there is a direct correlation to their annual income and the amount of “co-payment” they pay. Some pharmacies waive the co-payment fees if they are under $2.11. Staff will assist operators in applying for ODB co-payment form if they request assistance.
- will work with operators who would like assistance with income tax preparation through Revenue Canada’s support programs for residents with low incomes.

**Dispensing Fees**

- will no longer be paying dispensing fees for clients living in Domiciliary Hostels.

Effective communication between pharmacists, operators, staff and prescribing physicians is crucial. Staff will respond to special circumstances and consult with their supervisor to determine the best course of action as needed.

Please feel free to call me at any time should you have any questions regarding any of the above.

Sincerely,