

SCHOOL HEALTH SUPPORT SERVICES FOR CHILDREN WITH DIABETES

THE SOCIAL ORGANIZATION OF SCHOOL HEALTH SUPPORT SERVICES FOR
CHILDREN WITH DIABETES IN ONTARIO SCHOOLS: AN INSTITUTIONAL
ETHNOGRAPHY

By

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LAY ABSTRACT

Diabetes is a chronic health condition that requires individuals with diabetes or their families to maintain a daily well-coordinated and intensive diabetes self-care routine. Lapses in this complex daily regimen can have devastating immediate and long-term consequences. How children's diabetes, that is children's health and well-being, are cared for at school is of concern for parents. The inquiry begins in my personal experience as a mother of a child with diabetes starting kindergarten, and the troubles I encountered in getting the care needed to keep my child safe at school. Starting from experience, this thesis examines how the institutional context and routine practices of diabetes care in school affects the care children actually receive. Despite legislation that requires accommodations for students with disabilities, what I found in this study is that parental involvement (which is inequitably available) is essential to ensure diabetes care is adequate for children in schools.

ABSTRACT

This thesis is an institutional ethnography (IE) examining the social organization of Community Care Access Centre School Health Support Services (CCAC SHSS) for children with diabetes in Ontario schools. More specifically, it explicates the social relations embedded in, and coordinating the work organization of mothering (parenting) and nursing in the school setting. The inquiry begins in my personal experience as a mother of a child with diabetes starting kindergarten, and the troubles I encountered in getting the care and attention needed to keep my child safe at school. Starting from experience, a place outside of theory and institutionalized categories and discourse, I set out on a journey to discover the social organization that coordinates my experience, and to seek answers to my query: how are school health supports put together in such a way that I, as a parent, am left feeling worried about my child's safety when she is at school, have had to fight to secure the much needed 'diabetes care', and even then, am often called upon to provide voluntary supplementary healthcare work to ensure her safety at school?

I have structured this thesis into two main parts. The first part provides the set-up for this thesis. First, I orient readers to this distinctive way of doing an IE, directing their attention to how I used the core IE concepts in this research and calling upon them to read the remainder of the thesis taking up this distinctive theoretical and conceptual lens. Indeed, what we know and how we know it has much to do with how knowledge is socially organized. Then, I go on to examine the different ways of knowing about 'diabetes care', how these distinctive ways of knowing create a disjuncture for me as a

parent and how this disjuncture is used to establish the research standpoint to begin and direct the explication. The last chapter in this part situates health supports for children with diabetes within the services provided by public-funded home care. I sketch three decades of the history of reform and organizational restructuring of home care in Ontario, in particular, the introduction of privatizing relations into the local practices of community nursing and the creation of CCACs. These relations of privatization reorganized the home care sector, the workforce, and the relation between the 'state' and its citizens. What went on before sets the groundwork for what can happen next, and it is under this context and conditions in which my inquiry is set.

The second part consists of four academic journal manuscripts. They are the descriptive analysis for this IE. These four chapters describe what I have learned and discovered in doing this research, and three of them in particular provide an empirical analysis showing how school health supports for children with diabetes are put together such that the troubles I experienced came into being. These four chapters are conventionally referred to as research 'findings' in traditional qualitative research methodology. Each of these chapters speaks to a particular way of knowing about 'diabetes care'. One focuses on parents' experiential ways of knowing based on the actualities of their daily and nightly everyday world to show the amount of work and knowledge required to care for and to keep their children with diabetes alive; while the other three underscore the CCACs' institutional ways of knowing about 'diabetes care' in the school setting. I show how these objectified ways of knowing derived from institutional texts (*Standardized CCAC Medial Orders*, information technology software

and the *Diabetes Checklist for Independence*) are used to determine a child's eligibility to receive health supports at school. These objectified textual forms of knowing are removed from the actualities of people's real life circumstances, and differ significantly with how and what parents know is needed for their children with diabetes to stay well and safe at school. It is precisely this form of text-mediated social coordination that leaves parents feeling worried and draws them in to doing voluntary healthcare work at school, without which the child's safety and the continuity of care is not possible.

Tracing the institutional relations organizing how health support services for children with diabetes actually happen in the classroom, I show the kind of work expected of parents, and demonstrate that the CCAC SHSS policy and practices only 'work' as they should with the incorporation of parents' 'unauthorized' knowledge and their ongoing voluntary complementary healthcare work. While it is in parents' interests to ensure their children's safety and well-being at school, there are differences between parents in how, and if, they can deliver their knowledge and resources.

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My mother, Mak Mee Chun, even though you have never received any formal education in your lifetime, you recognized the importance of education and instilled in me the love of learning during my formative years. I still remember vividly how you explained why learning and acquiring knowledge is so important and useful. You told me that unlike money that can be stolen, knowledge is something that one possesses forever and can never be taken away, rather it will generate as one shares what they know with others. I am thankful for the wisdom and lessons you taught me in life.

My two older brothers, Fong Yik Sing and Fong Yik Wah, who passed away suddenly in 2013 due to illness. Your deaths, which occurred less than three months apart, were one of the most difficult and painful events I experienced. To this date, the thought of never able to see you again immediately brings tears to my eyes. You will always be remembered.

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LISTS OF ABBREVIATIONS

BG	Blood Glucose
CCAC	Community Care Access Centre
CHA	Canada Health Act
CHCA	Canadian Home Care Association
CHRIS	Client Health Related Information System
CWSE	Centre for Women's Studies in Education
DKA	Diabetes Ketoacidosis
IE	Institutional Ethnography
LHIN	Local Health Integration Network
MCSS	Ministry of Community and Social Services
mmol/L	Millimoles per Liter
NDP	New Democratic Party
OACCAC	Ontario Association of Community Care Access Centre
OECD	Organisation for Economic Co-operation and Development
OHIP	Ontario Health Insurance Plan
PC	Progressive Conservative
PDEC	Pediatric Diabetes Education Centre
P/PM 81	Intersectoral Policy/ Program Memorandum 81
RNAO	Registered Nurses Association of Ontario
SSHS	School Health Support Services
SSSP	The Society for the Study of Social Problems

INTRODUCTION

Growing up in a working class single parent family household with seven children in Hong Kong, I don't recall ever having the chance to play with jigsaw puzzles my childhood. There just wasn't the extra financial resource to afford one. I recall the first time I played with a jigsaw puzzle was with my roommate, when I was doing my undergraduate degree at university. The puzzle was lying around in our dormitory. She had bought it as a present, and had planned to put it together, frame it and give it to her boyfriend at the time as a birthday present. As his birthday approached, my roommate solicited any help she could get to complete the jigsaw puzzle. I started putting the pieces of the puzzle together and realized not only did I enjoy figuring out how to put things together, but also that I was actually quite good at it. If you've ever played with a jigsaw puzzle, you will know that within each puzzle, either on the cover of the box and/ or inside the box, there is a picture resembling what the completed puzzle will look like. This picture was instrumental for my success in completing the jigsaw puzzle. Having a guide that laid out the landscape of the puzzle allowed me to look back and forth from the loose pieces to the picture and fit the loose pieces together to form the complete picture. I can't imagine completing the jigsaw puzzle without such a guide.

As well, growing up poor, I was astutely aware of the inequities that are present in the world I live in. I was aware that I had to work much harder under harsher conditions than my classmates who had their own bedrooms and didn't have to study in a room shared with the rest of the family with the television blasting in the background;

classmates whose parents were able to sit with them to complete their homework and provide guidance, and/ or had the financial resources to hire private tutors to provide extra help with their homework. As much as I was told by the teachers that our grades were a reflection of our hard work, my lived experience told me otherwise. Our academic achievements were not merely based on our individual merits and our chances of success in life were not based on our ability, talent and hard work alone. I often wondered how an education system that did not take into account my knowledge and the circumstances of my life could claim to serve my interests. I was puzzled by how our lives are often shaped by decisions made outside of our immediate everyday world. For example, how did it come to be that the Hong Kong government decided to take back the ‘squatter’ area where my family home was built and many families were asked to leave their homes even though their families had settled there for decades and were quite content where they were? Later, I discovered the area was re-developed into apartment condos. My childhood upbringing and my ongoing queries about how things happen as they do in my everyday world continues to inform my academic curiosity and interests.

Indeed as I continue to ask questions about the everyday world around me, I come to realize much of what goes on in the actuality of my everyday life may not be decided and cannot be fully explained within it. For example, I noticed the lab at my family doctor’s clinic was mysteriously closed a few years ago and re-located to a different location outside of the clinic. This arrangement was puzzling and didn’t quite make sense to me as a patient. From my standpoint as a patient, it was more convenient to have the

consultation with the doctor and the blood test done at the same location during the same clinic appointment. If it was inconvenient for me as an able-bodied individual with access to a vehicle, I can't imagine how this may affect individuals who are constrained by their physical abilities and financial resources. I later realized that it might have something to do with the restructuring of primary health care and the introduction of the Local Health Integration Network in Ontario.

While it seemed challenging, almost impossible or absurd, to complete a jigsaw puzzle without a picture showing me what the completed jigsaw looked like, I find that in contemporary society, I am expected to figure out my way around various institutions in the dark and without a guide. For example, when my daughter with diabetes was about to start kindergarten, I didn't know who would take care of her when she was in school. This was concerning to me as a parent because she was only three years and ten months old, and she didn't know how to do any of the diabetes care routines. As well, she wouldn't reliably finish all the carbohydrates in her food on her own which could be very dangerous if she had already received her insulin dose matching the carbohydrates in her meal. I was making phone calls to the school and going between the school to the pediatric diabetes clinic five times at the beginning of the school year to figure out how to put in place the necessary care and support my daughter needed to be safe at school. Registering her into the school system was not sufficient. If I wasn't the type of person who is unafraid of asking questions, with the time to go from place to place to find the answer, I'm not sure what would have happened to my child. Wouldn't it be useful to

have a map showing me and other parents what the institutional process of securing diabetes care in school looks like? Much like the picture I had when putting together a jigsaw puzzle, a map showing me how the process works would allow me and other parents to go back and forth from the map to the lived actuality of our everyday worlds to figure out how to move along the institutional process of getting diabetes care in school. It would also allow me – and anyone who wants to make changes that support parents and children with diabetes – to see how things are ‘put together’ and thus how they might also be put together differently.

Institutional Ethnography (IE), developed by Canadian sociologist Dorothy Smith, offers precisely this distinctive way of doing empirical research that aims to investigate how particular institutional complexes and work processes are put together and how they work (Smith, 2005, 2006). The promise of IE to show and explain to people how their everyday experiences in where they live and participate come to be the way it is and how it is “being put together systematically, but more or less mysteriously and outside a person’s knowledge, and for purposes that may not be theirs” (Campbell & Gregor, 2002, p. 18) is what drew my interest in learning more about IE, and informed my decision to pursue my doctoral research by doing an ethnography about the organization of a particular institutional complex I encountered when my child with diabetes was starting kindergarten.

The institutional complex I will be investigating in this thesis is the Community Care Access Centre School Health Support Services (CCAC SHSS) for children with diabetes in Ontario schools. More specifically, I intend to explicate the social relations embedded in and coordinating the work organization of mothering (parenting) and nursing in the school setting. This research began with my personal experience as a mother of a child with diabetes and the difficulties I encountered in having to figure out in the dark, without a map or picture, how to get the necessary care and attention needed to keep my child safe at school. In Canada, federal legislation (*Canadian Charter of Rights and Freedoms, 1982*) recognizes all children's rights to education without discrimination irrespective of health conditions and/ or disabilities, and confirms the duty of public schools to provide accommodations for students with disabilities to ensure their integration, full participation and inclusion in the classroom. As well, in Ontario, there is a provincial policy (*Intersectoral Policy/ Program Memorandum 81 (P/PM81) titled: Provision of Health Support Services in School Settings, 1984*) with an explicitly stated purpose to ensure "no school-aged children should be denied access to education because of special health support needs during school hours" (Ontario Ministry of Education, 1984, P/PM81, para. 8). In the context of these federal and provincial policies, I was puzzled and disillusioned to find parents, including myself, persistently worried about our children's safety at school, often having to fight to secure necessary diabetes care, and called upon to provide voluntary healthcare work to ensure our children's wellbeing at school. I wanted to know how school health supports are actually 'put together' such that parents have these common and shared experiences.

To seek answers to my query, I first turned to existing literature on diabetes care in school settings. Existing literature has addressed the experiences and perspectives of students with diabetes and their parents (Amillategui, Mora, Calle & Giralt, 2009; Hayes-Bohn, Newmark-Stainer, Mellin & Patterson, 2004; Schwartz, Denham, Heh, Wapner, & Shubrook, 2010), as well as the experiences of school personnel such as teachers and administrators (Amillategui et al, 2009; Boden, Lloyd, Gosden, Macdougall, Brown, & Matyka, 2012; Schwartz et al, 2010; Siminerio & Koerbel, 2000), and the perspective of school nurses (Nabors, Lehmkuhl, Christos, & Andreone, 2003). While these studies indicate the need for improved support for children with diabetes at school, they take up a health services framework. The problem is constructed as a lack of adequate and up-to-date knowledge on diabetes in the school setting (Amillategui et al, 2009; Hayes-Bohn et al, 2004; Schwartz et al, 2010; Siminerio & Koerbel, 2000), and the research points to the need for more education on diabetes and more resources to support school personnel and school nurses. Studies of this kind do not answer my question regarding how health support in the school setting is put together and how it works (Smith, 2006). They do not attend in detail to how complex social and institutional relations enter into the local setting and mediate the actual practices conducted by actual people (such as teachers, nurses, parents) at the local level of the school, and in turn how these routine practices are articulated to policies and legislation developed elsewhere. Moreover, previous studies are not specifically focused on this topic in the Canadian context. This type of study that focuses on a specific work organization, in a Canadian context, has yet to be undertaken.

Indeed, recognizing school health supports/ diabetes care in the school setting as actual practices and a work organization coordinated among actual people raises different questions and offers a different basis for investigation than most research in this field. In this study I make people's actual practices in multiple settings (including their practices with texts) as extended work processes in a work organization an object of study. In doing so, I bring into view the coordination that connects people's diverse activities in multiple settings that put together what we come to know as the institution. By paying attention to the language, text and knowledge used in the local setting, we can get a glimpse of the coordination that enables institutions to govern, regulate and coordinate the local activities and practices but cannot be known within it, because the source of this coordination originates outside of the local setting (Campbell & Manicom, 1995; Grahame, 2004, p.183). The inquiry needs to move beyond the particular local settings of the everyday world to the trans-local settings, and questions need to be asked about how these local practices are shaped and organized, what type of knowledge is drawn on to coordinate this work organization, and whose benefit they serve (Campbell & Gregor, 2002; Miller, 2005).

In conducting this institutional ethnography, I hope to create knowledge about the social organization that governs the 'health support services' for children with diabetes in the school setting in Ontario. In doing so, I will offer a more accurate understanding of how the worries and concerns of parents of children with diabetes are socially organized, and provide an empirical analysis of how the work of parents of children with diabetes at

school are coordinated with the work of others, such as nurses and teachers, and are institutionally linked to the policies and practices of the Community Care Access Centres (CCACs), a ‘bureaucracy’ authorized to govern the administration and provision of School Health Support Services.

How I arrived at the study of the work organization of mothering and nursing in the school setting

Health support for children with diabetes at school involves two institutional complexes: education and health. In the beginning of this research, I was struggling to decide which institutional complex I should investigate, or should I study both, and if so, how? In trying to figure out the answer to these questions, I returned to the actualities of my everyday life, a standpoint outside of institutionalized discourse, as an embodied knowing subject in a particular local setting to identify which aspects of my everyday life circumstances troubled me (and thus, to identify which institutional complex was most salient to troubles I experienced).

The first of a series of perplexing moments was when I was at the pediatric diabetes clinic asking for a referral for services at school for my child who was about to start kindergarten. The physician at the clinic wrote the Medical Orders on the *CCAC Referral Form*. When I read the Medical Orders written on this form, I discovered that they were different from what I routinely do to ensure the health of my child, and different as well from what I was taught at the same clinic. From my knowledge, the

Medical Orders were grossly insufficient to ensure my child's safety at school, and I was drawn into doing work in an attempt to secure more health support services. I was successful in securing health support services in school that were more in line with what I routinely do to keep my child safe. But I was puzzled that some front-line nurses lacked knowledge of 'diabetes management' for children. They were knowledgeable about how to test blood sugar and administer insulin, but not knowledgeable enough to know that despite a low blood sugar level prior to lunch time testing, once the child is treated and the blood sugar level is above 4 mmol/L, insulin administration is still required to cover the amount of carbohydrates consumed by the child during lunch. Moreover, there were frequent changes in front-line nurses. It seemed to me that the frequent changes of nurses resulted in the unpredictability of the quality of care and a higher possibility of medical errors due to their unfamiliarity with my child's care. I couldn't understand how the scheduling of nurses was organized such that a nurse that was scheduled to care for my child one day was all of a sudden changed on the next day. Lastly, I was baffled to hear some parents of children with diabetes I interviewed talk about the nursing services for their child being terminated when their child was not quite ready to care for their diabetes without support, and how they were drawn in to do work to maintain services. The descriptive analysis (also referred to as research 'findings' in traditional qualitative methodology) in part two of this thesis correspond to each of the above mentioned puzzlements: Chapter five addresses the different ways of knowing about diabetes care in school, and how the CCAC's institutional way of knowing subjugates parents' knowledge and incorporates parents' supplementary voluntary healthcare work into the institutional

complex of SHSS program to ensure the child's safety at school; Chapter six looks at how a seemingly neutral institutional technology mediates how quality of care is known and shapes the scheduling of nursing visits and the conditions for community nursing and in turn, affects the quality of nursing care and the daily lives of children and families who rely on this care; and Chapter seven deals with how a pre-determined timeline for terminating nursing services in school and the institutional category of 'independence' coordinates the assessment work of the CCAC care coordinators with that of the nursing work of community nurses at school to accomplish a timely service discharge.

Given that all these incidents are linked to the organization of nurses' work, I decided to investigate how parents' work is coordinated with the work of nurses and trace the institutional complex this work is situated in and the social relations that shape this work organization. These incidences helped to provide direction as to what I should study next. In these experiences, I discovered that nursing work that occurs in the school setting is governed by CCAC SHSS policies and work processes, situated in the domain of home care. I went on to study the provincial policies on home care, and home care reform and restructuring that took place beginning in the mid-1980s. I discovered an ongoing story of an unsustainable home care sector due to rising costs and demands, and the necessity of privatizing home care asserted as the only solution to manage the costs and 'save' our valuable public health care system. As I will show in my analysis (see in particular Chapter three), the introduction of privatizing relations into the local practices of community nursing shifts the costs and responsibility of care for children with chronic

health conditions from the state to individuals and families, resulting in an intensification of the healthcare work of parents and caregivers of these children.

I am cognizant that the institutional complex of education is left out of this study. First, this is for practical reasons; it is not within the scope of a doctoral thesis to investigate both of these institutional complexes (after all, I do want to eventually graduate). Second, my concern is over the healthcare of my child, therefore I decided that it was more fitting to investigate the institutional complex of health in this study. Moreover, my troubles were not situated with the teachers' work organization around my child's health. In fact, teachers not uncommonly helped me to 'work around' the troubles with nursing care even though it was not within their mandate to do so.

The structure of this thesis

There are seven chapters (not including introduction and conclusion) in this thesis. There are two parts; the first part has three chapters that orient the reader to the distinctive way this research will be conducted and the background in which it takes place. Part two consists of four chapters that are single authored and written in the format of journal manuscripts. All have been submitted to academic journals to be considered for publication; to date two have been published. Given four of the chapters are written in a journal article format, there are some unavoidable overlaps in content, particularly in the sections on the conceptual and theoretical framework of this research, the SHSS policies, and data collection. The focus of each of the seven chapters is as follows:

In Chapter **one**, I orient readers to the distinctive way of doing research using Institutional Ethnography (IE). It is a non-traditional methodology chapter. Instead of simply writing about the conceptual and theoretical framework of IE, I first provide a brief overview of IE, and the reasons for my interest in this way of thinking and doing research. Then, I go on to describe how I learned and came to understand the central ideas used in IE and how I took up these central ideas in doing this research. There are a few reasons why I did not choose to write a traditional methodology chapter. First and foremost, because IE is not only a methodology, rather it is a distinctive and alternative way of conducting sociology, it doesn't make sense to write a methodology chapter. Second, I have found learning to do IE to be a challenging journey, particularly when I am steeped in doing traditional qualitative research using thematic analysis and grounded theory. It took me a long time to make the ontological and epistemological shift, and I continue to learn to do empirical research that produces a materialist account, instead of an ideological account. I found it helpful to hear how Susan Turner studied IE with Dorothy Smith. So, I hope writing how I learned to do IE will be useful to those who are new to IE and interested in using IE in their research project. The third reason is because in the four chapters written in journal article format, I have written how I drew on the IE framework to do the research and the descriptive analysis for each specific chapter. To avoid more repetition, I decided it was more useful to write this chapter in this non-traditional way.

Chapter **two** examines the term ‘diabetes care’ as referenced in different spheres of activities in different settings, as well as the framework underpinning the development and use of this term in those settings. I have examined how ‘diabetes care’ is understood by healthcare professionals in the pediatric diabetes clinic, by parents in their daily and nightly work of caring for their children with diabetes and keeping them alive, by teaching staff in schools, and by the CCAC care coordinators who work for and manage the CCAC SHSS programs respectively. In so doing, I make visible how knowing ‘diabetes care’ is organized in each particular setting, and how each way of knowing ‘diabetes care’ produces different consequences for how children’s needs in school are understood, and who is understood as responsible (or not) for meeting them. More importantly, these distinctive ways of knowing create a disjuncture for me as a parent and establish the research problematic in which I begin the explication for this study.

Chapter **three** sets the context for this research and describes what we know is happening in the home care sector. I first situate the SHSS within the services provided by home care. I go on to provide an overview of how home care is situated within the Canadian health care system to make visible the precarious location of home care services. While hospital and physician care is part of Medicare and is universally accessible, home care is not protected by the Canada Health Act, 1984. As a federally uninsured health service, it is open to funding cutbacks at a time when the provincial government is implementing austerity measures. I have come to identify the home care reform and restructuring in the past three decades as a form of privatizing relations. These

relations enter into the local setting of the community through the policies and operations of the CCACs, and in turn mediate the practices of community nurses. In addition, I have come to see the cooptation of the chronic disease self-management framework as another way in which privatization occurs. The construction of citizens as rational ‘consumers,’ actively engaged in improving and managing their health, further legitimizes the shift of costs and labour of care from institutions to the community, and from publicly funded health care workers to unpaid caregivers in private households. These privatization strategies reorganized the home care sector, the workforce, and the relation between the ‘state’ and its citizens. It is under this context that children with diabetes and their parents find themselves in conditions whereby they are called upon to take on more responsibility.

Chapters **four** to **seven** are written in academic journal format. Chapter **four** is an article that looks at parents’ experiences of caring for children with diabetes, with a particular focus on the emotional work involved in caring for children with diabetes. The analysis of this paper is based on the seven interviews I did initially with parents of children with diabetes. Despite the differences in their years of experience in doing diabetes carework and the ages of their children, they all identified worry as a significant and challenging part of caring for children with diabetes. Instead of taking parents’ expression of worry as an indicator of maladaptive coping, I show in this paper that parents’ experience of worry is often informed by a wealth of knowledge and experience, undertaken with care and intention, and done in relation with others. It is a form of

emotion work involving active, skillful engagement that I refer to as “doing worry”.

Parents actively and competently engage in doing worry. In paying attention to worrying as work, I show how worry is an embodied way of knowing the presence of potential threat to child’s health, and thus an essential aspect of the work of parents to ensure the safety and well-being of their children with diabetes. As such, interventions should encourage health care professionals to respect parents’ worry and the knowledge that underpins it. This article is submitted to *Qualitative Health Research*.

Chapter **five** is an article describing how as a parent I am drawn into the work of securing, advocating, and supporting the delivery of health support services for my child at school. In particular, I draw the readers’ attention to two specific texts - the *Community Care Access Centre (CCAC) Referral Form* and the *CCAC Medical Orders for Services at School*. In examining the work-text-work sequence around these texts, what becomes apparent is that the *CCAC Medical Orders for Services at School* is an authorized standardized text that is used to stand in for and subdue parents’ experiential knowledge of what is needed to ensure the safety of children with diabetes at school. Parents’ knowledge and their voluntary and supplementary healthcare work is incorporated into the institutional complex of SHSS program to ensure the child’s safety at school, and thus is essential for the institution of public schooling to operate as it does, and sustain the official ideal of equal and inclusive education for all. This paper is published in the *Journal of Sociology and Social Welfare* (see References for the complete citation).

Chapter **six** is an article examining the social organization of the scheduling of nursing visits and nursing work. The exploration opens up to view how an institutional technology, the Client Health Related Information System (CHRIS), shapes the conditions for community nursing and the quality of nursing care. The CHRIS program introduces a particular version of quality that is linked with the acceptance of service offers by a healthcare agency, each acceptance of an offer is automatically recorded in the CHRIS program and later taken up by the CCAC quality and financial officers to monitor, evaluate and determine the allocation of ‘market share’ to the agency. To prevent a decrease in market share, service coordinators and managers of healthcare agencies are organized to accept service offers for which they cannot provide a consistent nurse and as a result, the quality of community nursing care is affected. The article is submitted to *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*.

Chapter **seven** is an article exploring how the assessment work of CCAC service discharge is socially organized. The analysis shows how the activation of the institutional category of ‘independence’ by the nurses mediates their work, orienting their focus towards transferring primary care to children with diabetes. Children doing diabetes self-care work at school is then written up in nursing texts to stand in for children’s ability to manage diabetes ‘independently’. The textual production of ‘independence’ enables the discharge of children from nursing services at school. What is shown is how the institutional cost-containment intention enters into the local setting and draws parents, as

well as children with diabetes into doing the discharge work that ultimately benefits the institution. This paper is published in the *Journal of Comparative Social Work* (see References for the complete citation).

The **Conclusion** offers my concluding thoughts on how knowledge and power operate in the everyday world of parents and children with diabetes in the local school setting. Dorothy Smith (1999) contends that theory is itself a practice (p. 4). What and how something is known, and the conceptual framework embedded in knowing matters, as it organises what we do and what gets done in a particular time and space, and in and across multiple concrete settings. Knowledge mediates our relation with each other, and coordinates what we do in relation to each other. Throughout this thesis, I highlight the contested ways in which diabetes care for children is known in Ontario schools. Removed from the actualities of parents' and children's everyday lives and inattentive to the actual circumstances they are in, the institutional ways of knowing of the CCAC SHSS policy and practices are objectified forms of knowing that subjugate parents' own way of knowing their world and do not serve their interests or the interests of their children. I argue that it is this objectified institutional way of knowing that organizes parents to be concerned and worried about the safety of their children with diabetes at school. To relieve their worry, parents are drawn in to be on-call to offer guidance to nursing and teaching staff and to be at the school to actually provide care. In making visible how power relations operate at the local level of everyday experience, I show how parents' 'unauthorized' knowledge and their ongoing voluntary complementary healthcare work is

what enables the smooth operation of health supports at school. However, not all parents can engage in this work as called for by the CCACs and the schools. A policy that relies on parents' voluntary work to sustain its official ideal to provide an inclusive and equitable education is in effect reproducing inequality and exclusion.

Part One:

Theoretical and Conceptual Framework and Background

CHAPTER ONE

“How did you learn about IE?”: A journey of learning to do an Institutional Ethnography

In 2015, I attended an Institutional Ethnography (IE) workshop at the Society for the Study of Social Problems annual meeting. A seasoned institutional ethnographer, Marjorie DeVault, posed this question to me: “How did you learn about IE?” At first, I was tongue tied as I was not expecting this question. In my rush to come up with an answer, I interpreted it as a question asked in any everyday conversational setting. Recovering from my initial lack of words, I muttered that my initial exposure to institutional ethnography was reading Dorothy Smith’s book, *The everyday world as problematic*, which was a recommended reading for a course I took while doing my Master’s degree. Since then, I have had time to ponder this question, and realized that given I was at an IE workshop perhaps the question was intended in a particular way, differently than I heard it. My answer at the time seems to be responding to the question, “Where did you hear about IE?” instead of “*How* did you learn about IE?” Indeed, ‘knowing’, ‘*how* I come to know what I know’ and the social organization of knowledge are fundamental questions explored in IE. Reading this question from an institutional ethnographic framework now, I anticipate this question will require a different type of answer; an answer that will make visible the process of how I learn and come to understand IE.

In this chapter, I will attempt to answer this *how* question from an institutional ethnographic framework instead of writing a traditional methodology chapter for a dissertation. Often times, the traditional methodology chapter is written up objectively in a ‘report back’ sort of fashion outlining the concepts, methodology and methods used in the research. The work of the researcher in learning how to do research by taking up a particular framework does not make it to the final pages for that chapter; it is as if the researcher miraculously knew how to do the research without having to learn it. Of course, this cannot be the case. It is just that the process of how the researcher learned about and came to know how to do research using that specific framework and the work involved in the process of learning it is rarely written up and so it becomes invisible to the reader.

This reminds me of an interaction Dorothy Smith (2005) wrote about in *Institutional Ethnography: A sociology for people* where her son sought her advice on how to write up the science experiment he did in school, and thought that Dorothy’s suggestion of writing everything he did was stupid as no one would want to know the step-by-step details of exactly how he did it (p.157). I am guessing that since this was a school assignment, it is highly likely that the ‘no one’ he referenced was his teacher, the audience who would later read and appraise his finished written report. In this context, the teacher, who is knowledgeable about the science experiment and shares a world in common with him specific to the science experiment, may indeed find the step-by-step details to be redundant, and perhaps unsophisticated (especially if this was not what the

teacher was looking for in the report). However, an audience that has never done a science experiment or this particular science experiment and who do not share this common knowledge, would appreciate the step-by-step details and find them useful to better understand how to conduct the science experiment.

It is with this in mind that I write this chapter. I have to confess that as someone who was new to IE and was trained as a qualitative researcher using thematic analysis and grounded theory (which I have come to know is very different than IE), I struggled with learning IE. I was told that I needed to have a radical turn in my thinking, but what does that mean? What does it look like? How do I do it? It would have been helpful for me to read the process and tips of how others came to learn IE, and how they learned to do research using the institutional ethnographic framework. In my attempt to share my journey of learning how to do IE, very much like the way Dorothy suggested to her son writing up the report for the science experiment, I hope to make visible the ‘steps’ by which I came to understand the core tenets of IE. I want to show how I made the “ontological shift” (G Smith, 1990, p.633), what I paid attention to when collecting data, how I oriented to thinking and asking questions about the data analytically, and how I wrote up the descriptive analysis of the research, in the hopes that this way of writing will be useful to those who are new to IE, and will be helpful in their journey of learning and doing an IE. Moreover, I believe this way of writing is a more truthful description of the actual research process I undertook and the labour involved in the process.

In what follows, I will first provide an overview of IE and the reasons for my interest in this way of thinking and doing research. Then, I will discuss the central ideas institutional ethnographers orient to when conducting research, and how I came to understand what it means, and how it shaped my research.

Institutional Ethnography: An alternative sociology, not a methodology

Dorothy Smith, a Canadian sociologist, developed IE in conversation with her initial cohort of doctoral students at the Ontario Institute for Studies in Education where she taught (D. Smith, personal communication, November 2015). She refers to it as an “alternative sociology” (Smith, 2005, p. 7) that aims to explore the social relations that structure people’s everyday lives in contemporary societies, and their consequences for people. Drawing on her experience in the women’s movement, and her critique of established mainstream sociology where people are objects, their behaviours studied and explained, she developed IE as an alternative way of conducting sociology “that explores the social from women’s (people’s) standpoint and aims to be able to spell out for women (people) just how the everyday world of our experience is put together by relations that extend vastly beyond the everyday” (Smith, 2005, p.1, brackets added). In the institutional ethnographic framework, people are positioned as subjects and knowers, and the institutional ethnographer aims to develop empirically a body of knowledge that can explain to people how the social is put together and how society works. This knowledge will show people how the social enters into and shapes their lives and their activities by

extended social relations and organizations that they are a part of and participate in, yet are not fully visible to them at the local level where they are (Smith, 1999, 2005).

While the inquiry always starts with experiences from people's everyday life circumstances that trouble and perplex them, the investigation is not contained at the local level of experience. The focus of the investigation is on discovering the institutional organization that is constituted at the trans-local level, yet embedded in and shaping, coordinating, and limiting the local experiences and practices of people. This knowledge of "how the experience came to happen as it did" and "how it works" (Smith, 2006, p. 7) does not subjugate or replace people's own way of knowing their world, rather it expands what people already know at the local level to show them how their everyday world is linked with decisions made elsewhere; that is, how what happens in the local setting is linked to other settings through trans-local relations. This knowledge is invaluable to people as it maps and makes visible the aspects of power operating in their social life that otherwise lie hidden, mysterious or taken for granted, so that they can better understand, change and transform these power relations (Campbell & McGregor, 2002, Smith, 2005). Smith (1999) refers to these regimes of power as "ruling relations" (p. 49) (more on this in the section on social relations and ruling relations below).

Having the ability to make visible the power relations that operate at the local level of experience is one of the reasons why IE is generally considered to have a critical or liberatory purpose (Devault & McCoy, 2006). It is a sociology with "an activist

enterprise, situated outside the relations of ruling, while problematizing them” (Heap, 1995, p. xiv). This is the first reason why I am drawn to IE. The second reason is because of IE’s focus on how relations originating in the trans-local level enter into the everyday and shape local activities. I have always had an interest in the inter-connectedness of power and how it operates at the ‘micro’ and ‘macro’ levels. Influenced by the feminist movement, I believe “the political is personal” (as Bannerji, 2000, p. 88); individual acts are not merely the intent of the individual, they are also articulated to ‘social structures’ and ‘ideologies’. At the same time, these ‘structures’ can only be maintained and reproduced through the skilled interactions of social actors in everyday practices (Nash, 2001). Individual ‘agency’ has the ability to make structural changes and this also means that individuals are implicated in maintaining the social order as well. While Dorothy Smith is interested in how the social order is constituted and maintained, she does not use the terms ‘micro’ and ‘macro’, or ‘agency’ and ‘structure’. She finds using these reified concepts to be confusing as she cannot locate these concepts in the actuality of people’s lives. Moreover, starting inquiry in the theoretical glosses over the socially constituted and organized condition of knowledge production, and social relations expressed through these terms are presupposed, thus the knower’s relation to it becomes invisible and unquestioned (Smith, 1974; Smith 1990a). Instead, she proposes an alternative ontology of the social grounded in people’s doings, in time and space, and concrete settings. Smith’s proposed IE framework offers me a unique and useful way to think about and make sense of the power relations and inter-connectedness of the ‘micro’ and ‘macro’ systems, and how people participate in them. It also offers a way for me to see and show

concretely how people (often unknowingly) are hooked into participating in the power relations that shape their lives. It is precisely this ability to locate concretely how people participate and are implicated in these ruling relations that creates possibilities for people to affect change (Basailon, 2012). The third reason is because I was highly encouraged by my classmate and dear friend, Will Rowe, to pursue my doctoral work using the institutional ethnographic framework. He urged me to take the IE workshop taught by Dorothy Smith and Susan Turner at the Centre for Women's Studies in Education (CWSE), and so I did. I promise I will thank him in my thesis, and here I am delivering that promise. I am grateful for his prompting and encouragement. As well, the building of scholarship is never the work of one individual; ideas often emerge in conversation with one another. I am thankful for those conversations with my classmates in the Ph.D program, my supervisor, my committee members and other seasoned and novice institutional ethnographers. They are very much a part of how I came to learn and do an IE.

Before moving on to discuss the core tenets of IE and my journey of learning them, I want to underscore the importance of understanding IE as an alternative sociology. IE is often included as a chapter in research methodology and methods textbooks and as such it is misunderstood as a methodology for research. However, this is not a true depiction of IE. I have come to understand that IE is not just a methodology. Methodology refers to the theories about methods used in conducting scientific or social science research; it is a systematic, theoretical understanding of the methods employed in

a field of study. As an alternative sociology, I understand IE as a theory that provides the underpinnings for understanding a field of study, in this case, sociology. To equate IE as a methodology undermines its revolutionary intent and draws it back into the categories and frameworks set by established sociology that Smith sees as problematic. She critiques these categories and conceptual frameworks in established sociology for the production of objectified knowledges that are inattentive to the actual circumstances of the diverse lives people live in contemporary societies. She tries to break away from the universalizing mode of knowledge production in mainstream established sociology (Smith, 2005). To do so, she argues that it is not enough to supplement an established sociology by addressing what has been left out or overlooked.

In establishing an alternative sociology, Smith intends to turn sociological ontology and inquiry on its head and to reorganize the relations of knowing the social (Smith, 2005, 2006). To reorganize this relation of knowing, it is fundamental to understand IE as having a distinctively different ontology than established sociology, and having its distinctive IE terms and categories to speak about research and the social that we are a part of. This is not just a play on words, nor an exercise of arguing for the sake of arguing (though it is sometimes misunderstood as such), rather it is an effort to develop a theoretical framework and practices that break away from established sociology's objectifying discourse and objective methods of producing knowledge, and to develop a new framework (with corresponding discourse) to understand (and speak about) society that does not subjugate people's own ways of knowing, and to maintain people as

subjects and knowers of their world. At the same time, as Dorothy Smith contends, it is to produce empirical knowledge that “represents the social as it happens” (1999, p. 97).

I have come to learn that breaking away from the categories and frameworks established by mainstream sociology is critical in understanding the ideas in IE (such as the ontology of the social, more on this in the next section) and in learning to conduct an IE. The first step is to question the terms and categories used, and in so doing, what come to view are the social relations expressed through these terms, and the framework in which these terms are established. To illustrate what comes to view when we start examining the terms we use, I am going to share an incident from my everyday life as a mother. Every day after school, I stay with my daughter at the park with other parents. Our kids generally play happily. One day, an older boy came along and blocked the younger kids from using the slide. The younger kids were complaining and I went over to the children and another parent followed along. I inquired what was going on; the older boy muttered, “nothing” and left. After he left, the parent that came along explained that she came to be my ‘witness’ in case the boy later accuses me of verbal assault. I was surprised by her use of the terms ‘witness’ and ‘verbal assault’. I wondered how a caring and neighbourly parent trying to resolve minor conflicts among children playing in the playground and watching out for her kid was constituted as a possible ‘verbal assault accusation’? In paying attention to the terms ‘witness’ and ‘verbal assault’ and the contexts in which these terms originate, the legal system came into view. I can see how the legal system entered into the local setting and coordinated her action of coming along

with me, and thus the ordinary way in which parents overhear playground conversations occurring among parents and children in the park became bearing witness to a potential reported ‘crime’. From this example, I see traces of how a ‘crime’ is socially put together among the activities of people. To break away from the categories and frameworks already set is to learn to see a ‘crime’ not as something existing objectively, rather it exists in the activities of people coordinated with one another through the activation of the legal framework. Previously I had taken for granted the legal framework embedded in the word ‘crime’. When I question how ‘crime’, an illegal activity punishable by law, is brought into existence, I can see how the legal framework activated by the other mother entered into my everyday conversations with her. Learning IE is an ongoing process of unlearning my previous way of knowing the social, how I understand knowledge and knowledge production, and learning a new way of understanding, thinking, speaking, and writing about the social that does not exist over and above people, and can only be found from “within the practices/ activities of our own everyday/ everynight living” (Smith, 1999, p. 225).

Now, I will turn to the central concepts in IE, and how I learned and used them in my research. These are: ontology of the social, research problematic, social relations and ruling relations, and text, language, and speech genres.

Central ‘concepts’ in IE

Ontology of the social – making the ontological shift

As I have mentioned previously, IE's distinctive ontology of the social is fundamental to understanding and doing an IE. Ontology is concerned with questions regarding the nature of existence, the structure of reality, and what exists or what may be said to exist (Crotty, 1998, p.10); that is, it is a theory of being (Smith, 2005, p.226). In IE, the term is used to stand for a theory of how the social exists. Unlike traditional sociology where inquiry begins in theory, the abstract, conceptual organizations or relevances of institutional discourse where society or the social exists in the abstract through reified sociological concepts and categories such as 'organization', 'institution', 'social structure', 'social order', 'social function', 'social norms' to name but a few, IE grounds the inquiry in "an ontology that views the social as the concerting of people's activities" (Devault & McCoy, 2006, p. 16). The ontology of the social is understood as a world that is put together (being produced and brought into being) through the coordination of ongoing actual practices and activities under definite material conditions, in time and space, among actual people in their bodily existence (Campbell & Manicom, 1995; Smith, 1999). That means the social is not isolated or lifted out of time and space as a phenomenon separate from people's activities, rather it can be located among people and their doings. People are speaking, knowing subjects; we are active and are situated in the world and are always participants in the social that is always in motion and to be discovered (Smith, 1999). Through examining people's doings in relation to one another in and across various and multiple local and trans-local sites, we can begin to open up a way to see how society is put together. As such, the entry point of an institutional ethnographic inquiry always starts where people are as bodies in the actualities of their

lives in actual situations and everyday activities (Diamond, 1986; Grahame, 2004; Smith, 1987). It begins with what is of concern to people at the local level, a standpoint in the everyday world outside of institutionalized discourses (Smith, 2005). In so doing, the focus of sociological research is shifted away from questions generated by administrative or institutional concerns and toward the puzzles of people's everyday lives.

This commitment to seeing the social world as brought about in people's activities and in coordination with each other in and across various and multiple local and trans-local settings is critical to an IE research project (Mykhalovskiy & Church, 2006). George Smith (1990) describes this commitment to seeing the social as constituted in the actions of embodied people going about their everyday lives as an "ontological shift" (p.633). It orients the researcher to think about the social phenomena and its relation to people in a specific and concrete way. The inquiry occurs in the same world as that which the ethnographer is exploring (Smith, 2005, p.226). There is an explicit commitment to reject the abstract and speculative ways of knowing social phenomena and a validation of people's experiential, contextual, and particular knowledge of what happens in their lives at a particular site. The social relations that organize peoples' practices are analyzed rather than "presupposed" (Smith, 1990, p. 37). As Deveau (2008) explains, "making an ontological shift means transferring agency away from concepts . . . back into the embodied knower so that we come to understand how things happen the way they do" (p. 5).

However, making the ontological shift is easier said than done, particularly when the terms and categories used in our ‘society’ are so ingrained and widespread, and how we come to know what these terms mean and the framework in which these terms are established are taken for granted. We are not used to stopping and questioning what each term means and how they come to be understood this way every time. For example, in Alison Griffiths and Dorothy Smith’s research on schooling (2005), the term ‘school day’ seems readily understood by most people. It is often used to reference the time a child is at school, say for example from 9am to 3pm. It is a standardized order set by the school and school boards, and thus serves the interest of the school. This understanding of a ‘school day’ is what Dorothy Smith refers to as the objective and universalized (institutionalized) way of knowing. The institution of schooling is so embedded in our everyday life that when I ask my spouse to explain what ‘school day’ means, he is unable to explain it other than taking up the institutional discourse. He responds that it means, “School is in. Like, it’s a school day today!” If we strip off what we normally know as a ‘school day’, break away from this institutional way of knowing, and pay attention to the activities actual people engage in and how they talk about what they do, we will notice a ‘school day’ is not something that exists out there objectively. We come to see a ‘school day’ is constructed through the work the parent and the child do to get the child ready for school at a specific standardized time set by the school. Griffiths and Smith (2005) show in their research how this standardized order of a ‘school day’ enters into the local level of the family and organizes parents’ activities into producing a normal school day. At the same time, the school relies on the parents’ work to maintain this standardized order. The

authors find that not every family has the social and economic resources to accomplish the production of this standardized order of a school day, and for those families that struggle or fail to do so, there are negative consequences for their children's success in school.

I found this example particularly helpful in thinking through my own research into the social organization of SHSS for children with diabetes. In Ontario, it is written in the Education Amendment Act (1980) that every child has the right to access education regardless of their disabilities and special health support needs. The provision of SHSS is to ensure that this piece of law is materialized (Ontario Ministry of Education, 1984). For children with diabetes, the special health support needs required for them to attend school safely involve frequent blood sugar checks and blood sugar monitoring, administration of insulin, and the consumption of the correct amount of carbohydrates at the correct time throughout the time they are in school. When I requested supports for my daughter at the time she was starting kindergarten at age three years and ten months, I was told by the CCAC care coordinator that she needed 'nursing care' at school. What my daughter needs to stay well at school is categorized as 'nursing care' in the institutional intake process of the CCAC SHSS program. The moment I began to make the "ontological shift" was when I began to question the term 'nursing care' and recognize it is a service category established within the CCAC SHSS institutional framework. It stands in for the routine 'diabetes care' my child needs to stay alive at school. I began to see 'nursing care' for my daughter at school as being produced by people's activities in coordination with one

another. ‘Nursing care’ is brought into existence through my work of describing my usual diabetes care routines for my child which includes constant vigilance and frequent blood sugar checks to prevent hypoglycemia and how this is coordinated with the assessment work of the CCAC care coordinator. The CCAC care coordinator activates the eligibility criteria preset for a particular service and competently selects from my description what fits in the eligibility criteria to determine whether or not my child is eligible for ‘nursing care’. Once deemed eligible, the CCAC care coordinator contacts the service coordinator at a healthcare agency. The scheduling work of the service coordinator is then coordinated with the nursing work of front-line nurses at school. It is through the doings of multiple people at multiple settings mediated by the CCAC SHSS institutional process that ‘nursing care’ is produced.

IE’s distinctive notion of “work” is useful in understanding people’s doings. Work, in IE, refers to what people do that requires some effort and some acquired competence (Smith, 1987, p.165). It is used as an empirically empty term. It does not categorize some activities as work and limit other activities as not since IE is not concerned with making distinctions between what is work or not work (McCoy, 2006; Smith, 1987). Rather, the notion of “work” directs “analytic attention to the practical activities of everyday life in a way that begins to make visible how those activities gear into, are called out by, shape and are shaped by extended trans-local relations of large-scale coordination (what Smith calls relations of ruling)” (McCoy, 2006, p.110-111). Work knowledge refers to people’s ordinary knowledge of their everyday doings and how

it is coordinated with the work of others. It is a great resource for Institutional Ethnographers to put together the sequences of an institutional work process (Smith, 2005).

When I pay attention to what I do as a parent of a child with diabetes as work and also pay attention to how this work provides for the condition of the work of others, such as ensuring the presence of the Medical Orders and an abundance of medical supplies at school for the front-line nurses, teaching and sharing my knowledge of my child's diabetes care to the front-line nurses, and calling healthcare agency service coordinators when the teacher alerts me that there is no nurse that day to ensure there will actually be a front-line nurse at school, I can begin to see 'nursing care' is brought into being through my activities in coordination with the work of the CCAC care coordinator, the service coordinator and the front-line nurses from the nursing (healthcare) agency, and the teachers at school. Of course, nursing care would not exist if the nurse did not show up at school, nor would it exist if I did not ensure that the Medical Orders, as well as medical supplies available to perform the care, were present in the school. I am thankful to Susan Turner's friendly reminder to pay attention to people's doings and her recommendation for me to actually write out in big letters, "PEOPLE'S DOINGS", and post it in front of me on the wall where I work as a constant reminder of the distinctive IE ontology. This was helpful in facilitating this shift in my thinking and knowing. Recognizing 'nursing care' as actual practices and a work organization provides a different basis of investigation, and moves away from assigning agency to concepts. For example, some

parents attribute the frequent change in front-line nurses for their children at school to the lack of organization of scheduling work. Through empirical investigation of the scheduling work of service coordinators, I found the opposite is happening. In fact, the routine scheduling work of service coordinators is mediated by an institutional technology, the Client Health Related Information System (CHRIS), and is organized to prioritize the acceptance of service offers over the provision of a consistent nurse. As such, the frequent change of front-line nurses is not due to a lack of organization, rather it is a particular form of work organization that organizes the inconsistent nursing to occur. This commitment in seeing the social as accomplished in people's activities is critical in producing knowledge that is empirical and useful for those whose lives are caught up and subordinated to ruling regimes, and for activists who are interested in changing these ruling regimes.

Research problematic

As mentioned in the previous section, an institutional ethnographic inquiry always starts in the actualities of people's lives, however the problematic of the study is not empirically focused on the actualities of people's experiences at the local setting. A research problematic in IE is not understood as a research question or a topic to be studied by the institutional ethnographer. It does not aim to study individual people, their behaviours or their inner experiences; nor is the focus in discovering how activities reflect social structure (Devault & McCoy, 2006; Heap, 1995). A problematic for the sociological inquiry is discovered in and developed from a concern in people's everyday

experience whose social organization is to be explicated (S. Turner, personal communication, August 10, 2012). A problematic “sets out a project of research and discovery that organizes the direction of investigation from the standpoint of those whose experience is its starting point” (Smith, 2005, p.227), with the focus of discovering how people’s everyday experiences are drawn into and organized by the workings of institutions and the ruling relations (Smith, 2005).

Dorothy Smith used an example of a map at a skiing resort to explain the idea of a research problematic and its development in relation to doing an IE (D. Smith, personal communication, June 2013). Standing in front of a map resembling the landscape of hills and trails at the skiing resort, one can see the words “YOU ARE HERE” above the red arrow, indicating where you are in actuality at the starting point of the skiing route. This location where you are is where the different trails cross-over, and there are many different trails an individual can choose. The magnifying glass hung on the side of the map allows the skier to put it over the map, magnifying what is printed on the map so the skier can clearly see the different trails, and decide which route to take. This location resembles a concern or problem in people’s experience, similar to the starting point of IE research. Social relations are like these trails, they are complicated and complex, and there are multitude of social relations embedded in an experience. The development of the research problematic is like putting a magnifying glass over the location on the map where one intends to explore, and enables the researcher to formulate a research project from people’s everyday concerns to explore the social relations that go beyond this

location. How is this experience put together such that it becomes a concern or problem for people? While people's concerns and problems are often the motivation for the inquiry, these do not define the direction of the research. Putting the magnifying glass over the location is like looking closely, listening attentively to people's talk of their concerns, and identifying within this talk the institutional processes that they are implicated in and are relevant to what is happening to them that is of concern.

During the first year of my doctoral studies, I started off wanting to do my research on caregiving and 'diabetes care' for children. At the time, my daughter had just been diagnosed with diabetes almost seven months ago. It was a broad landscape, much like the map of the whole skiing resort. I knew I had to somehow narrow my focus. I recall just after my daughter got diagnosed with diabetes, I was introduced to a parent of a child with diabetes by an acquaintance and this parent alerted me to the challenges they encountered at school. She shared with me an electronic version of a 'binder' she created specifically for teachers and nurses at school (later, I realized the helpfulness of this binder). Of course, at the time, I had no idea what challenge she was referring to, but it piqued my interest. Since then, I have read many stories circulating within the on-line diabetes community about the problems parents of children with diabetes have in getting the supports they need to adequately care for their children with diabetes at school.

Here are some of the stories: A parent whose child was about to start kindergarten wrote about having to contact the school multiple times over the summer to set up

meetings and advocate to the school principal and to the CCAC staff on behalf of her child to get adequate supports for her child. Another parent wrote about the nurse administering a wrong dose of insulin during one of the nursing visits resulting in her child experiencing severe low blood sugar at school and being called to the school; another parent wrote about receiving a phone call from the nurse to go to the school because her child threw up right after she received the full lunch time dose of insulin and was unable to consume any food. The parent arrived at school to find out that the nurse had left her four year old sipping water with an educational assistant even though the mother specifically alerted and instructed the same nurse to give her child apple juice to prevent the child from experiencing hypoglycemia and to stay with the child until her blood sugar was back above 4 mmol/L at a stable level. I was puzzled and wanted to learn more about how these school health supports for children with diabetes happened as they did. How is it organized in such a way that parents are left frustrated and fearful about their children's immediate health at school, as well as in a position where they are called upon to secure adequate services, provide care, and to enable, guide and correct the care of adults around the child at the school?

When it came time for my daughter to start kindergarten, I learned from the pediatric diabetes clinic that there is a 'referral process' for services at school, and so I requested a 'referral' for services at the clinic. I remember leaving the clinic feeling confused and troubled by the Medical Orders written on the *Referral Form* by the same doctor who taught me how to care for my daughter. The Medical Orders written on the

Referral Form and what I was taught to care for my daughter were different. The Medical Orders were insufficient and did not orient to what my daughter actually needs to stay healthy while at school. From that time on, I documented in my journal the process of how I secured school health supports for my daughter with diabetes at school in detail and as concretely as possible. This proved to be a useful source of data to develop the problematic. In addition, I studied the *Referral Form* and the *Medical Orders*, and found traces of the institution and the institutional process I am interested in explicating. For example, printed on the top left hand corner of the *Referral Form* is the logo and the specific branch of the CCAC, and printed on the centre of the *Medical Orders* is the name of this document: *Medical Orders for Services at School*. The experience at the clinic was the starting point of my inquiry, where I identified a disjuncture between two different ways of knowing about the health supports needed for my child with diabetes to stay safe at school: my experiential way of knowing as a parent, and the objective, institutionalized way of knowing taken up by the physician at the clinic through the *CCAC Referral Form and the Standardized Medical Orders for Services at School*. My concerns regarding how my daughter's diabetes, that is her health and her life, is being cared for while she is at school became the entry point to develop my research problematic.

As I have shown from the above example, traces of the forms of organization that shape our lives are always present in the actualities of our everyday experiences in the local level. Although most of the time, the institutional complex we take part in is not immediately apparent to us. I entered into the institutional complex of CCAC SHSS at the

site of the pediatric diabetes clinic, but I was not aware of it at the time. It was only through studying closely what was said at the clinic, how it was said, and looking at the texts on the official forms that I began to identify which institutional process I was drawn into. The initial step of developing the research problematic provided the direction for the next steps in my research. Having identified that CCAC is a critical player, I decided I needed to speak to them to learn more about how school health supports are put together.

While I used my personal experience to develop the research problematic, it is worth noting again that while the problematic may start in an individual's experience, the exploration goes beyond the individual at the local level to discover the social relations in which that experience is embedded, therefore what is brought into view for investigation are the relations that are not specific to that individual. However, they may articulate differently in the particularities of each individual's local setting (Smith, 2005). These relations are part of a complex of institutional relations that coordinate what the individual is doing with what others are doing elsewhere (Smith, 2005). As such, these relations can generalize and universalize across multiple local settings, and it is precisely this generalizing property of social relations that make possible the coordination of different people's doings across multiple different sites. It also makes possible a research endeavour that explicates the generalizing social relations and makes apparent to people how they participate in these social processes being described and how their lives are shaped by it at the same time.

Social relations and ruling relations

In IE, the research problematic provides the direction for the research project, and points to the institutional complex or institutional process to be explicated. The concept ‘social relations’ provides the researcher with a way to see the coordination of people’s local practices and experiences across multiple local settings within an institutional complex. This term must not be confused with the way we usually talk about relationships, such as those between parent and child, or teacher and student (Campbell & Gregor, 2002; Smith, 2005). Smith (1987) defines social relations as “concerted sequences or courses of action implicating more than one individual whose participants are not necessarily known to one another” (p. 155). She contends that social relations in contemporary society are not wholly observable in the local setting and are enacted by participants who may not know each other and often “without their conscious knowledge” (Campbell & Gregor, 2002, p.31). George Smith (1995) contended that the notion of ‘social relations’ should not be treated as a reified, theoretical entity, “it is not a thing to be looked for in carrying out research, rather, it is what is used to do the looking” (p. 24). It is a procedure for investigation, and a technical term to orient the researcher to look for how people’s actual practices in a particular local work setting are articulated to sequences or courses of action or particular work processes that hook them up to what others are doing elsewhere and elsewhen (Smith, 2005). Smith suggested that it is useful analytically to look at “social relations as temporal sequences in which the foregoing intends the subsequent and in which the subsequent “realizes” or accomplishes the social character of the preceding” (Smith, 2005, p. 228).

‘Ruling relations’ is a concept used in IE to refer to the distinctive forms of consciousness and organization that are objectifying because they are constituted externally at the trans-local level separate from actual people at the particularized settings and relationships of their life as subjects (Smith, 2005). They enter into people’s everyday/everynight and mediate what happens there. This form of social organization is accomplished through texts, that is, the tools of ruling are discursive. The term “textually-mediated social organization” is used to refer to the idea of the use of text to coordinate and put together the actions and practices of people in the local setting and how they are linked up to trans-local settings (Campbell & Gregor, 2002, p.29). Text-based social relations and texts are recognized as essential coordinators of institutions and it is through people’s actual doings with text that the institutional order is accomplished (Turner, 2003, 2006).

Back to the above example in my research, the idea of social relations as temporal sequences of action alerted me to pay attention to the sequence of how people’s activities are concerted with one another. For example, how my request for a referral for services was articulated to the next step in the sequence of action where the physician at the clinic fills out the *Referral Form* and *Medical Orders*, and how the completed *Referral Form* is linked up to the next step in the work sequence whereby the CCAC care coordinator, upon receiving the *Referral Form*, is organized to conduct an assessment to determine the eligibility for nursing support for my daughter, so on and so forth. What I did not know at

the time was the social organization embedded within this work sequence. Social organization here refers to the distinctive form of extended trans-local relations of large-scale coordination of people's practices that can be reproduced again and again. The work of the institutional ethnographer is to discover how this institutional work process is organized.

At the time, I found it puzzling that the physician at the clinic wrote something different on the Medical Orders than what he taught me during clinic visits. I was worried that these Medical Orders would determine the amount of health supports my daughter would receive at school. I was pleasantly surprised at a school meeting that the CCAC care coordinator for my daughter's 'file' asked me to return to the clinic to request an updated Medical Order with the instruction for "constant glucose monitoring" after I raised my concerns regarding my daughter's fluctuating blood sugar levels. I was surprised again when the physician willingly updated the Medical Orders including the instruction for "constant glucose monitoring" when I told him that was what the CCAC care coordinator requested. Once the physician updated the Medical Orders, I began to see it is not the physician at the clinic that holds the authority to determine the type and amount of nursing care. Here, I see traces of ruling relations present at the clinic. What the physician wrote the first time on the *Referral Form* was not shaped by his knowledge or my knowledge, as a mother, of what my daughter needs to be safe at school, but by the institutional knowledge through the work of the CCAC care coordinator.

Following these clues, and the direction from the research problematic, I formally interviewed a CCAC care coordinator in the fall of 2013, and it was during this interview that the *Intersectoral Policy/ Program Memorandum 81 (P/PM 81) titled: Provision of Health Support Services in School Settings* was brought to my attention. Since the *P/PM 81* is part of what the CCAC care coordinator needs to know to do their work competently, she readily volunteered this information when I asked her how she goes about doing her work each day. The *P/PM81* is an example of what Smith (2006) refers to as a “regulatory text” (p.79). It is a higher-order text developed at the trans-local level, but enters into the work organization at the local setting and governs what happens there. The *P/PM 81* pre-determines who has the authority to assess the type and amount of health supports a student needs at school; it states that “the Home Care Program (former CCAC) of the Ministry of Health will be responsible for assessing pupil needs” (Ontario Ministry of Education, 1984, P/PM81, para. 4). As such, the physician is organized to write the nursing instructions that are institutionally actionable under the CCAC SHSS program. What is written on the Medical Orders, then, enables the front-line nurses to perform the nursing instructions as ordered by the physician.

Here’s another example of how text-based social relations organize local practices. I recently was involved in a four vehicle accident. Even though I was not physically injured, it was nonetheless a shocking experience. Having only experienced one other vehicle accident (a fender-bender) almost a decade ago, I was not familiar with what I needed to do. I was instructed by the police to report the case at the collision centre

even though the police on the scene had already taken ‘statements’ and the information from all the drivers involved in the accident. When I was at the collision centre, I was asked a list of routine prescriptive questions that I felt had nothing to do with my personal experience. I was asked: “What were the weather conditions?”, “What was the lighting on the road?”, and information about all the other drivers involved. As I was at a state of shock after the accident occurred, I failed to gather this information; as well, I was told by the police officer at the scene that she collected all the information, so I was relying on her to share this information. When I told this to the person at the collision centre, she expressed that it depends on the police officer: sometimes they will enter that information into the system, and sometimes that information just stays in their books. Moreover, it would also depend on whether the other drivers report the ‘case’ to the collision centre and if so, I would have all the necessary information.

What was interesting was I was asked the same set of prescriptive questions the next day when I reported the accident to my insurance company to open a ‘claim’. I could see this text containing a set of questions present at the site of the collision centre as well as on the other end of the phone line at the insurance company, wherever it was located, was organized by the same set of text-based social relations that was to determine which driver was at fault. As such, in asking the same set of questions, they were organized to gather information to determine whether or not I, as a driver, was at fault at the time of the car accident. It didn’t matter to the person at the other end of the phone line that I was in a state of shock and failed to gather the information. It seems having the information of

the other drivers, particularly the insurance information, is crucial to move onto the next step in the work sequence of determining whether or not I was at fault. In turn, this decision will determine who will be responsible and need to pay for the deductible, and so on and so forth. The expectation that I would remember the details of the road, weather, and environmental condition, as well as ask for the other drivers' information right after the car accident had just occurred was at odds with my experience of panic and shock. It felt almost unrealistic. By paying attention to the temporal sequence, I am able to see how the electronic form on the computer screen as activated by the person at the insurance company is embedded in a sequence of action, the work that went on before (my collecting of the other driver's information) provides for the condition of work called for in the moment (the person completing the form on the screen at the insurance company), and then what is going on in the moment is carried forward, and lays the ground for what happens next (completed form with all the information to determine who is at fault). I later read the following sentence on the bottom of the name card given to me at the collision centre: "Facilitators of Collision reporting – Serving the Insurance Industry under Contract to the [city] Police Service". Indeed, this institutional process of a vehicle accident insurance claim is organized to serve the interests of the insurance industry. Fortunately, the police officer involved entered all of the information into the computer system and the other drivers also reported to the collision centre. I was able to obtain all the necessary information to report to the insurance company to complete a work sequence that concluded I was not at fault.

Before learning IE, I would have felt frustrated that the individual at the collision centre was giving me a hard time when I was unable to provide the necessary information of the other drivers. As well, I would blame myself for failing to gather that information because a part of me recalls reading information from my insurance agent that says in the event of a car accident, call the insurance agent and ALWAYS gather the insurance information from the other drivers involved. However, I did not activate this knowledge when I was in a state of panic and shock. Now, having learned IE, I am fascinated at the pervasiveness of ruling relations, how the text on the screen enters into the site of the collision centre and the claims department at the insurance company and coordinates my relation with these individuals competently administering the electronic forms, and the demand of work it exerts on me, even in the event of a vehicle collision. Seen this way, I was less agitated and more able to converse with the individuals, asking them questions about how the institutional process works which somehow interested them, and proved to be more helpful for me to go about getting information about the institutional work process and on what I could do next. In the way contemporary society is organized, it is inevitable that we will participate in some sort of ruling relations. When I pay attention, I realize traces of ruling relations present everywhere in our local setting.

Learning to see social organization: Text, language, and speech genres

As noted above, ‘social relations’ are not something one can look for and see, so how can we identify social relations and access these extended trans-local relations of large-scale coordination? In doing an IE, attention to text is fundamental to the inquiry

because texts and what people do with texts are material forms of social relations (Smith, 2005). Unlike social relations, texts and people's doings with text are locally observable and accessible. Smith (2006) refers text "to words, images, or sounds that are set into a material form of some kind from which they can be read, seen, heard, watched, and so on" (p. 66). For texts to be ethnographically visible, it is critical to view texts not as objects, specimens to be examined on their own for their meaning, rather texts are conceptualized as 'active', as 'occurring' in time and space, as a moment in a sequence of action in definite local places where it is present as a material entity and being read by an actual person doing the work (Smith, 2005). It is the reading and activation by a subject that brings the text to life. Institutions are recognized as being put together by local subjects working with text and doing the work the text calls on them to do. In activating an institutional text, the subject becomes the agent of the text and the institution; and he or she does the work that was intended or set out by the text. This is referred to as text-based work (Turner, 2006, p. 139).

Smith uses the "act-text-act" sequence (Smith, 2006, p.67) (or 'work-text-work' sequence) to refer to the coordination of work activities from one site to the next through the competent activation of a text (for example, from the physician at the diabetes clinic to a CCAC care coordinator through the *CCAC referral form*). Knowing how to read the text the way it is intended is critical to get the work done. Smith (2005) refers to the way people know how to interpret and do the work called for by the text as the "text-reader conversation" (p.104). Therefore, the competent reader doing the reading of a text is

doing two things: one, he or she is activating the text by following the instructions provided in the text for how it should be read (the reader of the text is also socially organized), and two, he or she is responding, and acting on it in ways that are relevant to the work (Smith, 2005). By exploring the text-reader conversation as a process, and mapping the actual sequences of work and texts in people's accounts, and showing how their work processes and work organization are articulated from one setting to another, social relations can be mapped and explicated (Smith, 1987; Turner, 2003, 2006). In taking up texts and textual practices, the institutional ethnographer is looking at how texts draw people into relations and organize the work and activities they do for the institution.

Smith contends that text forms the “bridge between the everyday/ everynight local actualities of our living and the ruling relations” (1999, p.7). It is its materiality, the presence of a text in the local setting as it is read in the actuality of the individual that the local is connected to the trans-local setting where the text is produced. Through the identification of an institutional text as it is used in the local setting and tracing the origin of this local text and its links to any higher-order text where it is produced, the institutional ethnographer will be able to discover the extended trans-local social relations and organizations that permeate and enter into people's local practices (Smith, 2006). It is precisely through text and language that institutions are enabled to govern, regulate and coordinate the activities and practices in the local settings (Campbell & Manicom, 1995). The possibility of the replicability of a material presence of the same text in different settings at different times and the “recognizable identity of a text from one site of

activation to another is integral to the text’s distinctive form of coordinating ruling relations” (Smith & Turner, 2014, p.5). George Smith (1995) refers to this idea of how particular local experiences of people having the same social configuration of experiences as others at other times and places as they are organized trans-locally through the same text as recursion or the concept of recursivity (p.24).

We see in the above example, the *CCAC Referral Form* is present at the local setting of the pediatric diabetes clinic, waiting to be activated. There are likely many different forms used at the local setting of the pediatric diabetes clinic, and I was able to identify the *CCAC Referral Form* as the text that had something to do with shaping my daughter’s care at school because it was activated by the physician at the moment I requested school supports for my daughter at school. Texts must be examined as they coordinate people’s activities (Smith, 2001). Paying attention to what people do with which particular text for what purpose provides directions to which text I should investigate. The CCAC logo on the *Referral Form* and the title of the *CCAC Medical Orders for Services at School* indicates that the ‘services at school’ for children with diabetes is one of the programs provided by CCAC. A search on the internet shows the SHSS program within CCAC is the specific program mandated to provide special health care services to children who otherwise will not be able to attend school without such services. Tracing upwards and speaking to the CCAC care coordinators who are situated closer to institutional authority, I learn of the higher-level text, *P/PM 81*, and how it enters into the local practices through the activation of the *CCAC Medical Orders for*

Services at School (a local operational text) at the site of the pediatric diabetes clinic, the school meeting, and governs what each agent (e.g. physician, CCAC care coordinator, front-line nurse) within the institutional work process is authorized to do. George Smith used the example of “Russian dolls inside of Russian dolls” and “a story inside a story” to explain the idea that different levels of texts used to conduct the work of the same institutional process also carries something of the same form (1995, p.33). Much like a story being a part of a larger story, the *CCAC Medical Orders for Services at School* is also a part of the higher governing text, *P/PM 81*, and thus also carries the intentions and forms of the governing text.

In addition to studying and finding the linkages between text used locally and trans-locally, I also paid considerable attention to how people talk about their work, and the particular language they use to account for the work they do. Language, used ordinarily in the mundane routine institutional work processes, is recognized as the conceptual coordinator of social action (G. Smith, 1995). Language links people to each other and to a material world shared in common (DeVault, 2013). Language is the coordinator of people’s subjectivities or consciousness and it is through language that we come to know the world we inhabit (Smith, 1990a, 2005). When a spoken word is heard and the listener responds, the word uttered brings the speaker and hearer in relation to each other in a social act, and coordinates their doings with each other. Smith adopts Bakhtin’s (1986) concept of speech genre to refer to relatively stable forms of utterances that have developed in a sphere of activity (as cited in Smith, 2005, p.86). Further, his

distinction of a primary and secondary speech genre is helpful in differentiating language used at the level of direct experience (primary speech genre), and that based on text removed from the particular actuality of people's lives (secondary speech genre). Institutional and professional genres are secondary speech genres. Each sphere of activity, such as in the professions of psychiatry, education and policing to name a few, are secondary speech genres and carry their distinctive forms of speaking, writing and usages of language, and actively organize what people say and do in a particular way in that institutional or professional mode (Smith, 2005). What is spoken or can be spoken is guided by a particular speech genre. By paying attention to the stable ways words are spoken and used in a given moment at a particular setting, the institutional discourse embedded in the organization of the local activities of people is brought into view. It is crucial to always bear in mind that language is active, and it is understood as 'organizer' that has the ability to transmit 'organization' from one site to other multiple sites, governing the local activities of people (Smith, 1999).

For example, during one of my routine conversations with my child's primary nurse, she confirmed that she would provide care for my child the next day. Knowing whether or not my child will get a familiar nurse is crucial to how I organize my day. When I expect a new nurse, I will organize my day in such a way that I can make myself available in the morning to review my child's diabetes routines with the nurse when she/he arrives at school. When the next day came, I received a text from the primary nurse informing me that "*she has[d] been scheduled to provide care for another patient*",

and a different nurse would be providing care for my child. This text message led me to squeeze out time from my work day (which was more possible as a graduate student) to go to my child's school to ensure I could review my child's diabetes routines with the new nurse. At the same time, I was baffled as to how the work of the nurse was arranged such that she confirmed she would provide care to my child the day before and this suddenly changed the next day. I suspect the words she used to text me was a typical utterance used in her work setting at the healthcare agency. As I paid attention to her text, I noticed the verb 'schedule' carries a clue for where to trace the form of organization that coordinates her work of caring for another patient in another setting (likely at his/her home) with the work of another at the healthcare agency who is doing the scheduling. Following this clue, I went on to explore the work organization of scheduling nursing visits, and how this coordination provides the conditions for community nursing work.

In addition, adopting Volosinov's conception of language as "inter-territorial", Smith (1999) recognizes "a word is a two-sided act. It is determined equally by whose word it is and for whom it is meant" (p.142). The meaning derived from the words used are relational, processual, and 'two-sided' (Smith, 1999). It is this two-sided nature of words that coordinates the consciousness between the speaker and hearer (and between the writer and reader) and brings the social into being. As well, the double relation of words and language offers an opportunity to investigate the frames of reference taken up in the interchange between the speaker and hearer (and between the writer and reader). The speaker's use of a particular word is from a particular frame of reference and the

hearer may or may not hear the same word from the same frame of reference. Paying attention to the frame of reference embedded in a word and its use in an institutional course of action helps me to understand what gets done in an institutional process and whose interests are being served. For example, when reviewing a transcript of an interview conducted with the healthcare agency manager, I noted the word ‘quality’ was used in several occasions in describing her work of managing the business of the healthcare agency in relation to the contracts with CCAC. Here’s one of the excerpts:

The competitive model, I don’t think necessarily ensures *quality* at the end of the day. So now the model is, I am not sure whether they’ll ever go back to RFPs, but those that have contracts have contracts. They watch our metrics in terms of missed visits, events, the client satisfaction surveys. They make decisions, so in some areas where a provider hasn’t been doing well in all those metrics, it may affect their market share. So that’s how the CCAC kind of manages us going forward now, in terms of *quality* (emphasis added).

In the first instance, the word ‘quality’ is used in reference to the competitive model’s lack of interest in ‘quality’ when allocating contracts to healthcare agency. Here, she is referring to ‘quality’ of direct client care known from the professional nursing practice knowledge. In the second instance, the use of the word ‘quality’ is not understood from the same frame of reference as in the first instance. In the latter use, ‘quality’ is understood through the metrics. I later found out that these metrics are fields to be entered into an institutional web-based computer software called the Client Health Related Information System (CHRIS) where ‘quality’ is automatically calculated based on these metrics. In the above quote, the healthcare agency manager articulates two different ways of knowing ‘quality’ and it is the latter understanding of ‘quality’ that is institutionally authoritative in determining the future market share for each particular healthcare agency providing services for a particular region. In order to maintain the

business for the healthcare agency (which depends largely on the market share allocated by CCAC), the latter understanding of ‘quality’ is taken up by the healthcare agency manager and organizes her to instruct the service coordinators to accept service commitments for which they cannot always provide a consistent nurse, resulting in my experience of having several different and differently qualified community nurses delivering care for my daughter with diabetes at school. In some of these incidents, the different nurse who delivered care to my daughter was not familiar with her care, and thus made an error on the amount of insulin my daughter should receive to stay well at school. You can see knowing ‘quality’ derived from the web-based computer software does not serve the interests of those actually receiving care.

Data, analysis and writing up what is discovered

I have described the central ‘concepts’ in IE and how I learned to do IE orienting to these ‘concepts’. I have purposefully positioned these core ‘concepts’ in a linear fashion as a suggestion to what I think might be the best route to go about learning and doing IE. As you can see, understanding the ontology of the social is the fundamental first step. Next, is the development of the research problematic. A well-developed research problematic is critical as it can help to keep you and your research on track, and prevent you from veering off to explore a different trail. If you find yourself veering off or overwhelmed by the various ways and directions you could go about doing the research, please return to the research problematic, pick up that magnifying glass, and re-examine the particular experience which drew you into doing this research and was used to

develop the research problematic. If the research problematic is well-developed in the first place, the trail will be relevant, it will help to keep you on track and focused, and connect you back to that particular experience. If not, you might want to consider re-developing your research problematic. What I am proposing is only a suggestion based on hindsight, and the process is never linear, rather it is circular. There will always be some going back and forth. As you continue on this journey, your knowledge will deepen, much like learning any sport or instrument, one begins to learn that the more you practice, the better you will become. I have been encouraged to learn to speak in IE terms, and I find that particularly helpful in deepening my knowledge on IE. Indeed, it is a distinctive discourse or speech genre. Since text/ language coordinates consciousness and doings, speaking in IE terms has helped me to become more aware of when my experience has become objectified and lifted out of actuality. I am more aware and can more readily pay attention to the conceptual frame embedded in the words people use and how that coordinates what they intend for me to do or for any reader to do. That is, how we get hooked into participating in certain social relations through language and reading practices.

As for this doctoral research, the entry point of inquiry starts with my personal experience as a mother taking care of my daughter with diabetes after her diagnosis. I first interviewed seven parents of children with diabetes in the summer of 2011. They were recruited from a parent support group to help refine the focus of this research project. They were asked general questions about their caregiving experiences. What

stands out in these interviews is that they all described it is most challenging when their child is left in the care of someone else. A few of the parents with younger children described the struggles and the work they were involved in to keep their children safe when they are at school. Around the same time, I joined an on-line diabetes community, and I read many similar stories posted by other parents of children with diabetes. When it came time for my daughter to start school, I encountered similar problems and uncertainties every step of the way. I decided to keep a journal documenting my ongoing experience of what happened, and what I did to keep my daughter safe at school, from the first step of requesting ‘nursing care’, to advocating and securing adequate nursing care, coordinating nursing care so there’s actually a nurse at school for my child, being on-call for the nurses, the troubles I experienced with different nurses caring for my child, and teaching and preparing my daughter to graduate from needing nursing care. In my journals, I documented my conversations with people involved in the process, such as the talks with the physician and pediatric diabetes nurses at the clinic, teachers, CCAC care coordinators, front-line community nurses, and service coordinators at the healthcare agency, I made note of the official texts used or mentioned, the unofficial text I created and how it was used, as well as how I felt, what I did and continue to do to ensure my daughter is safe and well while at school. As described earlier, keeping a journal was helpful in the development of the research problematic for this study. As well, gathering data is not limited to formal interviews, it is better to conceive of ‘interviews’ more generally as “talking to people” (DeVault & McCoy, 2006, p.756) across a “continuum of conversations” from formally scheduled to more serendipitous and less pre-planned and

pre-arranged occasions, and at times rich and valuable data are discovered through the latter (Grace, 2013, p.596).

Relying on my own extensive experience and the in-depth interviews with parents, I developed and refined the research problematic for this project. The problematic laid the grounds for the next steps in the exploration of the social organization of school health supports for children with diabetes in Ontario schools. I then conducted 11 interviews with staff from four healthcare agencies (3 community nurses, 1 clinical educator, 2 nursing supervisors, 1 scheduling supervisor, and 1 manager) and staff from one CCAC (2 care coordinators and 1 CCAC manager) between September, 2013 to June, 2014. They were not done in any particular order as this was not often within my control, and I had to rely on the CCAC manager to have access to the participants from the healthcare agencies. I interviewed whoever contacted me first to express an interest in participation. The interviews with parents received ethic clearance from the University Research Ethics Board and the interviews with the healthcare agencies and CCAC staff received ethics clearance from the university as well as the CCAC.

Data collection, analysis and writing up of what I discovered occurred simultaneously. I found writing to be a very useful tool in the whole research process. I wrote from my personal experience to generate data. There were two different types of writing that I did to generate data. The first type I refer to as a more general writing, which intends to capture every single event that occurred in relation to my daughter's

health supports at school. I did this general writing in point form, and included information about what happened, who was involved, what they did, what I had to do in relation to what they did, and the resolution if any. After reviewing this first level of data, I picked certain significant incidences to write about in more detail. The incidences I chose to write about in a detailed description were the ones that I found puzzling or troubling. I especially focused on contradictions between what was happening, and what I as a parent know needs to happen to keep my daughter safe at school. In this detailed description, I made an effort to write as specifically and as concretely as possible about who was involved, where it happened, what each person was saying and doing, how they relate to each other in terms of the work they do, what called for this work, and what happened next. Often writing about one specific incident in a concrete manner pointed to other incidents that linked to the incident that I was writing about. For example, when I wrote about what happened in the pediatric diabetes clinic, questions about where the referral form was going to go next and to whom were raised. Later, I found out in the meeting at the school that the referral form should have been sent to the CCAC care coordinator at the local CCAC, so I wrote about the school meeting and later about CCAC and what happens at the site of CCAC, and so on and so forth. In writing about the different events that occurred at specific sites and tracing the relation and coordination that occurred from one site to the next, I was able to map out a sequence or courses of action that I did not know existed prior to knowing and learning about the distinctive approach to inquiry of IE.

In writing about sites that I have no direct access to, such as the CCAC or the healthcare agency, I relied mainly on the interviews conducted with staff from healthcare agencies and the CCAC. In order to write in a specific and concrete manner meant that during the interviews, I needed to ask for concrete and specific details, and think visually during the interview to see if I could imagine how the process works, and how each person's work is linked with the work of others. The challenge of visualizing the whole process during an interview is that often times the person being interviewed is situated at one site of the institutional process and does not hold all the knowledge to map out the whole process. Using the second type of writing I mentioned earlier, I wrote about what happens at each site based on what I found out from these interviews with the incorporation of my own knowledge derived from routine interactions and casual conversations with the different people involved in the process who so happen to provide care to my child. Much of this writing and sorting out is like detective work, piecing together different clues to solve a mystery. For example, one of the mysteries is why there are frequent changes in the community nurses that deliver care for my child with diabetes at school. Starting from the site of the school where my child and the nurse were located, I traced backwards to how a nurse was organized to be at a specific school during a specific time. Drawing on the knowledge from the interviews with the community nurses, I found out their visits are coordinated by the service coordinators. Then, I drew on knowledge from the interviews with the supervisor of the service coordinators, the manager of the healthcare agency, and later with CCAC manager, and discovered an institutional technology, the Client Health Related Information System (CHRIS). Once I

had discovered this technology I was able to ask more about it, and learn how it mediates the routine work of service coordinators in community healthcare agencies, and shapes the scheduling of nursing visits, and thus the experience (of discontinuities of care) of students with diabetes and their families.

Writing in a concrete and detailed manner is a powerful tool to open up to view empirically what people are doing and how their doings are coordinated with one another locally and trans-locally. Paying attention to people's talks enabled me to see the type of knowledge they draw on to do their work, and provide traces to discover the source of this way of knowing and thus explicate the social relations embedded in these local practices that I was writing about. In a sense, the second type of writing that I was engaged in is not simply to generate data, it is in itself a way to analyze data. That is through writing ethnographically, I am attempting to produce what Susan Turner (personal communication, July 2015) refers to as a descriptive analysis that shows empirically and ethnographically how a specific institutional process (in this case, it is the institutional process of the school health support services) is put together. Such a descriptive analysis will show people how this institutional process works, and address the questions: what does it accomplish and whose interests does it serve?

Conclusion

In this Chapter, I have chosen a non-typical way of writing the methodology chapter of a thesis. There are a few reasons I chose to do so. Firstly, I find the traditional

‘report back’ way of writing the methodology chapter does not truly reflect the actual research process. In writing about how I came to learn to do IE and how I actually engaged in doing an IE research project, I want to make visible the actual labour involved in the process, and provide a more truthful description, with the recognition that it will never be the ‘Truth.’ There is also a part of me that is rebellious and does not want to be constrained by institutional expectation of writing a traditional methodological chapter, and I am thankful that institutionally where I am located, I have the space for freedom, acceptance and creativity to do so.

Secondly, I am hoping in providing a glimpse of how I came to learn and understand the core IE concepts and how to do an IE, that this writing will be helpful to others who are new to IE and who share similar interests in exploring and discovering the social that we are a part of, how it is put together, and how it enters into and shapes our lives in consequential ways. Lastly, I hope that this way of writing also makes visible that IE is not simply a methodology. It is an alternative way of conducting sociology that pays attention to the socially constituted and organized condition of knowledge production, and questions the social relations that are embedded in how established authoritative ways of knowing organize what people think and do. In constructing this not as a methodological chapter, I hope to shift, in a small way, how we think, talk about, and approach researching and producing knowledge. Indeed, none of this is neutral, and I do not take the task of producing knowledge lightly. I hope in sharing how I learned to do research this way, I am able to share as well the revolutionary intent of using an

alternative way of producing sociology, that is to treat people as knowing subjects, and to produce empirical knowledge that is able to show how the world in which we live, take part, and suffer is put together, and how we may be able to go about changing it (Smith, 1987).

CHAPTER TWO

Contested ways of knowing: How is care for a child with diabetes in school ‘known’?

In conducting an institutional ethnography, I am interested in and am oriented to how knowledge and power are related, and how particular forms of knowing are taken up as the authoritative way of knowing to organize what happens to people in the everyday world and accomplish the work of a particular institutional complex, in this case, the organization of the institutional complex of CACC SHSS. Before I came into contact with the school and the CCAC, I was naive to assume my knowledge of ‘diabetes care’ to be the same as that of others (such as teachers, CCAC care coordinators, and community nurses) involved in this extended institutional work process. I couldn’t understand why other parents of children with diabetes had difficulty ensuring the necessary ‘diabetes care’ was provided at school. I was puzzled when I read what was written on the very first Medical Orders on the *CCAC Referral Form* I requested from the pediatric diabetes clinic. It was in sharp contrast to what I routinely did to care for my child with diabetes, and it didn’t make sense to me that she had to have sub-optimal care because she was in school. It is in the course of conducting this research that I realized I have taken for granted how ‘diabetes care’ is known. In questioning the term ‘diabetes care’ and situating its use in particular settings, I realized what it means is dependent on the sphere of activities and framework in which the term is established and used. Similar to what Darville noted in his study of literacy work among literacy teachers, “knowing is anchored in particular places and particular uses” (as cited in Campbell & Gregor, 2002, p.12), and that knowing is always grounded somewhere (Campbell & Gregor, 2002).

In reviewing the different ways of knowing about ‘diabetes care’, I am attempting to make visible how knowing ‘diabetes care’ is organized in each particular setting, and how each way of knowing ‘diabetes care’ produces different consequences for how children’s needs in school will be understood, and who will be understood as responsible (or not) for meeting them. More importantly, these distinctive ways of knowing create a disjuncture for me as a parent and establish the research standpoint to begin the explication. The notion of standpoint in IE anchors the research in a subject position that is located but not confined in people’s everyday lives, it creates a point of entry to discover the social organization in people’s lives and to explicate that organization beyond the local setting (Smith, 2005). In making explicit the standpoint I am taking, I make visible the location in which this thesis is written and what can be revealed from where I stand.

‘Diabetes care’ known as diabetes self-management regimen in the pediatric diabetes clinic

‘Diabetes care’ and ‘diabetes management’ are terms used interchangeably in the pediatric diabetes clinic where I received training on how to look after my child with diabetes. I heard of these terms for the first time the day after my child was diagnosed with diabetes in the hospital. The training was provided by the diabetes nurse educator, as part of a work process of diabetes education and treatment. It was a series of diabetes education sessions where I learned about diabetes and what I need to do to keep my child alive and healthy. ‘Diabetes care’ was presented to me as a list of activities in a daily

diabetes management regimen or protocol, as well as training materials on ‘diabetes education’ in a binder. During the first training session, I learned about diabetes, how to test blood sugar using a glucometer, inject insulin with an insulin pen, and treat hypoglycemia with fast-acting carbohydrates such as juice or honey.

During the subsequent training sessions, I learned how to count carbohydrates and nutrition, how to treat severe hypoglycemia and hyperglycemia (by injecting glucagon and increasing insulin dosage respectively), insulin dosage adjustment and site rotation, sick day management (by checking ketone, injecting mini-glucagon dosages, preventing Diabetic Ketoacidosis), and the overall monitoring of blood glucose levels. I was told the goal of ‘diabetes management’ is to maintain the blood sugar levels as close as possible to the normal range for my child’s age to prevent immediate short-term and future long-term diabetes-related complications.

Later I learned from a conversation with an endocrinologist that diabetes care in Canada is guided by the Clinical Practice Guidelines of the Canadian Diabetes Association (2013). It is developed by a group of expert physicians in the field of endocrinology. Using knowledge produced through clinical trials, the guidelines are developed to support medical professionals to teach people living with diabetes and their caregivers to manage diabetes. As such, medical knowledge is embedded within these guidelines, and the goal is to promote adherence to the guidelines (Canadian Diabetes

Association, 2013). This document is not geared towards individuals, rather it is focused on managing a population of individuals living with diabetes.

The pediatric diabetes clinic adopts the chronic disease self-management approach to patient care. Within this model, the provision of education and information on ‘diabetes care’ to the caregivers, and children with diabetes is key to the successful management of diabetes. As education is the focus of this work process, the complexities of ‘diabetes care’ need to be made teachable, and transformed into a list of daily self-management tasks or self-care activities to be followed by the caregiver, and later by the child with diabetes. The expectation is that with adequate knowledge of diabetes and ‘diabetes management’, and strict adherence to the diabetes self-management protocol, children with diabetes or their caregivers will be able to manage this chronic disease on their own. This understanding embedded in the chronic disease self-management model is misleading and inaccurate, and does not take into account the inter-dependent nature of chronic disease management, as most disease care is actually shared by family members and others within the individual’s social network (Piette, 2010). As I will show in this dissertation, the understanding of ‘diabetes care’ through the lens of this framework has important consequences for how the needs of children with diabetes in school are understood when taken up by the CCAC care coordinators in conducting their assessment work.

Diabetes care known from embodied experiential knowledge

On paper, ‘diabetes care’ as I learned from the pediatric diabetes clinic, consists of a list of daily self-management tasks as mentioned in the previous section. In actuality, diabetes care as I know it from caring for my child and keeping her alive and well is far more complicated and changes frequently due to her changing body as well as her cognitive and emotional maturity as she grows.

During the initial stages of diagnosis, diabetes care involves chasing after a crying two year old to prick her finger to do a blood sugar check or to poke her with an insulin needle, and begging her to finish her food so she won’t experience low blood sugar due to excessive amounts of insulin in her body. It also involves being attentive and constantly alert to the child’s embodied and emotional signals such as quietness and a pale-looking face for signs of low blood sugar, doing frequent blood sugar checks throughout the day and night to ensure her blood sugar is within range, and to correcting it by either giving her carbohydrates or insulin if it is too low or too high respectively. In addition, it involves keeping detailed accurate records of all the blood sugar readings, insulin dosages, food, and physical activities in a log book, and analyzing the blood sugar readings with various factors that affect her blood sugar to look for patterns and trends to help anticipate and plan for future care practices. For example, my child experiences low blood sugar every time she goes to gymnastic lessons. To ensure her safety, in addition to checking her blood sugar at the beginning of the lesson, I will also check her blood sugar in the middle of her lesson, and make sure she has an extra snack with carbohydrates before her lesson.

As my child gets older and more used to the diabetes management routines, diabetes care involves slowly teaching her how to check blood sugar, administer insulin through an insulin pump, count carbohydrates, provide opportunities for her to practice these diabetes self-management routines, and reminding and double-checking that she has done so, and at times, stepping in to do it when she is exhausted and expresses a need for a break from doing these diabetes self-care routines, while at the same time, continuing to keep track of the blood sugar trends and patterns and the myriads of factors that interfere with the management of diabetes.

Diabetes care known from my practice experience requires constant watchfulness and juggling precisely because there is nothing predictable about diabetes management. Diabetes is not the type of illness that one can achieve optimal glucose control by strictly following the diabetes management routines. I have discovered that my child can do exactly the same thing, eat the same food, and receive the same amount of insulin on two separate days and the blood sugar readings will be different. While at times there might be periods of stability and predictability, diabetes can throw you off without warning. A sudden onset of a cold or a growth spurt or an insulin injection on the body where a lipohypertrophy (the accumulation of fat and scar tissue due to repeated insulin injections in the same location) has developed can lead to high blood sugar levels, and at other times, a stomach bug or an accidental insulin injection that hit a blood vessel can lead to stubborn low blood sugar levels. Therefore, frequent blood sugar checks, close monitoring of blood sugar, attentiveness and familiarity of the effects of diabetes and

diabetes treatment on my child and her response to it, flexibility, and intuition are necessary to ensure my child's present and future health and well-being. Diabetes care understood from my experience is another form of mothering and I am doing the work of mothering (parenting) for health. It requires much more than following a list of prescribed diabetes self-management tasks. My location and knowledge as a mother of a child with diabetes provides the standpoint for this research.

'Diabetes care' known as a point of crossover between two major institutional complexes

In schools, the primary concern and mandate is education and learning. As such, schooling is predicated on students having good health (Thies, 1999). When students with chronic diseases attend school, the schools are only responsible for providing educational supports when the academic performance of the student is deemed compromised by the health impairment; otherwise, children's health issues are considered the concern of the parents and the health system (Mukherjee, Lighfoot, & Sloper, 2000; Thies, 1999).

Diabetes is considered a health issue and not the domain of special education (Superintendent of Special Education at a local school board, personal communication, February, 2013).

The Tri-ministry (Ministry of Health and Long-Term Care, Ministry of Education, and Ministry of Community and Social Services) *P/PM 81* issued in 1984 was a response to the increasing number of children with chronic health conditions and/ or disabilities

attending mainstream schools. Within this document, it clearly states the responsibility for the provision of health support services at the local level will be shared by the school boards, the Home Care Program (the former CCAC), and agencies operating under the Ministry of Community and Social Services (MCSS) (Ontario Ministry of Education, 1984). In the context of the school, the school boards and the CCACs will share this responsibility, whereas the agencies operating under the MCSS are responsible for the provision of services for children living in residential settings. The document specifies schools are responsible for non-medical care with the exception of administering oral medication when such medication is prescribed for use during school hours by a medical professional. Other health supports such as injection of medication is to be provided by medical professionals from the CCAC. In the event that students are in need of such health supports, the schools are responsible for making an application to CCAC for such services.

In reviewing a few *Medical/ Health Supports Policies* developed by local school boards in Ontario, I have made a fascinating discovery in one of these local operating texts. It is stated in this text on *Specialized Health Support Services in School Setting* that the application to CCAC for SHSS from the school constitutes “an invitation from ‘Education’ to ‘Health’ to become involved in the school setting” (Lake Head Public Schools, n.d., p. 3). This invitation points to key tensions: what happens when ‘education’ invites ‘health’ into the school setting? How does this invitation organize how ‘education’ and ‘health’ understand the diabetes care needs of children and their responsibility in

meeting them? How is the work of teachers coordinated with the work of nurses? What happens when ‘health’ turns down this invitation? These are questions I will explore in this thesis.

‘Diabetes care’ known as ‘nursing services’ in the CCAC

As mentioned in the previous section, the CCACs, formerly known as the Home Care Program, share the responsibility in the provision of health support services at the local level with the school boards (Ontario Ministry of Education, 1984). The CCACs are assigned the authority to assess student needs, and when the student is deemed eligible for school health supports, they will coordinate and oversee the actual delivery of these services provided by professional staff hired by private for-profit or non-profit healthcare agencies that hold a contract with the CCACs. It is in moments when the student is deemed eligible for services that the CCACs will accept the education sector’s invitation to be involved in providing care for the child in the school. Therefore, the knowledge the CCACs draw on to know the needs of a child with diabetes in school is consequential to whether or not the child will be deemed eligible and offered school health supports.

It is unclear within the *P/PM 81* how the CCACs actually conduct the assessment of student needs or what the criteria are for eligibility for health support services at school. However, there were a few instances in the parents’ encounters with CCAC, including my own, which show how CCACs way of knowing is at odds with how parents know the care needed for children with diabetes to stay safe at school. These instances

offer empirical ground to trace the form of knowing taken up by the staff at CCACs, and organize how they conduct the assessment, determine the eligibility for services, coordinate the actual delivery of services, and terminate services for children with diabetes in school. This will be a central focus of inquiry in this thesis.

The first instance was from my experience of requesting a referral for CCAC services at the pediatric diabetes clinic. The CCAC staff was not present in this encounter, however, the intentions of the CCAC were carried through a specific text, the *CCAC Referral Form* (see Appendix A). Within the *CCAC Referral Form*, the physician wrote the instructions for diabetes care my child needs in school under the section: Medical Orders. When I reviewed the Medical Orders, I found what was written was distinctively different to what I, as a parent, know is needed to keep my child well at school, and is not what I was taught to do to care for my child by the same physician at the clinic. This shows neither the parent's nor the physician's first-hand knowledge is authorized to determine the child's need at school. It seems that 'something' within this text is mediating what the physician knows and organizes what he is able to or will write; this 'something' needs further exploration. How 'something' within this standardized text subordinates the physician and parents' knowledge and how parents are drawn into do the work of securing, advocating, and supporting the delivery of health support services for children with diabetes at school will be examined in more detail in Chapter five.

The second instance was at the case conference in the school where my child's eligibility for CCAC services was assessed by the CCAC care coordinators. It was in this meeting that I realized the 'diabetes care' needed for my child was categorized as 'nursing care'. I later discovered from reviewing the *CCAC Application Form for School Health Support Services* (see Appendix B) that 'nursing' is among a list of categories of services offered through the CCAC SHSS program. The rest of the categories include: occupational therapy, physiotherapy, nutrition, speech therapy, safety and accessibility, equipment, and re-referral. Categorizing 'diabetes care' as nursing leaves out the non-medical but necessary aspects of diabetes care such as supervision of food intake, and double-checking child's completion of the diabetes self-care routines, and raises questions regarding who can and is responsible to provide the full range of care activities necessary for children with diabetes. I discovered that it was in this meeting that I was able to advocate for services that are similar to what I routinely do to care for my child. However, a higher level of services does not automatically translate to the child receiving the necessary care. The frequent changes in front-line nursing staff disrupts the quality of care provided to children with diabetes at school. How the scheduling of nursing visits are socially organized will be discussed in more detail in Chapter six.

The third instance is drawn from the interviews I did with other parents of children with diabetes. Two parents in particular expressed their concerns regarding the premature termination of nursing care for their children with diabetes at school. Their concerns brought into view how the care coordinators at CCACs conduct the assessment

for service discharge. In interviews with the CCAC care coordinators and front-line nurses, I learned that the assessment for service discharge is conducted by using the *Diabetes Checklist for Independence* to assess a child's level of independence in doing diabetes self-care routines. The categories listed in the *checklist* are a list of diabetes self-care tasks (see Appendix C), and were developed by a pediatric diabetes clinic at a particular hospital as shown by the hospital logo printed on the top left corner of the *checklist*. As mentioned previously, the clinic adopts the chronic disease self-management approach to patient care, and this framework is in tension with parents' understanding of diabetes care, and obscures the relational inter-dependent nature of chronic disease management. In Chapter seven of this thesis, I will explore how the category of 'independence' within this institutional framework is taken up by the CCAC care coordinators to legitimize their service discharge work, and at the same time obscures parents' work in co-creating children's 'independence'.

CCAC is the institution that governs the provision of SHSS. Their way of knowing about the needs for a child with diabetes in school is the official and authoritative way of knowing and it is consequential in governing the type of care and support a child with diabetes receives (or not) at school, as well as who is responsible for providing that care. Difficulties arise for parents when CCAC's way of knowing comes into conflict with parents' experiential knowledge, for example when CCAC deems a child with diabetes not in need of nursing services at school when he/she is able to test blood sugar and inject insulin, yet from parent's knowledge the child may not be reliable

in consistently performing these diabetes self-care tasks and they cannot rely on schools to supervise and ensure that their children have actually done all the necessary diabetes self-care tasks. In addition to the instances I described above, I hear similar stories circulating within the on-line diabetes community about the problems parents of children with diabetes have at school. One example is a mother of a 9 year old child who is 100% independent in testing blood sugar and injecting insulin. Her child will no longer receive nursing services. While the mother has no problem with terminating nursing services, her child has trouble adding numbers and dialing the right dosage of insulin on the insulin pen. She needs help from an adult to make sure her child adds the numbers for the insulin dosage for lunch and the correction dosage for high blood sugar correctly, and that in fact she has dialed the correct amount of insulin before administering the dosage. However this mother is having difficulty finding someone at the school to oversee her child doing the injections.

Another example is a mother of a 7 year old child who will no longer receive nursing services in the coming school year because the child can do her own injections 50% of the time. This mother is worried about what will happen the other 50% of the time, when her child is feeling too anxious to do her own injections. More importantly, she believes that it is inappropriate to put this type of pressure and responsibility on a 7 year old given that she has the rest of her life to take on these diabetes management routines. Without nursing services and the support from school, the child is left to care for her diabetes on her own. Or the other alternative is the mother must go to the school to

supervise her child. Not all parents have time and can financially afford to go to school every day to monitor their children.

Conclusion

In this Chapter, I have described the different ways of knowing about ‘diabetes care’ as it is being used in different settings. These different knowledges activate different responses from parents, the schools and the CCACs, and the different ways they ‘know’ the care needed for children with diabetes at school and who is responsible for what. Here is a line of fault, a disjuncture between contested ways of knowing about the care and support needed to ensure the wellbeing of a child with diabetes at school between parents and other institutions, in particular the CCAC who is authorized to assess and determine the eligibility for SHSS. In IE terms, this is the research problematic and the point of entry to the inquiry. The different ways in which care for children with diabetes in school is ‘known’ raises important questions about the nature of school health supports: are these ‘special’ health support needs too much to ask of public schools where their mandate is to provide education? Or are they an essential feature of an equitable and inclusive education? If so, who should be responsible for its implementation? Furthermore, it brings into question the privileging of medical care over social care, as well as how the boundary between the public/private and the collective/individual responsibilities in the provision of such care is organized in the public institution of schooling.

CHAPTER THREE

The Backdrop: Situating the SHSS program in the broader institutional context of home care reform and restructuring

Children with chronic conditions often require support services at school in order to access education and to sustain their health. In Ontario, the Canadian province in which this study is set, these services were initially established in 1984 after the issuance of the Intersectoral Policy/ Program Memorandum 81 (P/PM 81) titled: *Provision of Health Support Services in School Settings*. This is a Tri-ministry agreement governing health support services for all school-aged children with special needs during school hours. The stated purpose is to ensure school-aged children with medical and health support needs have the opportunity to attend school and receive an education (Ontario Ministry of Education, 1984). Under this policy, students assessed as in need of school health support services receive the necessary services delivered by the Home Care Program. Although this policy has not been updated since it was issued in 1984, and children with special needs were never the focus of home care reform (Peter, Spalding, Kenny, Conrad, McKeever, & Macfarlane, 2007), nonetheless the restructuring of the home care sector over the past three decades inevitably has had an effect on the delivery and organization of school health support services, and the experiences of children and families receiving these services.

In this chapter, I will first provide a brief overview of how home care is situated within the Canadian health care system. I describe the ongoing debate over whether or not

home care should be universal and where to draw the line between the role and responsibility of the state and that of individuals and families in caring for the aged, and children and adults with disabilities and chronic health conditions. This positioning of home and community care and the privileging of acute care through federal legislation generates the circumstances in which subsequent shifts in health care costs are made possible. This tension has been exacerbated over the past three decades as Ontario's health care system has undergone significant reform and restructuring. The provincial government, in various ways, imported market relations and managerial ideologies and practices into the health care sector. As a result of the marketization of hospital and home care services, the cost of health care has been shifted further away from hospitals to the community and towards individuals and their families.

In a separate but related trend also addressed in this chapter, the demand for the democratization of health care and the calls for patient-directed care have been taken up by provincial policy advisors and policy makers to further advance their agenda to 'save' the health care system by saving costs. The construction of citizens as rational 'consumers' actively involved in improving and managing their health has legitimized the further shifting of responsibility for health care to individuals and their families in the private sphere. I have come to see and call these changes put forth by the provincial government as forms of privatizing the home care sector. Indeed, it is within such wider social, political, and institutional processes shaping home care that individuals in need of home care services find themselves worried about safety and wellbeing (their own or that

of their family members), fighting to secure necessary care, and called upon to engage in voluntary and supplementary healthcare work. In the case of this research, parents of children with diabetes are prompted to engage in multiple forms of unpaid care work to ensure that their children with diabetes can attend school and are safe at school.

The place of home care in the Canadian health care system

Health and health care are highly valued, and as Canadians, we find ourselves relieved that we have access to a universal health care system, particularly in times of illness. Health care in Canada has been described as the most valued social program and Canadians have known health care to be a social good and a right of all citizens of Canada (Armstrong, Amaratunga, Bernier, Grant, Pederson, & Willson, 2001; Browne, 2000). Canadian health care is publicly funded through a system composed of ten provincial and three territorial health insurance plans known as “Medicare” (Armstrong et al, 2001). Constitutionally, health care is under the jurisdiction of the provinces and territories with fiscal contribution from the federal government, and it is through this ‘doctrine of the spending power’ that the federal government attaches conditions to the financial contribution and exerts its influence as a nation, and secures provincial support for a universal health care system (Browne, 2000, p.18).

The foundation for a universal public health care system was laid by the federal government through the federal Hospital Insurance and Diagnostic Act in 1957 whereby the federal government agreed to share approximately half of the cost of provincial

hospital insurance plans (Baranek, Deber, & Williams, 2004). In 1966, with the passage of the Medical Care Insurance Act, the cost sharing was extended to insurance for physician services (Browne, 2000). By 1977, all of the Canadian provinces had provincially-administered insurance plans that covered private providers of hospital and physician services. Around the same time, the federal government moved away from the previous commitment to pay approximately half of all provincial costs. The federal government introduced a new formula, Established Programs Financing, to reduce and better manage federal fiscal contribution in the face of mounting health care costs and foreseeable economic recession (Armstrong et al, 2001; Baranek et al, 2004).

In 1984, the Canada Health Act (CHA) (CHA, 1985) was issued. The federal government further consolidated the foundations of a federal health care system by outlining the terms and conditions the provincial and territorial health insurance plans need to meet in order to receive the full allocation of federal funding. These criteria are: universal coverage, public administration, comprehensive coverage, portability, and accessibility (CHA, 1985). Provincial governments are free to not adhere to the CHA terms and conditions when administering and delivering their healthcare programs, however the federal government has the authority to impose fiscal penalties or withhold federal funding if CHA terms and conditions are not met (Baranek, et al, 2004; Browne, 2000). Given the high costs of health care, it is unlikely the provinces will not abide by the CHA terms. Under the protection of the CHA, Canadians have universal coverage for medically necessary hospital and physician services free of charge.

While hospital and physician care are protected by the terms and conditions of the CHA as universal entitlements for Canadian citizens, not all health services are protected by the CHA. Services such as extended health care services (prescription glasses and dental care), and prescription drugs, are deemed outside of the ‘mainstream’ of Medicare and are considered the responsibility of individuals rather than the collective responsibility of the state. Provinces and territories are under no legal obligation to cover the cost of these services. Individuals either pay out of pocket or through private insurance, with the exception of vulnerable populations where the provinces and territories provide partial coverage for some of these services as a form of social assistance.

Home care is categorized as an extended health care service in the Canada Health Act and thus is not included among the universally “insured health services” (Browne, 2000). Home care, community care, and long-term care are terms often used synonymously in Canada to refer to “an array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for the family caregiver” (CHCA, 2016). These services range from professional medically-based interventions such as nursing and rehabilitation therapies, to non-medical social services like personal support and home-making services, friendly visits, and Meals-on-Wheels. Home care services are necessary

to enable people of all ages to continue to live safely and function well in their homes and communities. From a health system perspective, home care services can save long-term health care costs as they can prevent, delay or substitute for institutional long-term care or acute care (Abelson, Tedford, Woodward, O'Connor, & Hutchison, 2004; Browne, 2000). However, without protection from the Canada Health Act, there are no mandated minimum standards for the coverage of basic home care services (Armstrong et al, 2001; Peter et al, 2007). It is up to provincial and territorial governments to decide who to cover, for what, for how long and under what circumstances. As a result, there are vast variations between the standards and funding policies across the provincial and territorial health insurance plans (Baranek, Deber, & Williams, 1999, p. 73). Moreover, individuals in need of these services often have to pass a means-test before they are deemed eligible for these services. When services are not covered by the provincial or territorial insurance plans, and when individuals are deemed ineligible, the responsibility to provide this care often falls on the shoulders of individuals and their families, particularly on women, who provide significant unpaid care labour (Armstrong et al, 2001).

This demarcation on what is considered necessary hospital and physician care, and what is considered 'optional' home care is not accidental, and can be traced back to the way medicine was practiced in 1957 when the foundation of Canadian Medicare was laid (Baranek et al, 2004; Browne, 2000). At the time, medical practice was dominated by the medical model and medical professionals (particularly physicians, and some may argue that this is still the case now) with a focus on cure or alleviation of underlying

pathologies, rather than care (Browne, 2000). On the one hand, the dominance of a curative model meant that people who were sick were expected to be treated in hospitals and all professional medical care was provided to them there as an in-patient. Moreover many people with chronic health conditions were either living in hospitals or institutions rather than in the community, therefore the state did not consider it necessary, nor their role, to cover the provision of health care to the sick outside of hospital settings and physician's offices (Baranek et al, 2004). On the other hand, the dominance of medical professionals meant that in order to secure the support of private insurance plans and physicians who were then resistant to a federal Medicare system, the federal government had to propose a system that safeguarded their interests (Browne, 2000). The historical context of how the Canadian Medicare system is set up created a hierarchy within a supposedly universal health care system whereby home care is defined as residual, supplementary, and subordinated to medical care performed in hospitals and by physicians. As well, because home care is provided out of the public view in people's homes, it is perceived to be the primary responsibility of individuals and families in the private domain with the state stepping in only when individuals and families can no longer provide or pay for such care.

As I will show in the next section, the location of home care as residual and not an insured health service protected by the CHA (1985) makes home care an easy target for funding cutbacks in times when the government is implementing austerity measures. These government measures also known as “restraint”, “retrenchment” or “restructuring”

further disadvantage the already marginalized location of home care and those in need of such necessary services.

Privatizing Ontario home care

Even though the provision of home care is not mandatory under the Canada Health Act (1984), the Ontario government has chosen to cover the costs of home care services under the Ontario Health Insurance Plan (OHIP) since 1974. Prior to the mid-1990s, these services were provided to individuals who were deemed eligible by a physician without user fees. Therefore, most Ontarians have known home care services to be part of Medicare, and as such, perceived them to be universally accessible and a fully insured entitlement based on need.

In this section, I will show how the policy changes proposed and implemented by the provincial government, in particular the provincial government during the mid-1990s, to reform the home care sector not only changed the allocation and delivery of home care services, but drastically re-defined how Ontarians came to know home care services from a universally accessible public service to a market commodity or a service with limited access. These changes in turn shaped the relations between the ‘state’ and the public, transforming the welfare state, with its apparent valuing of collective responsibility for the well-being of all citizens to a neo-liberal state that emphasizes the power of the market and individual responsibility of the consumers to meet their own needs. The state is no longer the provider and protector of public infrastructures for a collective good, but

a purchaser and administrator of services on behalf of the public. Policy changes during the mid-1990s also altered relations between care providers and those receiving care. In conducting this research, I have come to see and call these policy changes put forth by the provincial conservative government during the mid-1990s in the home care sector as forms of privatization.

Privatization is generally understood as the selling off of government-owned public assets such as property or businesses to for-profit privately owned entities. This is the most common form of privatization discussed and thought of by the general public. However, privatization can occur in many different forms. Some are explicit and direct such as the direct transfer of ownership of Canadian crown corporations to private businesses, as in the case of the sale of Canadian National Railway to a for-profit private corporation and some others are implicit and indirect, such as the government's withdrawal from the provision of services that used to be covered by public funding as in the case of eye examinations. Browne (2000) proposed that "privatization is not a one-off event, or even a number of isolated incidents" (p. 6), rather it "is a *process* with a specific:

- *content* (the dismantling of welfare state social protection, or re-commodification, and the loss of social rights);
- *structure* ("cascading privatization");
- and *ideological form* ("reinventing government," "patient-centred care," "community")" (Browne, 2000, p.133).

Armstrong and colleagues (2001) defined the practices of privatization that they saw happening in the health care sector even more broadly. Accordingly to this definition,

privatization involves a range of processes much like an endless “cascade” and includes the following:

- Privatizing the costs of health care by shifting the burden of payment to individuals;
- Privatizing the delivery of health services by expanding opportunities for private, for-profit health service providers;
- Privatizing the delivery of health care services by shifting care from public institutions to community-based organizations and private households;
- Privatizing care work from public sector health care workers to unpaid caregivers; and
- Privatizing management practices within the health system by adopting the management strategies of private sector businesses, by applying market rules to health service delivery and by treating health care as a market commodity (p.9).

The research of these critical scientists on Canadian health care reform and restructuring developed a critique to talk about what was going on in the Canadian health care system and the effects of health care reform. It provided me with a language to name what I located as a set of coordinative policy and practices in the wider institutional context that shape what happens on the ground. As well, it offers a body of knowledge where I can engage in conversations about what is known about this topic, in this case the home care reform (specifically health supports in school), and what needs to be discovered about this topic with the focus on its social organization.

Before I continue, I want to point out that I did not conduct this research starting with this concept. However, I had a hunch that the standardization of health supports for children with diabetes to one daily community nursing visit for children with diabetes during school hours had something to do with funding and the “hollowing out of the welfare state” (Roberts & Devine, 2003, p.309). One parent I interviewed (Kylie) who

works in social services and is knowledgeable of the changes happening in the public services sector had explicitly spoken about the premature termination of nursing services for her child having something to do with “what was going on behind the scenes with the restructuring of CCAC” and her refusal to be the “sacrificial lamb”. Other parents in the diabetes on-line community have other speculations; some think the trouble is due to the teaching staff and nurses’ lack of adequate knowledge about diabetes and diabetes care, others think that there is no legislation in place similar to the Sabrina Law where school staff are mandated to administer an epi-pen to a student in the event that the student has an allergic reaction at school. Instead of taking these speculative accounts at face value, I set out to investigate them.

I began this research in a position outside of theory, in the actualities of my world as a mother of a child with diabetes figuring out how to find a knowledgeable adult to care for, watch over, and ensure my child is safe at school. As I mentioned in the Introduction Chapter, it was the concern and worry over the lack of adequate health supports in school, having various different and differently qualified nurses delivering care to our children, the frequent occurrence of medical errors, and the premature termination of nursing services that provided the direction for this research. I wanted to know how the standardization of health supports in the school came about, how nurses’ work became organized such that parents are drawn in to provide guidance and correction to the care of nurses at school.

I interviewed nurses, supervisors, and a manager from healthcare agencies, and care coordinators and a manager from the CCAC to learn how they go about doing their work and how their work is coordinated with each other, and with parents. In listening to their talk about their work, I identified various interesting terms that I think are institutional terminology or words that carry the intention of the institution, such as “managed competition,” “doing a business,” “market share,” “lean management,” and “independence”. Following the clues provided by these terms, I discovered that the way health support services at school are currently organized is linked to the reforms of home care that occurred in the mid-1990s. These reform efforts reorganized the practices and policies of the home care sector through the creation of the CCACs, the ‘regime’ that currently governs and regulates the home care sector and the provision of home care services in Ontario. I turned to the literature to investigate the institutional complex of the CCACs, tracing the history of what was happening in home care, what brought about the creation of the CCACs and for what purposes, what policies were created and when were they implemented, and how the CCACs’ policies organized and shaped local practices. In what follows, I will describe some of what I found in researching this history about home care reform. I’ve identified the different ways – explicit and implicit – the provincial government used in privatizing the much needed home care services for the aged, and for children and adults with disabilities and chronic health conditions, and the effects it has on the care providers and those receiving care. In presenting this material, I aim to make visible how what is happening in the local site of the school is connected to and shaped by the ongoing activities and policy practices conducted somewhere at the provincial

level over the past 30 years. What went on before prepares the grounds for what can happen next. The three decade history of reform and organizational structuring of home care occurring behind the scenes provides the context and conditions within which my inquiry is set.

Home care reform and restructuring as an explicit form of privatization

Home care services were introduced in Ontario in 1958 as a pilot project, the Acute Home Care Program, to provide acute home care services for patients discharged from hospitals, and it was limited to a small group of patients who required short-term post-hospital care (Randall, 2008). With the success of the Acute Home Care Program and the increasing need in the community for these home-based services, the admission criteria for the Acute Home Care Programs were relaxed and were expanded to cover the entire province in 1972. By 1974, not-for-profit Home Care Programs were set up locally and received OHIP funding without caps and without any significant degree of governmental control to manage and deliver home-based professional services and, to an extent, some social services such as homemaking and personal support services (Aronson, 2006; Baranek et al, 1999; Randall, 2008). These services were intended for the acutely ill rather than the chronically ill patients with a time limit based on eligibility for services (Baranek et al, 2004). Services were universally available based on professionally assessed ‘needs’ (Baranek et al, 1999, p.79). Over time, with the advancement in technology, change in population demographics, and the deinstitutionalization movement, these services were extended to chronically ill patients and seniors. In 1984, the scope of

home care services was expanded to include programs for school age children in the school setting, and the School Health Support Services Program was introduced with the objective of providing support for disabled and special needs children who need these services in order to attend school.

Given Home Care Programs were implemented in Ontario over time in a piecemeal manner, with no single regional authority responsible for their operations, there were increasing public concerns over the fragmentation, lack of continuity of care between institutional and community-based care, and inequity and inconsistency in the availability and accessibility of home care services across Ontario (Denton, Zeytinoglu, Kusch, & Davies, 2007). In addition, the increasing demand for home care meant the cost of these services was skyrocketing, and there was no mechanism to hold these government-created Home Care Programs accountable for the quality, standards, and performance of the services delivered (Baranek et al, 2004). By early 1980s, the provincial government under the leadership of the Progressive Conservative (PC) party had acknowledged the need to find new ways to reorganize and coordinate the delivery of home care services, but before they could implement these reforms, they were defeated by the Liberal government.

Subsequently, between 1985 to 2002, the provincial Liberal, New Democratic Party (NDP) and PC governments proposed various reforms in the home care sector. These reforms were also known as long-term care reform in the policy arena (Baranek et

al, 2004). Although there were differences in what was proposed under the three governments, the need for reform was framed primarily as a managerial issue about the lack of efficiency and effectiveness of the current public sector organization of home care services in meeting the rising demands and costs of care. As well, discourses were circulating that universal programs would encourage dependency and stifle choice, as such the ‘dependency’ of users needed to be managed to not over-burden the system (Armstrong et al, 2001). The growing concerns over the rising costs of home care, reduction in federal funding and an increasing budget deficit signalled a need for change so as to sustain the Ontario’s health care system. The goal of these provincial reforms was to standardize practices across the province and integrate institutional and community-based care, as well as to improve the cost-effectiveness and efficiency of the system.

Even though the reforms during the Liberal and NDP leadership were incremental, there were two significant lasting effects that paved the way for the PC reforms. First, there was a shift in discourse from a focus on treatment to an emphasis on health promotion and community-based care. Recognizing the limits of public care and the effectiveness of traditional medical care to determine the health and well-being of the population, the provincial Liberal government adopted a broader definition of health, “which acknowledged broader social, economic, environmental, and lifestyle determinants of health” (Premier’s Council on Health Strategy, 1991, as cited in Baranek et al, 2004, p.75), and refocused the reform on strengthening community care, health promotion, and disease prevention (Baranek et al, 2004). The focus on community and

prevention made logical sense as the provincial government was attempting to shift away from the medical model as a response to public demand for democratization and decentralization of care since the later 1960s. However, critics suspected that the provincial government's adoption of this approach may have been a possible cost-containment strategy, particularly when it was not allied with equivalent financial commitments (Baranek et al, 2004). The provincial Liberal government proposed to shift the current budget line for home care services covered under OHIP (under the protection of CHA as insured entitlements) to a new budget line and combined with the budget of the long-term care facilities and community-based services under the Ministry of Community and Social Services (not protected by CHA) to enable the integration of community services. This shift paved the way for the possibility to put a cap on the budget which would be implemented under the provincial NDP government (Baranek et al, 2004). Moreover, the discourse on health promotion and prevention, as well as the discourse on chronic disease self-management encouraged individuals to take on managing their own lifestyles and health, and enabled the shift of responsibility and costs to individuals and their families in the community. This will be discussed in detail below.

Second, is the passage of Bill 173, the Long-Term Care Act in 1994. The drafting of this bill was intended to better promote effective and efficient use of resources, integration of community services, and decentralization of the decision-making, participation, and delivery of home care and community-based services to a regional level (Randall, 2007a). Under this bill, the home care services budget from OHIP (which are

considered to be universal entitlements protected by CHA) would be moved into the long-term care facilities and community support services budget to ensure the costs of home care would be more predictable and better managed (Baranek et al, 1999, 2004). As a result, the formerly open-ended budget would now be capped, and while assessments were mandated and services would be fully funded when provided, it was made explicit through this legislation that there was no longer any requirement that care would necessarily be provided when needed. In effect, this bill marked the shift of home care as an entitlement under OHIP to a service with restricted access (Baranek et al, 2004, p. 151).

As I will show below, during the provincial PC reforms, private sector relations and practices were entered into the public sector to manage the problem of a “bloated, bureaucratic and ineffective” public sector organization (Armstrong et al, 2001, p.16). Discourses of unmanageable costs and deficits created a state of ‘crisis’ and in order to manage this ‘crisis’, market relations and private-sector business strategies were offered as solutions. The importing of economic language into debates about home care increasingly subjected the home care sector to market relations, and the penetration of market relations into home care commodified what used to be a social good (Browne, 2000). As a commodity, it is the responsibility of the individual to ensure these services are available to them. These changes have significant consequences for the accessibility and quality of care and the relationships between those receiving care and those who provide formal and informal care (Wyatt, Harris, & Wathen, 2010).

The introduction of market and managerial ideology and practices

The reforms of the PC government carried an explicit ideological commitment to privatization. Once in office, they were eager to introduce business strategies and management ideologies to transform the ‘inefficient’ public administration. The PC government advocated for the superiority of the private market and market mechanisms in maximizing outcomes, and in increasing efficiency, cost-effectiveness and accountability of the public bureaucracy (Randall, 2008). In what was known as the *Common Sense Revolution*, they declared “that government [should do] business like a business, [i.e.] in an efficient and productive manner that focuses on results and puts the customer first” (as cited in Browne, 2000, p.25). Since health and home care expenses were the most expensive social programs, they were the early targets of restructuring (Randall, 2007a). They introduced changes to the long-term care reform only a few months into their leadership (Baranek et al, 2004).

In early 1996, they announced the creation of 43 Community Care Access Centres (CCACs) to replace the existing 38 Home Care Programs and 36 Placement Coordination Offices (Baranek et al, 2004). The CCACs are autonomous non-profit incorporated organizations. They are set up as a single point of access to manage and coordinate long-term care and home care services with the goal of improving coordination, integration, and continuity in the delivery of home and community-based care (Randall, 2008). Although they were intended to be independent from government, they were required to

sign accountability agreements with the government with defined terms of their operation. Unlike the previous informal arrangements that were without any significant degree of scrutiny from the provincial government, these accountability agreements explicitly laid down the government's expectations, particularly the financial management of the centres which included a clause specifying that the CCACs would not spend beyond their approved budgets (Randall, 2007b). As such, it is the provincial government that determines CCACs' funding and their priorities. The CCACs continued to be given a capped budget on home care spending (which was introduced in the NDP reforms). Moreover, unlike the previous Home Care program, the CCACs had no direct responsibility to provide services; instead (ostensibly to avoid conflicts of interest) they were assigned the role of assessing and determining clients' eligibility for services and monitoring clients' progress. In effect, the CCACs became purchasers and administrators of care, instead of providers of care. This distinctive split between the purchaser and provider according to scholars who study public governance is a key feature of what is known as the "new managerialism" (Light, 2001), and is a strategy used to enable the further shift of public services delivery to for-profit community-based organizations.

To further the 'market' ideological agenda of the PC government to privatize the public sector and boost the for-profit private sector, the CCACs brought in the "managed competition" model, a market-based system of selecting service providers and allocating funds, to better manage the cost, quality and efficiency of home care (Baranek et al, 2004; Browne, 2000). According to the Organisation for Economic Co-operation and

Development (OECD) (1992), “managed competition” is defined as “government regulation of a health care market which uses competition as the means to achieve efficiency objectives within a framework of government intervention designed to achieve other policy objectives such as equity” (as cited in Armstrong et al, 2001, p.24). In adopting this model, the government has chosen to frame the issue in the delivery of home care as primarily a managerial problem of inefficient use of public funds. It is believed that when the government applies market principles and competition to public service delivery, it will increase performance, sensitivity, efficiency, cost-effectiveness, and innovation in the delivery of public-funded services (Baranek et al, 1999).

Prior to the implementation of managed competition, established provider organizations (which were mostly non-profit) would have their existing contracts automatically renewed; many researchers contend that this promoted a culture focused on service and allowed stability for the work force and continuity of care for service users (Light, 2001; Williams, Deber, Baranek, & Gildiner, 1999). Under the new model, the CCACs would put a tender for a Request for Proposal every three to four years and all provider organizations (both non-profit and for-profit providers regardless of their existing contracts) would have to submit a bid or proposal to compete for government funding (Denton et al, 2007, Williams et al, 1999). The successful bidder would be the one who offered the “highest quality of services at the best price” (Baranek et al, 2004; Randall & Williams, 2006). While there were ongoing emphases on quality care alongside cost effectiveness and efficiency, in actuality the CCACs, regardless of their

commitment to quality, were forced to award the contracts to the provider organization with the lowest cost given their tight budgets and high demands for home care (Armstrong et al, 2001).

Even though CCACs were not allowed to spend over the approved budget, in practice many CCACs were running on a budget deficit. This was due to funding constraints caused by the decreasing cash transfer from the federal government. In 1995, the federal government introduced a new funding formula, the Canada Health and Social Transfer, which combined the previous Established Programs Financing and the Canada Assistance Plan into one block fund and created a situation whereby healthcare and post-secondary education and social assistance were competing against each other for scarce funding (Browne, 2000). Under such financial constraints, the provincial government implemented measures to downsize the hospital budgets, such as increasing use of day surgeries, outpatient treatments and facilitating earlier discharges, and further shifting care from the hospitals to the community sector. Given that home care was neither protected by the CHA (1985), or OHIP, the PC government was not legally required to cover this downloading of care with a corresponding transfer of resources to the community (Baranek et al, 2004). As a result, the CCACs were struggling to meet the needs of increasing numbers of post-acute care patients from hospitals and the long-term care needs of people (the elderly, people with disabilities and chronic health conditions) in the community. To facilitate the shift of care from institutions to community, the PC government introduced new eligibility regulations giving priority to the post-acute

hospital discharge patients in 1999, further subordinating the needs of those requiring social and personal services to those needing medical services (Baranek et al, 2004; Denton et al, 2007). People in need of social and personal community-based services found themselves having to ‘re-medicalize’ their needs if they were to be included for eligible services (Baranek et al, 1999, 2004). This is particularly significant for children and adults with chronic health conditions, as in this study regarding diabetes care in school, many of the supports needed to ensure the safety of children with diabetes in school are contested, and can fall under the category of social or medical services depending which framework is taken up to define them.

Despite the continuing rise in demand for home care, and many CCACs operating with a budget deficit, the provincial government announced in 2001 that the CCACs’ funding would be frozen and capped at the 2000/ 2001 levels and they were no longer permitted to operate under a deficit. This was met with opposition from many CCACs as it would further compromise their ability to meet the needs of the vulnerable in the community (Denton et al, 2007). In response, the government passed legislation to change the CCACs to statutory corporations in 2002, which gave the government sole authority to directly appoint all CCAC executive directors and remove the community volunteer board with a government appointed board who would likely be more in compliance with the government-driven directives (Aronson, Denton, & Zeytinoglu, 2004; Randall, 2007b; Randall & Williams, 2006). In an attempt to stay within budget, the CCACs strictly interpreted the eligibility criteria and the maximum amount of hours and

number of visits of nursing, home-making, and personal support services were cut even for those who were eligible for service (Abelson et al, 2004; Randall & Williams, 2006). The CCACs' efforts to increase financial accountability to the government led to a decrease in accountability to the need and care of those in need of home care (Randall, 2008), and the care work that was performed by public sector home care workers was transferred to unpaid caregivers in individual households.

The provincial PC government was voted out of office in April 2002. What have been described are a series of policies proposed and undertaken by the provincial PC government to reform the home care sector. Even though children did not emerge as a population of focus in the debate and in these reforms, the reforms have significantly changed the work organization of the home care workforce that provides community and school-based care for children. As noted earlier, privatization is not a single incident. While changes were small during the Liberal and NDP government, what they proposed prepared the grounds for the PC government to implement extensive privatization to the public home care sector. In addition to these explicit changes in policies and regulations, the PC government also took up indirect ways to advance their privatization agenda. In what follows, I will describe another way the provincial government further privatized health care. This strategy coincided with the community's demands to democratize health care (Browne, 2000).

The co-optation of chronic disease self-management as an implicit form of privatization

The medical model has been adopted since the foundation of the Canadian Medicare. The medical model refers to the scientific knowledge about the anatomy and pathology of the human body with a focus on signs, symptoms, treatments and prognosis of diseases. The goal of medicine is to cure diseases. This knowledge was traditionally held within a small group of elites who had tremendous authority over the patient's body as well as the health care system. This approach to medicine made sense during the early days of Medicare. Over time, with the accessibility of knowledge, people became more knowledgeable about their health and illness. Moreover, with medical and technological advancements, there were increasing numbers of people living with chronic health conditions. The emphasis of the medical model on cure is not appropriate for people who are living with chronic health conditions or other disabilities that cannot be cured.

In the late 1960s and 1970s, a women's health movement emerged at a time where public resistance to social institutions was promoted and progressive movements of citizens were active in demanding reform and sovereignty for citizens (Irvine, 2002). Women were active "in demanding access to services, in offering health education and in promoting self-regulation, as well as better conditions, for paid care providers", and these demands are similar to what we currently call the determinants of health and health promotion (Armstrong et al, 2001, p.15). Empowerment, self-help, community, health promotion and disease prevention were central strategies in the women's health movement (Armstrong et al, 2001). Under such social and political climate, more people began to express their dissatisfaction with public care and were questioning the authority

and domination of the medical model, medical professionals and institutional care, as people perceived these practices to be inattentive and apathetic to the interests and preferences of patients (Irvine, 2002). People demanded the democratization and decentralization of health care, and to have more say in their own health and health care. This context gave rise to a democratic model of health care that espoused the prevention of illness and promoted a holistic approach to health and wellness (Browne, 2000). Patients and their families demanded more choices and the ability to take part in the decisions that determine their health and the health of their family members.

The provincial Liberal government during the mid-1980s began to adopt a broader definition of health and emphasized the social determinants of health and health promotion in the policy documents as mentioned in the previous section. Then, the provincial PC government in the mid-1990s took advantage of the ongoing dissatisfaction of the public towards the domination of medicine and used it as a vehicle to import private sector business and managerial practices to health care in the name of responding to the preference of Ontarians to be more involved in their care and to be cared for closer to home (Armstrong & Armstrong, 2010; Irvine, 2002). There was a shift of care from “institutions to regional support of home and self-managed care; and from a reliance on medical specialists to a recognition by all citizens of all citizens to assume greater responsibility for their own health” (Canadian Network for the Advancement of Research, Industry and Education, 1997, as cited in Bella, 2010, p.25). Veinot (2010) suggested that the government’s emphasis on empowering patients and the emphasis on health

promotion and various chronic disease self-management care were designed to conceal their policy agendas, to ration health resources and to shift the burden of care from the collective to the individual.

This was possible because there were commonalities between “the ideas of ‘health promotion’, namely ‘the process of enabling people to increase control over, and improve their health’ and the ideas of empowerment defined as ‘the process by which people, organizations and communities gain mastery over their lives’” (Labonte, 1994, as cited in Bella 2010, p.23). Moreover, the language of ‘choice’, ‘empowerment’, and increased ‘control’ appealed to those who desired the democratization of health care. The government took up the language of the people and appropriated these ideas, strategically altering them to produce a framework that was common in language but had no real similarities in substance (Irvine, 2002). Those who initiated the empowerment movement used empowerment to refer to a collective and political process initiated by the people traditionally situated on the margins to gain mastery over their lives (Bella, 2010). The government on the other hand used the language of ‘empowerment’ to refer to a ‘top down’ initiative to ‘empower’ the individual to take on greater responsibility for their own health. The role of the government hence shifted from providing care and improving the social and economic determinants of health to ensuring adequate health promotion information was available to enable individuals to make better-informed choices, and adopt these health promotion practices (McDonald, Mead, Cheraghi-Sohi, Bower, Whalley, & Roland, 2007).

The adoption of the chronic disease self-management approach from the top-down is another way that healthcare was privatized by shifting care work that used to be performed by public health care workers to unpaid caregivers. By encouraging Ontarians to take on more responsibility for their individual health needs and for their use of the health care system, the government was able to manage the increasing demand for home care and community-based services. Chronic disease self-management is defined as “strategies that enable people to minimize their symptoms, share in decision-making about their treatment and gain a sense of control over their lives despite their chronic conditions” (Kendall & Rogers, 2007, p.135). Other terms such as self-care, and adherence, are often used interchangeably with self-management (Schilling, Grey, & Knalf, 2002). In this context, ‘health’ is constructed as the management of symptoms and it is achievable as long as the individual with the chronic disease makes good choices and follows the correct ‘self-care’ routines to manage their own lifestyles, their chronic health conditions and well-being, and as a result requires less direct use of hospitals, and home care services. This approach assumes the individual as a rational, autonomous being, self-directed, and who has control over themselves, their lifestyles, and their life circumstances. It values self-sufficiency, endurance, and hard work, therefore, when individuals fail to make good decisions to follow the ‘self-care’ routines to maintain health or exhibit signs of dependence or need, it is perceived as a failing of the individual and they are to be blamed for their predicament, as well as for misusing the already under-resourced health care system (Aronson, 2006; Veinot, 2010).

In promoting individual rationality, autonomy, independence and choice, the responsibility of the state to foster conditions for equality and access to health and health care is pushed aside. As well, the relational aspects of care, and the inter-dependent nature of human relations, are neglected. Not everyone is equipped to be competent in improving or managing their health. Even with individuals with access to the best resources, the unruly nature and unpredictability of illness often puts individuals in positions where they need to rely on others for care and support. Discussing patients with chronic illnesses, Piette (2010) states that “‘self’ management is a misnomer since their disease care is actually shared by their family and broader social network” (p.4). This is particularly so for children with chronic health conditions or disabilities as children generally do not have the competence and maturity to master the tasks to care for their illness. However the reliance on parents and families to share the care often does not take into consideration the huge demand of complex, medical care on them (Peter et al, 2007), and the social and economic resources that dictate the kind of ‘choices’ and involvements the individual and their family can make (Browne, 2000). Locating the capacity and responsibility for managing one’s health at the individual and family level (Kendall & Rogers, 2007) conceals the wider social relations that structure how the individuals (and families) can fully implement the prescriptive health information and disease management routines (Sinding, Miller, Hudak, Keller-Olaman, & Sussman, 2012). Harris and colleagues (2010) contend that individual and collective responsibility should go hand in hand, and refuse “the idea that citizens should be personally responsible for health and self-care if it means that there is no corresponding collective responsibility to

ensure both access to needed ‘expert’ care and ongoing work to improve the social and economic conditions that contribute to ill-health” (p.223).

The discourse on ‘self-care’ or chronic disease self-management not only legitimized the responsibility of care onto the individual, it ‘normalized’ and de-medicalized the self-management routines of individuals with chronic health conditions as ordinary activities of daily living. As such, it was argued that the services needed to support these self-management routines should not be the responsibility of the state, and should best be met by the private market and individuals and their families (Baranek et al, 2004). As a result, this shift in emphasis from the state to the individual, and from institutions to the community enabled policy makers to shift costs from the public sector to the individual households (Baranek et al, 2004). The progressive discourse advocated from the ground to democratize and decentralize health care to the community and to enable patients to take part in directing their own health care had been hijacked by the government; instead of politically transforming the practice of medicine, it had been co-opted for the purposes of the legitimizing the privatization process and cutting down health care costs (Browne, 2000). Several scholars confirm that the involvement of individuals to take greater responsibility for their health and care coincided with the pressure to contain healthcare spending, and, more broadly, to discourage individual reliance on social resources (Kendall & Rogers, 2007; McDonald et al, 2007). In my study, I see the discourse of self-care enter into the local practices of the nurses at the school, and direct the nurses’ attention away from providing nursing care to transferring

primary care to children with diabetes, and accomplishing the discharge of children from nursing services at school. As I will show in Chapter seven, this institutional process not only draws parents into doing teaching work, children with diabetes are also drawn into doing the discharge work at times at an age when they are not emotionally and developmentally ready to do so.

Effects of the commodification and privatization of the Ontario home care sector

The provincial reforms of the 1985 to 2002 period, particularly under the leadership of the PC government, brought about drastic changes to the home care sector. While home care in Ontario had been publicly funded, it was mainly delivered by private non-profit organizations. The introduction of the managed competition model expanded opportunities for private, for-profit organizations to deliver public-funded home care services. For the first time, the private for-profit provider organizations could compete directly with the non-profit provider organizations for public funding (Randall, 2007a, 2007b). This not only further opened up the delivery of home care services to private for-profit organizations, it also brought in market and economic principles to organize community healthcare as more and more non-profit organizations were forced to adopt these market rules and practices to remain competitive (Heitlinger, 2003). Some argue that the competitive model was more favourable to the for-profit organizations who were accustomed to market and business practices, as well as having the ability to pay lower wages and employ less skilled (and non-unionized) labour (Baranek et al, 1999). To remain competitive, this forced the non-profit provider organizations to take up

management ideologies and business practices, and leaner forms of work organization to remain competitive (Aronson et al, 2004; Aronson & Neysmith, 2006). While the PC government promised Ontarians the introduction of private market and market mechanism into the public sector would increase efficiency and bring about better care with less costs, in actuality, the research conducted by Armstrong and colleagues (2001) found that competitive market mechanisms not only led to an increase in administrative costs, and government regulations and control, it also pushed the focus on quality and continuity of care to the back burner when the survival of the provider agencies took priority. In some instances, competitive bidding led to the closure of highly respected non-profit home care providers that were known to provide consistent and high quality home care (Browne, 2000; Zeytinoglu, Denton, Davies, & Plenderleith, 2009).

The closure of respected provider organizations, and the unpredictability and uncertainty of securing contracts led to the destabilization and demoralization of the home care workforce (Zeytinoglu et al, 2009). It also led provider organizations, who were struggling to remain competitive or ensure their survival, to focus more on the financial bottom line and what would bring in money for the organization to keep the business afloat. In preparing for the proposal/ bid, the provider organizations were required to shape home care services to resemble a commodity in the market, ready to be sold to CCACs. To do so, they needed to quantify their services into measurable deliverables and tasks with their corresponding time units and costs for competitive bidding purposes. Fitting care work into measurable tasks would leave out the most crucial relational aspect

of care. Research shows that relationship is the key component of quality care (Aronson & Neysmith, 2006; Twigg, 2000), however it is difficult to measure and quantify relationships. When only those aspects of carework that can be accounted for in measurable terms and fit into a list of tasks would bring in revenue, the emphasis of the organizations were shifted away from the relational aspect of care and the continuity of care staff (which does not bring in revenue) to maintaining a profitable business. In addition, the organizations resorted to cost-cutting and revenue enhancing measures, such as using more casual, undertrained and under-qualified staff, and increasing staff caseloads (Abelson et al, 2004; Aronson et al, 2004; Aronson & Neysmith, 2006; Denton et al, 2007). These measures created poor working conditions for front-line staff, resulting in high staff turnover, in turn affecting the quality and continuity of care provided to the recipients of care. Holistic care, that promoted well-being and prevention of illness, was only possible when there was familiarity and continuity of staff, as well as time to attend to the changing needs and health status of the care recipients (Denton et al, 2007). The combination of over-worked staff, inadequate training, a lack of continuity, and tight daily caseloads increased the possibility for error and the risk of harm to the care recipients, particularly in situations where the client required on-going monitoring by a consistent provider (Abelson et al, 2004). These changes contribute to the work conditions of the community nursing work force. As I will show in my investigations in Chapter six, when quality is measured using performance indicators derived from a managerial framework and automatically calculated through an institutional technology to determine the allocation of 'market share' to the organization, managers of the

organizations are thus organized to accept service commitments for which they cannot always provide a consistent nurse – directly affecting the quality of nursing care.

The managed competition model also reorganized the relationship among the provider organizations, and between CCAC and the provider organizations from that of a cordial, collaborative and trusting relationship to one of suspicion and apprehension. As competitors, provider organizations were pitted against each other to fight for funding. When survival of the organization became dependent on the ‘winning’ bid, what used to be a culture focused on a service mentality was replaced with a competitive mentality, and this undermined trust and solidarity of the home care workforce (Light, 2001). As purchasers of services, CCACs held power to police and monitor the performance of the provider organizations and had control of the possibility of their future contracts and as such the provider organizations were apprehensive towards the CCACs (Randall, 2007b). As well, the CCAC care coordinators were granted the authority to determine who gets services, instead of the physicians who referred the patient for services. This not only undermined the authority of the physicians, it clearly showed eligibility of services were not only based on needs but also based on the availability of funds (Armstrong et al, 2001). It is clear that quality services and people’s well-being were eclipsed by the government’s fiscal priorities on cost-effectiveness and efficiency (Baranek et al, 2004).

Although the global cost containment of home care was achieved, this was only possible through cutbacks, a capped budget, tightening of eligibility criteria, reduction in

services and a deterioration of quality care (Randall & Williams, 2006). In other words, these measures shifted the costs of home care from the public sector to the private households. The discourse on chronic disease self-management and self-care, and the emphasis on patient participation and involvement further legitimized the transfer of care from institutions to the community in the name of ‘consumer’ preferences for care ‘closer to home’, and thus moved care beyond Medicare’s public boundaries and open to private market forces (Randall & Williams, 2006). The explicit and implicit strategies that were taken up by the government to privatize the home care sector have severely damaged the morale and the working conditions of the home care workforce, as well as the quality of care provided to care recipients (Armstrong et al, 2001).

Ontario Home Care after 2002

After the PC government was out of office, CCACs continued to operate using the managed competition model. In 2006, it was announced by the Liberal government that the CCACs would be amalgamated into 14 CCACs and funded through a newly created regional body, the Local Health Integration Networks (LHINs). In 2008, the Ontario Ministry of Health decided to suspend the competitive bidding process after mass protests and media campaign from care providers and care recipients following two well-known non-profit provider organizations losing their contracts through the competitive bidding process (RNAO, 2012; Zeytinoglu et al, 2009). From then on, the provider organizations that had contracts in place with CCACs continued to keep their contracts, and there continued to be differences among the provider organizations in terms of rates and

corresponding units of hours depending on how the ‘winning’ proposal was written. Even though the “managed competition model” is no longer in use, the market and economic principles that were introduced at the time continue. For-profit provider organizations and non-profit provider organizations continue to compete for their share of the ‘home care market’.

As well, the amalgamation of the CCACs meant that the previous CCACs brought with them their unique practices, computer systems, and distinctive ways of operation into the new CCACs. As a result, there were multiple client files existing in one CCAC, a lack of integration of information between various parties involved with CCAC such as the hospital, provider organizations, and long-term care facilities, and an inefficient way to manage and transfer client information. In 2008, the Ontario Association of CCACs (ONCCACs) piloted a new web-based electronic health information system to the CCACs to improve the process of gathering, coordinating, storing, sharing and accessing of client health information and of connecting with diverse healthcare stakeholders that deal with the CCACs. The developer of this web-based program claimed that this electronic health information system would “deliver a seamless experience..... providing equitable access, individualized care coordination and quality health care” (Zvaniga, 2011, p.9) and it would enable the CCACs to do the work of caring in the most efficient way possible (Zvaniga, 2011). The use of electronic medical records or electronic health information systems are becoming more prevalent in the health care sector. While this software is often presented as a neutral tool to better the quality of care for patients by

improving the efficiency and effectiveness in the transfer of information and coordination of services, this software is never neutral and neither is the information produced using this software. The text-based information produced through computer-assisted information technology software presents a particular way of understanding a field, in this case home care services, and I contend that actions based on this way of knowing through text may not best serve the interests of those receiving care. How this electronic health information system and text-based information organize a particular way of knowing and mediate the practices of home care services providers will be further discussed in Chapter six of this thesis.

Furthermore, there was the recommendation by two highly publicized healthcare commissions, the Kirby commission (2002) and the Romanov commission (2002), to establish a national publicly funded home care program to ensure minimum services would be available across the country, however this recommendation was not taken up by the federal government. Even though the reports confirm the need for a national publicly funded home care program, at the same time, the Romanov commission affirmed the need for better management of the high costs of health care and supported the efforts taken throughout the 1990s to reform health care (Motiwala, Flood, Coyte, & Laporte, 2005; Romanov, 2002). The previous federal conservative government continued to reduce their funding transfers, and the home care budget continued to remain inadequate (Armstrong et al, 2010; Motiwala et al, 2005; RNAO, 2012). Although there was a sporadic release of pockets of funding to CCACs for specific initiatives from the provincial government, it

did not catch up with the rising demand for home care. In fact, Ontario spends less on health care than most other provinces; according to the National Health Expenditure Trends conducted by the Canadian Institute for Health Information, Ontario ranked eighth out of 10 provinces in health funding. Underfunding inevitably leads to cuts and a decline in home care services, resulting in delays in client-care assessments and long wait-lists for home care services. In the 2010 report that was prepared by the Auditor General of Ontario, it was found that wait lists existed in 11 CCACs totalling approximately 10, 000 people, and what was more concerning was that these issues were identified as early as 1998 (as cited in RNAO, 2012). This finding is a testament to the ineffectiveness and failure of the market and business strategies to improve home care services and to save costs.

As we look to the fate of home care, it seems that history continued to follow this trend. There were increasing proposals from different stakeholder and interests groups, such as the Ontario Nurse's Association, to dismantle CCACs. Even though the competitive bidding process was suspended, the economic ideologies and business practices that were introduced during this period remain. The Ontario government continues to promote similar ideas that call for "more bang for the buck," "Better client care through better value from our health care dollars," and "empowering" Ontarians to care for their health and health care by having them and their families take on more responsibilities. The language of economy and cost-effectiveness continues to underpin Ontario home care policy.

Research using IE to explicate social relations of health care reform and restructuring

Using the research studies conducted by critical social scientists and policy analysts on home care reform and the effects of home care reform, I have mapped out some of the significant policy changes and strategies proposed and implemented by the provincial government to reform and reorganize home care services during the past three decades. This literature provides a vital resource for understanding the wider institutional context in which my study takes place, and establishes a critique to counteract the official claim that the home care reforms will improve the efficiency and cost-effectiveness of the home care sector and improve the quality of home care for service recipients. In my research, I draw on these understandings and critiques, and consider them in relation to services for a specific set of care recipients, in a specific setting: services for children with diabetes, while they are in school. In pursuing this study I take up an approach not often used in studies of home care: institutional ethnography.

While many studies make a conceptual case for the effects of health care reform on particular service sectors, IE as a method of inquiry enables me to make these links empirically, explaining in concrete detail how the everyday experiences of parents of children with diabetes are hooked into these wider features of social organization. My research benefits from studies that have used IE to investigate the relations of health care reform and restructuring in other settings, particularly Rankin's (2003, 2004) work on the

social organization of nursing work and nursing knowledge in the hospital setting in British Columbia, and shows how a new managerial way of knowing brought about by hospital restructuring subordinates nursing knowledge. Campbell's (2008) study investigating how the provision of home support for people with disabilities is socially organized such that services are fragmented, impersonal and unsatisfactory despite the official commitment to continuity of care. She shows how the new contracting and accounting arrangements introduced through what is known as the "new public management" replaces continuity with budgetary priorities in spite of officially stated goals. Mykhalovskiy's (2001) work exploring how health service research is taken up to justify particular medical and managerial practices that organize the speedy discharge of heart attack patients, and Jung's (2003) institutional ethnography illuminating how the University of Victoria's disability policy intended to benefit students disabled by chronic illness, in actuality shifts the responsibility for change to individual students and instructors.

Conclusion

In this chapter, I have first laid out how home care is situated within the Canadian universal health care system. The location of home care as an uninsured health service left it as an open target for funding cutbacks at a time when the government was implementing austerity measures. The increasing demand for home care due to an aging population and the advancement of medicine and technology, coupled with the fragmentation of the home care sector, created an avenue for the government to frame the

issues of home care as a managerial problem of inefficient and ineffective management of the finances and operations of a huge public sector. Home care was constituted as in ‘crisis’ due to the mismanagement of a public bureaucracy. Framed as a managerial problem, the solution was to improve the efficiency and cost-effectiveness of the home care sector by importing market and business ideology and practices. The Ontario government took on explicit and implicit strategies to privatize the home care sector. They used reform and policy changes as an explicit strategy, and the promotion of ‘empowerment’ and the chronic disease self-management approach as an implicit strategy to further legitimize the relocation of care work from paid health care workers to unpaid caregivers.

However, the privatization of home care not only failed to improve the efficiency and effectiveness of home care as promised, it led to the disruption of the previous trusting and collaborative relationship among the providers, poorer working conditions, and the deterioration of the accessibility and quality of home care. Privatization also led to the relocation of care from hospital to community, and from the state to private households. The changes that were undertaken in the home care sector shape the conditions and work organization for the home care work force that is responsible for delivering care in the schools. The shrinking public responsibility for home care services has significant consequences for children in need of School Health Support Services and their families. The inquiry I am undertaking is set in this broader institutional context.

Informed by previous institutional ethnographic research that studies how the ruling relations of the “new public management” shape what is happening in hospital and community health care in British Columbia, this inquiry takes the experiences of parents of children with diabetes as the point of entry to investigate the social organization of health supports for children with diabetes in Ontario schools.

Part Two:

Journal Articles – the descriptive analysis of an institutional ethnography

CHAPTER FOUR

“Her life rests on your shoulders”: Doing worry as emotion work in the care of children with diabetes

Abstract

Existing research on parents’ caregiving experiences in the context of diabetes management have consistently shown that parents experience high levels of pediatric parenting stress, anxiety, depression, and general worry. However, how parents understand their worry is largely unexplored and little attention is paid to the work parents are already actively doing to manage their worry. Adopting Arlie Hochschild’s (1983) concept of ‘emotion work’ and Dorothy Smith’s (1987) generous concept of ‘work’, this article sets out to examine the emotion work of doing worry that parents engage in when caring for their children with diabetes. In paying attention to worrying as work, I show how worry is not only an individual emotion, but an embodied way of knowing the presence of potential threat to their child’s health, and thus an essential aspect of the necessary work done by parents to ensure the safety and well-being of their children with diabetes.

Introduction

Type 1 diabetes (henceforth referred to as diabetes) is one of the most common childhood chronic illnesses (Haynes, Bulsara, Bower, Jones, & Davis, 2015; Soltesz, Patterson, & Dahlquist, 2007). The medically optimal management of diabetes involves a well-coordinated and intensive daily routine that balances the administration of insulin,

constant blood sugar monitoring, a well-regulated meal plan at set times, as well as a consideration of a myriad of factors such as the amount of physical activity undertaken, the level of stress, sickness, and growth. It is crucial that children's blood sugar levels be monitored and controlled so as to remain as close as possible to a normal range throughout their lifetimes, as lapses in this complex daily regimen can have devastating immediate as well as long-term consequences for children with diabetes (Diabetes Control and Complications Trial Research Group, 1994). As such, a diagnosis of diabetes in children requires tremendous adjustment for the whole family, a reorganization of family life, and places great demands on parents.

As increasing numbers of children are diagnosed with diabetes, and at younger ages, there is growing interest in the experiences of parents who care for their children with diabetes. Previous research on parents' caregiving experiences in the context of diabetes management have consistently shown that parents experience high levels of pediatric parenting stress, anxiety, depression, and general worry (Hatton, Canam, Thorne, & Hughes, 1995; Lowes & Lyne, 2000; Monaghan, Hilliard, Cogen, & Streisand, 2009; Streisand, Swift, Wickmark, Chen, & Holmes, 2005). Even though the daily routines of diabetes care are demanding, these studies found that the treatment tasks are not the main cause of parental stress and anxiety. Rather, parents' level of emotional distress is associated with their fear of hypoglycemic episodes, the worry over the children's fluctuating and unpredictable blood sugar levels, the anticipatory worry when entrusting their children to another's care, and their concerns over their children's future

health and possible long-term health complications (Hatton et al, 1995; Haugstvedta, Wentzel-Larsend, Rokneb, & Grauea, 2011; Monaghan et al, 2009; Smaldone & Ritholz, 2011; Streisand et al, 2005; Patton, Dolan, Henry, & Powers, 2007; Wennick, Lundqvist, & Hallström, 2009). Indeed, worry is a common experience among parents of children with diabetes.

However, much of this research is psychological in nature with a focus on parental stress, adaptation, and coping. Parental adaptation to the diabetes diagnosis and its daily demands of care is understood to be critical to parents' ability to manage diabetes and to successfully care for their children with diabetes. Embedded in the psychological discourse, worry, as an emotion, is often understood to be passively experienced by individuals and as a sign of negative adaptation, or a failure to cope. As such, interventions are often devised to decrease parental worry (Rearick, Sullivan-Bolyai, Bova, & Knafl, 2011). How parents understand their worry is largely unexplored and little attention is paid to the work parents are already actively doing to manage their worry.

Adopting Arlie Hochschild's (1983) concept of 'emotion work' and Dorothy Smith's (1987) generous concept of 'work', worry or worrying is understood as an aspect of emotion work involving active, skillful engagement: I call it 'doing worry'. In this article, I will examine the emotion work of doing worry that parents engage in when caring for their children with diabetes. In contrast to the psychological discourse, I hear in

parents' talk that their experience of worry is often informed by a wealth of knowledge and experience, undertaken with care and intention, and done in relation with others. I will first explore how parents understand and come to experience worry, and the knowledge parents draw on in 'doing worry.' I then show the actual practices of 'doing worry' that parents engage in competently and actively to manage – contain, or express and amplify - their worry and that of others, including their children, family members, and professionals who are involved in their children's care. In paying attention to worrying as work, I show how worry is not only an individual emotion, but an embodied way of knowing the presence of potential threat to their child's health, and thus an essential aspect of the necessary work done by parents to ensure the safety and well-being of their children with diabetes.

Emotion as work

The term 'emotion work' was first introduced by Arlie Hochschild to refer to an individual's intentional effort to manage or display one's own feelings to influence those of others in desirable ways (DeVault, 1999; Steinberg & Figart, 1998). Hochschild made a distinction between 'emotional labour' and 'emotion work.' The former is required by employers in paid employment, whereas the latter refers to the unpaid efforts that occur in family and personal life, often conducted by women (1983, as cited in DeVault, 1999). It is important to note that 'emotion work' refers to the efforts – the act of trying – taken in a broad sense to shape, evoke or suppress a feeling, and not to the outcome, which may or may not be successful (Hochschild, 1979, p.561). Moreover, emotion work can be

undertaken by oneself upon the self, by oneself upon others, and by others upon oneself (Hochschild, 1979, p.562).

In the context of caregiving research, the idea of ‘emotion work’ is significant as it draws attention to the often neglected emotional dimension of caregiving which involves the emotional interactions between the caregiver and the care recipients and the management of their emotions. A number of scholars underscore emotion work as an intrinsic, albeit invisible, part of caring work (Clarke, 2006; Mac Rae, 1998). In viewing emotion as ‘work’, the experience of a particular emotion is no longer understood as a passive state experienced by caregivers or care recipients. Nor are emotions such as worry necessarily an indicator of an individual’s maladaptive coping. Rather, it is suggested by Clarke (2006), in her research on the healthcare work of mothers of children with cancer, that these emotions are a “rational”, “normal”, and often necessary responses under the circumstances of caring for a sick child (p.59).

In addition, I will draw on Smith’s ample and generous conception of ‘work’ (1987) to examine how parents engage in doing worry when caring for their children with diabetes. ‘Work’, in Smith’s conception, is understood to be activities that people do that require some effort and some acquired competence, occurring in real time under definite material conditions and means (1987, p.165). The notion of ‘work’ directs “analytic attention to the practical activities of everyday life in a way that begins to make visible how those activities gear into, are called out by, shape and are shaped by extended trans-

local relations of large-scale coordination (what Smith calls relations of ruling)” (McCoy, 2006, p.110-111). In taking up this notion of ‘work’, my attention will be oriented to the practical activities that parents do on a day-to-day and moment-to-moment basis, and how this work is connected to the work of others (McCoy, 2006). Both scholars underscore the relational aspect of emotions and work.

Methods

Ethical approval was obtained from the University Research Ethics Board, and participants provided informed written consent for their participation. The participants’ names are pseudonyms to ensure their confidentiality. The results described here draw on data from a larger study using institutional ethnography to examine the social organization of School Health Support Services for children with diabetes in Ontario schools. Institutional ethnography is a method of inquiry developed by Canadian sociologist Dorothy Smith (1987, 2005, 2006) to investigate the social relations embedded in aspects of people’s everyday life circumstances that trouble them (McCoy, 2008). This method of inquiry typically takes up people’s experiences in everyday life as the starting point of inquiry, and further explores the trans-local relations embedded in and shaping the experiences and routine practices of people in the local setting (Smith, 1987, 2005). The interviews with parents constituted the beginning stage of this institutional ethnography, and helped to develop and refine the direction of the research (S. Turner, personal communication, August 10, 2012).

Seven parents were interviewed in this study, and this data is used in the analysis here. They have an average of about five years' experience in caring for their children with diabetes, ranging from about one year to over ten years' experience. Their children were diagnosed with diabetes between the ages of nine months and fourteen years of age. The parents were recruited from a parent support group and were from two-parent middle class families. They were asked general questions about their caregiving experiences, such as daily routines of diabetes care, rewards, challenges, and what they find helpful and unhelpful in the process. The interviews were audio-recorded and transcribed with their permission. During the interviewing process and upon reading the transcripts, I noted that all of the parents interviewed expressed that worry is a significant challenging part of caring for children with diabetes as articulated below:

Just the emotional strain that, hm... the worry, the... the feeling like her life rests on your shoulders, that's the hardest part (Brenda, child aged six, diagnosed at age five).

When I'm not around it I can notice it, I can notice I don't have to worry. So there's a challenge, I'm worried all the time (Steve, child age thirteen, diagnosed at age nine).

Adopting the concept of 'emotion work' and the generous concept of 'work', I conducted a second read through the interview transcripts focusing more closely on the portions of data where parents talked about their worry. Analysis involved asking questions of the data such as: how parents understand their worry, what evokes the need to doing worry, the actual activities of doing worry, how they talk about this work, the knowledge and skills they draw on to 'do worry,' and how doing worry arises in relation to others and their work (McCoy, 2006).

Findings

Knowledge of diabetes care: Being on-call for diabetes 24/7

Parents described the initial learning of the complex and intensive diabetes management regimen as being like climbing up a steep curve as they are required to learn a large amount of information about diabetes care instantly as their children rely on them to know how to do diabetes treatment to stay alive. The knowledge of the diabetes management regimen was conveyed to the parents as part of the professional work process of diabetes education and treatment conducted by the diabetes nurse educators at the pediatric diabetes clinic. Diabetes education practiced at the clinic follows the Clinical Practice Guidelines of the Canadian Diabetes Association which entails blood glucose (BG) monitoring, BG and ketone testing, insulin administration and dosage adjustment, carbohydrate counting and nutrition, exercise, as well as prevention, detection, and treatment of hypoglycemia (Wherrett, Huot, Mitchell, & Pacaud, 2013).

Parents initially followed the diabetes management regimen closely. Over time, as they embed this knowledge in their minds and through their everyday practices, they came to the realization that nothing is predictable about diabetes. As Steve articulates: “You’d think there would be a science to it but there isn’t. Like, it changes every day.” Indeed diabetes is not the type of illness whereby good results can be guaranteed if you follow a standard treatment procedure; the child can do the same activities, eat the same food, with the same exact diabetes care procedures on two separate days and the BG readings will be different.

Through their repeated experience of doing diabetes care, parents identified that doing this work is complex as there are many changing factors that need to be taken into account; flexibility and constant adaptation is required to achieve optimal glycemic control. Achieving optimal glycemic control means keeping the child's BG level within a normal range for their age as much of the time as possible. It is critical to prevent acute problems (hypoglycemia and Diabetes Ketoacidosis [DKA]) and minimize the risks of developing long-term complications (such as heart attack, stroke, kidney failure, blindness, amputation due to microvascular and neurological complications) (Diabetes Control and Complications Trial Research Group, 1994).

Bob (child aged fifteen, diagnosed at age 10) summarizes the goal of diabetes care for his child is to achieve: "Best possible quality of life for her. Minimum of intrusions in her daily life with the best possible blood sugars and no bad lows." He went on to explain how he achieves this optimal care,

I mean if I try and do insulin regimen and it doesn't work it's obvious very quickly. And then, I either go back to what I was doing if it's better than the new thing I've tried or I tweak the new thing and make it work better. That's what managing diabetes is all about. Your child's insulin needs are always changing, the patterns... the patterns ... like governing the amount of insulin they need over a 24 hour period are always changing so you need to be flexible. You have to be flexible, you have to be able to adjust.

Here, Bob tells of how he fine-tunes his daughter's insulin regimen by paying close attention to his child's BG patterns to decide on an insulin regimen that works best to keep his child's BG level within range. Knowledgeable of the many factors that change the child's insulin needs, he emphasizes the need to be flexible, and to make adjustments accordingly.

In addition to being watchful to the changing BG patterns, parents also explain the importance of taking extensive notes to keep track of the various activities, types and amounts of food, and events that may associate with the changing BG readings. In the following quote, May (child aged sixteen, diagnosed at age 9) provides an account on how taking notes and analyzing them has helped her to figure out what worked and, in relation to her son's significant athletic pursuits, to become more confident in caring for his diabetes:

I would say what I've had to do is keep up with him. He comes home and decides to go skateboarding for 2½ hours, snowboarding all day. Its like how do you, what strategy, what do you do? What works? And so writing down what works. Every half an hour we give him a box of Smarties. Did that work? Yes it worked. Remember that for next time..... He played soccer so it was like ok his soccer, he'd come off the field and he'd be sky high so we would treat him with insulin and he would be crashing low so then we realized you don't treat that you just let it go, it'll come down by itself..... Writing down, remember what we did before, keeping good notes.

May is attentive and meticulous. She pays attention to the immediate moment, as well as to the overall trend of how certain food or activities affect her child's BG level. For example, through repeated experience, she learned that following the protocol (correcting high BG by injecting insulin) did not work on every occasion. In this instance, she learned that high BG after soccer games is likely due to increased adrenaline from excessive physical activity and no action is needed. Whereas on other occasions, a high BG reading may signal a lack of adequate insulin in the body or a miscalculation of the amount of carbohydrates consumed, and an injection of insulin is required to keep the child's BG level within range. Each time, she documents the unique patterns of her child's diabetes-related care needs for future use. It is from their practice knowledge that

parents emphasize the persistent, unrelenting attention and vigilance is necessary precisely because, “Diabetes never takes a break” (May).

Lily (child aged 17, diagnosed at age 14) describes diabetes as an “exhausting 24/7 disease”, and she says she is constantly worried. Parents, like Lily and May, are well aware from experience that diabetes does not take a break, even throughout the night. Brenda explains her worry stems from the knowledge of children dying from extreme hypoglycemia during the night, “Kids do die from it, children just don’t wake up sometimes, it happens, it’s not common. Thank God. But it does happen and people don’t, I don’t think they get that.” Brenda is somewhat relieved that children dying don’t happen often, but that does not prevent her, and other parents in this study, from being constantly watchful. They know intimately the experience of waking up in the middle of the night to check their children’s BG to find it unexpectedly low, and that they have to force feed their sleeping children with carbohydrates. At the same time, feeling thankful that they woke up to check, it is their watchfulness and vigilance that keeps children safe throughout the night and day. The unpredictability of diabetes is the reason why Joy is hesitant to feel confident about ‘managing’ diabetes:

I am less nervous because, I don’t want to say you can predict those [low blood sugar], but you kind of have a better feel of when they may occur sometimes, because diabetes is not a perfect science, it will throw you off. But I think.....we try to test him, that’s just for our peace of mind [laughed]. Yeah, I think that’s always, they [low blood sugar levels] still scare me.

After caring for her child with diabetes for more than 4 years, Joy has accumulated knowledge and experience about her child’s diabetes care, and is

feeling less anxious with ‘managing’ diabetes. She describes that she is now more able to make an informed guess as to when her child may experience low BG levels, and hopefully do something before it happens. However, this does not put her at ease, she is still scared because her child, lacking the ability to feel low BG levels, is unable to alert her when he is experiencing low BG. More importantly, diabetes is unpredictable, it will throw her off perhaps at the least expected times. Therefore, it is foolish to feel confident as it might lead to lapses in diabetes carework that may put the child at risk. She is most concerned about the effects of prolonged periods of low BG on her child’s cognitive development, and potential death, and decides to do something about it. She resorts to doing frequent BG testing throughout the day and night to keep on top of it, which eases her worry (more on this on the next section).

It is with this wealth of knowledge about diabetes and extensive experience of doing diabetes care with their children that parents experience worry. While parents describe diabetes as being always on their minds; I hear from their accounts that they experience different degrees of worry. For example, Kylie was worried when her older child (age twelve, diagnosed at age two) was in kindergarten because of an instance in which her son’s lethargic behaviour was understood as misbehaviour by the teaching staff. He was left slumped over in a chair in the principal’s office until the nurse came during the nursing visit and found him in a coma caused by extreme low blood sugar level. Here we see how the work of observation, so critical to the effective management of diabetes, can be

compromised by assumptions that an adult has about a child, or labels that have been applied to the child. In contrast, she feels at ease with her other child (age nine, diagnosed at age five). Kylie's daughter is perceived to be well-behaved and responsible; teachers are thus unlikely to attribute diabetes-related symptoms to 'problem' behaviours. More importantly, she can and will perform the necessary diabetes self-care reliably. Joy spoke of feeling reassured when her child is at school with a consistent nurse that has repeated experience of providing care for her child. Joy assesses that this nurse has acquired the knowledge about child and child's care and is able to perform the work skillfully as proven by her ability to keep child's blood sugar levels within range by adjusting child's intake of carbohydrates according to the changing blood sugar levels.

From these accounts, we see parents draw on their embodied practice knowledge and engage in a process of thinking through the various factors, such as child's BG patterns, their response to diabetes treatment, child's personality, their maturity in 'managing' diabetes, the environment, and the competence of the individuals caring for child, to determine if the child is safe. Seen this way, parents' experiences of worry is not an individual psychological state, rather it is an indicator of whether their child's health and well-being is at risk. It is a result of their engagement in what I call the work of "knowledgeable vigilance". Here, I use the term "knowledgeable vigilance" to refer to complex practices that involve knowledge of a normal BG range and the short-term and long-term consequences of

out of range BG, monitoring BG, and observing a child (and responses to insulin, food, sickness, physical activity and other factors) in the moment and over stretches of time, and responding to the child's changing needs and circumstances in order to sustain a normal BG range. Their feeling of worry is invaluable. It is essential to their diabetes carework to keep their child safe. In the interviews, I hear parents engage in doing work that manages or suppresses the worry for themselves, and others, particularly their children; and at times, they attempt to induce worry in others, such as healthcare professionals, who don't understand diabetes and child's diabetes care, with the goal of keeping their children safe. In what follows is a description of the work of doing worry.

Doing worry: The relational aspect of emotion work on oneself and on others

Managing worry: working to achieve a 'satisfactory' number

Having knowledge of the changing nature of the child's BG levels and insulin needs, many parents resort to keeping watch and frequently checking their children's BG levels to ensure it is within range. This is particularly difficult throughout the night. Joy expresses the most challenging aspect of caring for her child with diabetes is the worry of the possibility that her child may experience severe hypoglycemia during the night. To relieve this worry, Joy resorts to setting an alarm to wake up in the middle of the night to check her child's BG levels. She explains the number representing her child's BG level provides her with information that gives her comfort:

I still test him in the middle of the night, and I know that not everyone does, but for us, it's just peace of mind, it's knowing that for those 12 hours that he's asleep. Hm If we test at you

know 11, and we test as 3, 99.9% of the time it's absolutely fine, but what if something happens, what if he's high. And do you want him to be high for 12 hours, no, we can do something about it. Again, we're empowered to do something about it, so we just do. But what if I didn't, what if something happened in the middle of the night when he's sleeping. I think that is the worry.

In addition to paying attention to her child's immediate well-being, Joy is also attentive to the long-term effects of prolonged periods of high BG levels on her child. Waking up throughout the night relieves her two worries: the worry of her child's potential death due to severe hypoglycaemia and the worry of possible long-term complications. Other parents set up a different set of routines. In the following quote, Bob explains his night time diabetes care routines for his child:

Depending on how the day and the evening have gone, if she's gotten a lot of exercise, if she's had weird foods there is often a need to measure at night. So we've actually adjusted our family's routine. I'm self-employed so I have very flexible hours and I will simply stay up at night working on my work and keep measuring until I'm satisfied that we've got nothing to worry about for the rest of the night.....But until I've got a trend that I'm satisfied with I'll stay up and keep working and measuring every couple of hours.

Bob describes how he works at getting a 'satisfactory' number. He takes into consideration the activities and the food his child had during the day, the BG trend (which is the BG patterns of the past few days) and the child's current BG level to adjust child's insulin needs. He will keep checking and making adjustments until he gets a 'satisfactory' number. He considers a 'satisfactory' number as one that gives him nothing to worry about throughout the night and allows him to go to bed peacefully. Kylie, Steve, and Lily describe similar routines. They, too, rely on a 'good enough' BG number at bedtime to decide whether or not to get up in the middle of the night. Achieving a 'satisfactory' number gives parents a peace of mind. The activities that ensure that BG levels stay in range are exactly the activities that help to manage their worry.

Containing worry: building positive attitudes towards life-long diabetes care

Being mindful that diabetes is a life-long illness their children have to live with for the rest of their lives, parents are wary of the emotional burden of having a chronic illness on their children. While it is inevitable that diabetes is something that they need to pay attention to, they are concerned if they let diabetes take over, their children will resent living with diabetes and that might have an influence on how their children will engage in diabetes self-care or not in the future. Parents work at creating a positive experience of living with diabetes with their children. May's son is sixteen and 'manages' his diabetes himself. She offers support and supervises from a distance. Here, she describes how she tries to not let diabetes dominate and mediate her relationship with her son:

I had to really watch it because my first question to him in the morning was what's your blood sugar and now I had to really change that and say did you have a good sleep? You know what's your day hold for you today? Like wow how late were you up last night? Did you get that essay done? What's your blood sugar?

As mentioned in the previous section, knowing a 'satisfactory' number gives parents peace of mind. May's need to ask about her son's BG in the morning stems from her worry about whether his diabetes is being well managed. However she makes an effort to hold back her need to know and attends to aspects of him and his life beyond diabetes. Here, she does not want her son to know that she is anxious to know his BG level. Instead, she suppresses her automatic response to ask about his BG to create a 'normal' family life and a relationship with her son that is not solely mediated by

diabetes. It is her attempt to not let diabetes dominate their life, and to try to minimize the possibility of his resentment of being treated only as a 'diabetic' and not a person.

Brenda is careful in how she responds to her child and the type of messages she gives her about living with diabetes. She describes engaging in a process of always having to think through why and what she plans to say and do to prevent her daughter from having negative feelings towards living with diabetes and associate living with diabetes as limiting.

I don't want her to resent any of these, I don't want her to feel like diabetes is, makes my life suck..... it's like everything I answer her will have implications because I am sending a message to her with everything that I do. And then where I feel like I am so cautious when I say no about something, why am I saying no to this, you know, she wants to go do an activity say with a friend somewhere, and how do I say 'no, because you are diabetic, I can't, I can't let you' because then she is going to really hate it [sighed] and so I'm so conscious of trying to prevent that.

Here Brenda describes two worries: the worry about the activity on the child and the worry about what the effects will be on the child if she expresses the worry about the activity by saying no. Her worrying about diabetes keeps her child safe, but expressing her worry about diabetes to the child might lead the child to dislike diabetes. Brenda cautiously chooses to downplay the role of diabetes in the hopes that her child will not resist having diabetes. Ultimately, she is worried that if her child hates diabetes, she will be less likely to engage in diabetes self-care in the future, and hence her child is put at risk.

Joy is aware of her worries related to diabetes and how her child may pick up on her worries and become worried himself. She works at not expressing her worry in front of her child. In addition, she is working actively to change their relationship to the BG numbers by removing her feelings related to the number and instead focusing on the number as information and what they can do about that number. She does not want her child to activate a feeling of worry every time he sees an out of range number. She explains,

It's hard not to transfer that worry onto him all the time. I know I don't want him to feel worry not going to places, or doing things or that sort of thing, so a lot of it, you just try and, I don't want to say keep to yourself..... So, I try not to make it about this specific number, yeah, but what I can do about that number. I don't want him to feel anxious waiting for that thing to tell us what it is. No, it's not that, it's we can do something about it. The fact that we see it and we know what we can do, that part is comforting.....I don't want him to be anxious about it, so in return, I can't be anxious about it. It's a number, that is what it is. And more about what you do about it. So that's sort of our approach to it. When he's low, we tell him, [name of child] you are low right now, do you feel funny, do you feel, cause we are trying to get him to identify his lows.

By treating the number as information, Joy directs the focus on how to use the number representing child's condition in that moment to best care for her child. At the same time, she tries to activate his embodied knowledge of what it feels like when he is experiencing high BG, and what it feels like when he experiences low BG, so he can alert her sooner to do something to keep his BG in range.

Parents recognize that caring for and living with diabetes is hard for themselves and their children respectively, but it can be managed. Having worked through her own fears, Kylie describes how beneficial it is to help her children to do the same:

You know maybe cause I think how I felt about diabetes was reflected in him. So when I started figuring out that I didn't have to, I didn't have to be scared I started to be able to give him that right. Like saying to him I know you're scared but it's going to be ok. Then all of a sudden it means something if I believe in it right. So I do think they [the clinic] have to address the parents.

In addition to realizing how her worries and her son's fears are interconnected, in her efforts to support her son to understand his fears, Kylie discovered his BG levels improved as his emotions are in less turmoil. Parents' experiences bring forth the importance of emotional work in chronic illness management and the need to support children with diabetes emotionally as well as medically.

Releasing worry

Parents shared that knowing they are not the only ones that are worried allows them to feel more normal and less isolated. It is validating to know that other parents caring for children with diabetes share the same frustrations, concerns and worries about their children. Joy finds attending support group meetings to be helpful:

I am in a diabetes support group with moms and I find I've learned a lot from what other moms do..... I think it would have felt more, isolated. Like, I am doing this for my child that I know will be taken care of, but I don't know that I am being taken care of or that I have a group that I can say, oh my goodness, today is making me crazy, and I can't figure it out and diabetes is not fun right now and I don't want to say that in front of [name of child] or I don't want him to feel that, I don't want him to think that I, you know, he's causing me this frustration.

Joy not only learns from other parents' cumulative knowledge and experiences of providing day-to-day diabetes care, more importantly, the meetings provide a space where she can talk about her frustrations, concerns, and worries, and ensure she is taking care of herself to continue to take care of her child. Kylie reflects on how she comes to

terms with her own fears and the difficulties of caring for her children with diabetes and recognizing her need to acknowledge and release her fears.

I think I'm stronger because you can't live in fear for your whole life so I've had to really figure that out and process that. Recognize that how I felt would impact on them. You know like so much stronger in the sense of being self-aware. And coming to terms with something that's not easy. I'm not trying to say like it's not easy, it's not like a pity party. Sometimes I let myself have a pity party, like I'll just say yea this really sucks and I'll let myself have those moments and I never use to I use to be just like that's the way life is just you just deal with it. But then you can't, then when you kind of explode or have the big meltdown, you realize ok sometimes I just need to let myself have the pity party and acknowledge that this is really hard.

Kylie's reflection highlights her changed perception of a 'meltdown'. Rather than seeing it as a sign of a failure to cope, she now accepts it as a normal aspects of caring for her children with diabetes and realizes that when she gives herself permission to experience these emotions, such as worry, fear, and frustrations, it helps to make her stronger, and more able to take care of herself and her children.

Amplifying worry

Parents identified that diabetes is an invisible chronic illness that can at times put their children at risk, particularly when there is limited knowledge and much misunderstandings about type 1 diabetes and diabetes care in the community. In the context where parents have to leave their children under the care of other caregivers such as a family member or at school, at times, they find it critical to amplify their worry about diabetes (with other caregivers) and the serious consequences of not following diabetes care. Brenda expresses frustration towards one of her family members. Her attentiveness and vigilance is being judged as being controlling:

I had a comment from a sister-in-law that, 'you are way too strict with her, you should just let her enjoy it.' I can't, it's her life. I am not doing this because I want to control her..... It is her life I am protecting, I am protecting her eyes, her kidneys, her limbs, her heart, this isn't just about you know freedom at Christmas, she has this, it doesn't take a break, and they don't get that. There are repercussions from not taking care of it in one day, and there can be very serious repercussions.

Brenda tries to convey her knowledge and the consequences of poor diabetes care to her sister-in-law without much success. Realizing her sister-in-law is not convinced, she decides to not entrust her child in her care.

Other parents also conduct ongoing assessments of the competence of other people when they engage in diabetes carework for their children, including in schools, and healthcare settings. Kylie shares one incidence during her older son's hospitalization where she had to intervene to ensure his safety. Kylie's son was frequently hospitalized during the initial years of diagnosis due to seizures or sickness. On one of those occasions, her son's BG was very high and the nurse was going to follow the doctor's orders to administer two units of rapid insulin. Knowledgeable about her child's BG patterns, and the effects of the amount of insulin on her child, Kylie raised concerns that two units would cause her child to experience severe hypoglycemia. She expressed her worry with the intent to influence the nurse. The nurse went and checked with the endocrinologist and returned insisting the same dosage as ordered by the endocrinologist:

She came back and she said [name of endo] said give 2 units and if you're refusing medical treatment for your child you're going against doctor's orders. And I was like ... So I said to her ok if you give him 2 units bring me juice. I need juice on hand because I'm telling you I really think he's going to go low. So she went ahead, she gave him 2 units. She did bring the juice and sure enough 2 hours later he was 1.8.

Lacking knowledge derived from daily diabetes care for this child, the nurse and the endocrinologist were not convinced by Kylie. To be proactive in minimizing the effects of possible hypoglycemia, Kylie asked for juice in advance so she had the resources to treat hypoglycemia in the event that her son experienced low BG levels due to the excessive insulin dose. Parents often have to assess when it is necessary and effective to articulate their worries for the interests of their children. Moreover, parents have to be alert at all times to their child, their changing needs and circumstances to manage diabetes well. Bob summarizes this succinctly:

It's the fact that every hour of the day ... and possibly of the night as well at some level you have to be conscious of the diabetes and what you need to do to be managing it. It maybe doesn't take a lot of your time or a lot of your conscious effort but it's always there.

Discussion

Based on the qualitative interviews conducted with seven parents of children with diabetes, I have explored parents' engagement with worry as a form of emotion work to ensure the safety and well-being of their children with diabetes. Parents' experience of worry arises from their knowledge of the importance of maintaining a normal BG range, the consequences of having out of range BG, and the complexity and unpredictability of diabetes management. As well, parents have developed an embodied way of knowing and detecting potential risk or danger to their child through their every moment-to-moment, day-to-day relentless engagement with doing diabetes care for/ with their children. I refer to these complex practices as the work of "knowledgeable vigilance". It is from this embodied way of knowing, caring and practicing knowledgeable vigilance that worry – a feeling of concern about something bad that might happen to their child –

emerges or not. Parents actively and skillfully engage in work that manages their worry. Once they are able to achieve a satisfactory BG reading, and their children are in the care of other competent caregivers who are drawn into the knowledge and activity needed to care for their child, they can relax. The knowledge presented here expands the way worry is traditionally understood. Contrary to the psychological framework where worry is seen as maladaptive coping and a deficit, the findings from this study show that worry is directly related to parents' knowledgeable, experienced activity of caring for their child with diabetes. It is also a form of necessary work: parents' 'doing worry' – their efforts to contain and amplify worry – is essential to ensuring their children's safety and wellbeing. Given this new understanding, parents' expression of worry should not be perceived as a sign of failure to cope, rather parents' knowledge and their expression of worry should be further explored and included in the care of the child with diabetes.

In addition, a few parents expressed that it is helpful to have physical and emotional space where they can express their worry, frustrations and dislike towards diabetes. Some days, doing diabetes care is very challenging and difficult, and they just need to release their worries in order to continue to care for their children. This emotional release is a normal part of caring for children with chronic illness. Parents indicated that they need to take care of themselves emotionally in order to take care of their children. Indeed, caring work is not just doing a list of tasks, caring “refers to the mental, emotional, and physical effort involved in looking after, responding to, and supporting others” (Baines, Evans, & Neysmith, 1991, p.11). Parents in this study emphasized the

hardest part of caring for a child with diabetes is the emotional demands and the necessity to self-regulate their emotions. Therefore, it is important to provide parents with emotional support and an avenue to support a better understanding of the dimensions and conditions of their emotion work. Parents described support groups to be helpful. However, not all parents are able to access the help from support groups or find it suitable for them. More options should be available for parents to access emotional support, perhaps during regular diabetes clinic follow-ups. Emotional support for parents should also go hand-in-hand with emotional support for children, as Kylie pointed out how emotions affect children's BG levels and their diabetes management. Parents are concerned about their children's future long-term health, and these supports are critical to assist children in the development of a positive approach to life-long diabetes self-care routines.

Parents in this study have an average of five years' experience in doing diabetes care; their experiences range significantly from about one year to over ten years. While they have developed the skills and competence to care for their children with diabetes, none of the parents expressed full confidence and mastery of their child's diabetes care precisely because of the unpredictability of diabetes. This is consistent with the research conducted by Wennick and Hallström (2007) where the parents in their study described only being able to make "qualified guesses", indicating they have no full control over the results of treatment. Similarly, Smaldone and Ritholz (2011), and Sullivan-Bolyai and colleagues (2003) also found that parents did not report achieving mastery in diabetes

care for their children. Given the ever-changing nature of diabetes, parents need to be equally dynamic and adaptable in doing diabetes care for their children and that can feel like they can never be proficient enough in diabetes care. It is important to help parents recognize the difference between mastery of outcomes and their competence and knowledge in doing diabetes care. Parents' sense of uncertainty is a reflection of their deep knowledge of the unpredictability of diabetes and the unpredictable outcomes of interventions. Since mastery of outcomes is not possible, parents will benefit from encouragement that they are making the best informed decisions for that moment based on the information they have.

Parents often find themselves in positions where they need to express their worry and advocate for appropriate care for their children. At times, they are frustrated that they are not being trusted, and their worry is being minimized. Other times, they are dismayed that so little is taken up about their child's diabetes and diabetes care by their child's regular caregivers, which often can lead to dangerous situations for the child (as in the case of Kylie's son whose lethargic behaviour was not activated as a sign of low blood sugar by the school staff, but instead what was activated was the label of the child as difficult and having misbehaviour, and hence leaving the low blood sugar untreated) and in turn contribute to parents' worry. It is important for professionals in the school and general medical settings where children are often entrusted in their care to have general knowledge about diabetes and diabetes care, and specific knowledge about that particular

child's diabetes and diabetes care. As well, professionals can listen and make use of parents' wealth of knowledge to provide better care.

The findings described here should be read with the following in mind. First, it is based on the interviews of a small number of parents, therefore it cannot be used to generalize a representation of the experiences or activities of all parents of children with diabetes. It is also not my intention to do so. These interviews were conducted as part of the first stage of an institutional ethnography that begins to identify trans-local social relations embedded in local experiences and practices. Secondly, the parents interviewed were recruited from support groups; they may differ in some significant way from parents who do not attend support groups. For example, parents who attend support groups have the time and resources to do so. Moreover, these parents are from middle class two-parent families and all had post-secondary education, they are more likely to have adequate social and material resources and literacy skills to engage in diabetes carework compared to parents who are differently positioned in society.

In conclusion, taking up worry as a form of emotion work makes visible parents' experience of worry as not automatically a sign of failure to cope or over-protection, rather the experience of worry is a useful tool for parents to assess their children's need, the circumstances they are in, and to care for and ensure the safety and well-being of their children with diabetes. As such, interventions that aim to decrease parental worry may not be helpful for parents. Moreover, parents in this study are already engaging in ways to

manage – contain or express – their worry and that of others. It is likely more useful for professionals – physicians, nurses, CCAC coordinators, teachers – to listen to parents express their worries and concerns, and the circumstances in which they experience worry, in order to better support them in understanding the relationship of their worry to their effective response to child’s diabetes care needs and in living with their child with diabetes.

CHAPTER FIVE

(Un)safe at school: Parents' work of securing nursing care and coordinating School Health Support Services for children with diabetes in Ontario schools.

Abstract

Using Institutional Ethnography and its approach to mapping institutional sequences (Smith, 2005; Turner, 2006), this paper examines the social organization of School Health Support Services (SHSS) for children with diabetes in Ontario schools. The inquiry starts with my own situated experience as a mother of a child with diabetes starting kindergarten, and the trouble of securing the health supports necessary to care for my child's health and safety while she is at school. The paper takes up two specific texts - the *Community Care Access Centre (CCAC) Referral Form* and the *CCAC Medical Orders for Services at School* - to explore and describe how I am drawn into the work of securing, advocating, and supporting the delivery of health support services for my child at school. The paper makes visible how the *CCAC Medical Orders for Services at School* is an authorized standardized text that stands in for and subdues parents' experiential knowledge of what is needed to ensure the safety of children with diabetes at school. While the public school system in Canada is formally committed to the equality of access to education for every child without discrimination irrespective of the child's health conditions and/ or disabilities (Canadian Charter of Rights and Freedoms, 1982), what is shown is how parents' voluntary and supplementary healthcare work and unauthorized knowledge is incorporated into the institutional complex of School Health Support Services and secures the safety of children with diabetes at school. Parents' work and

knowledge is essential for the institution of public schooling to operate as it does, and sustains the official ideal of equal and inclusive education for all. However, there is a difference on how and whether parents can deliver their knowledge and resources.

Introduction

Using institutional ethnography, this paper examines the social organization of School Health Support Services (SHSS) for children with Type 1 diabetes (henceforth referred to as diabetes) in Ontario Schools in Canada. My experience as a mother of a child with diabetes starting kindergarten (at age three years and 10 months) and the troubles I encountered in getting the care and attention to keep my child safe provides an entry point for examining how my work as a parent at the local level (the clinic, the home, and the child's school) is articulated to the policy of SHSS. This paper shows how my work as a parent and my knowledge of how to care for my child (though unauthorized) is incorporated into the institution of schooling and is subordinated to the SHSS policy and practices. What is shown is how my knowledge and my voluntary supplementary healthcare work at school is not only consequential for the safety of my child at school, it is also essential for the institution of public schooling to operate as it does and sustain the official ideal of an equal and inclusive education for all students.

In Canada, federal legislation (Canadian Charter of Rights and Freedoms, 1982) states every child has the right to education without discrimination irrespective of the child's health conditions and/ or disabilities. Public schools have the duty to provide

accommodations and health support services to ensure integration, full participation and inclusion of students with health conditions and/ or disabilities in the classroom. In Ontario, the SHSS program is responsible to deliver health supports for students with special health support needs during school hours. Despite these legal and institutional mandates, parents of children with diabetes consistently report troubles in getting school health supports for their children.

Diabetes is a chronic health condition that requires individuals with diabetes or their families to maintain a daily well-coordinated and intensive diabetes self-care routine. Lapses in this complex daily regimen can have devastating immediate as well as long-term consequences (Scheiner, 2004). Students with diabetes require supports in the school setting in order to access education and sustain their health while at school. These supports are particularly essential for students who have yet to master the knowledge and practical skills for checking blood sugar levels, injecting insulin, balancing the intake of insulin with food and exercise and the timing of these activities, and for interpreting the numbers associated with their blood sugar levels (Lange, Jackson, & Deeb, 2009). Many children are not able to perform these intensive diabetes self-care routines at school without the assistance and support of a knowledgeable adult (Nabors, Lehmkuhl, Christos, & Andreone, 2003).

How their child's diabetes, that is their child's health and well-being, is cared for at school is of concern for parents. Previous research has shown that many children with

diabetes and their parents feel that “dealing with diabetes in school is among the worst experiences they have faced while growing up” (Schwartz, Denham, Heh, Wapner, & Shubrook, 2010, p. 48). While Schwartz and colleagues (2010) indicate the need for improved support for children with diabetes at school, they take up a health services framework. The problem is constructed as a lack of adequate and up-to-date knowledge on diabetes in the school setting (Amillategui, Mora, Calle, & Giralt, 2009; Hayes-Bohn, Newmark-Stainer, Mellin, & Patterson, 2004; Schwartz et al, 2010; Siminerio & Koerbel, 2000). Conclusions point to the need for more education about diabetes and more resources to support school personnel and school nurses. Studies of this kind do not consider the complex social and institutional relations that shape care for students with diabetes, nor do they attend in detail to how actual practices (by teachers, nurses, parents) at the local level at school are articulated to policies and legislation developed elsewhere. To date, no empirical study has examined how the actual practices and the work organization of school supports for students with diabetes actually happens at schools in Ontario, Canada. Recognizing diabetes care/ school supports as actual practices and as work organization provides a different basis of investigation.

The theoretical framework for conducting an institutional ethnography

Institutional Ethnography (IE) is developed by Canadian sociologist Dorothy Smith, based on her work on the social organization of knowledge (Smith, 1990a, 1990b, 1999). Smith is interested in how knowledge and power are related, and how institutional forms of knowing become the authoritative knowledge subordinating all other ways of

knowing. Knowledge is a resource for ruling (Smith, 1990a). IE is uniquely designed to investigate the institutional organization of aspects of people's everyday life circumstances that perplex and concern them (McCoy, 2008). People's standpoints and experiences are taken up as the starting point of inquiry, that is, the inquiry starts from where people are as bodies in the actualities of their lives in actual situations and everyday activities (Diamond, 1986; Smith, 1987). The inquiry focuses on what people know as subjects of the actualities of their everyday experiences and then moves beyond the horizon of the local and routine experiences to explicate the extra-local relations embedded in their local experiences and practices (Smith, 1987, 2005). Smith refers to these forms of extra-local relations of large-scale coordination as "relations of ruling," (1987, p.2) and contends that the organization and coordination of local setting by extra-local relations is made possible through texts and textually mediated practices.

Drawing on my experience as a mother of a child with diabetes starting school, data for analysis include my journal documenting my experience, my ongoing voluntary work to ensure my child's health is taken care of at school and the conversations with healthcare professionals I have along the way, information from a parent's blog, two specific texts that are part of the process of requesting and securing adequate services: the *Community Care Access Centre (CCAC) referral form*, and the *CCAC Medical Orders for Services at School*, and one regulatory text: the *Ontario Government Policy/ Program Memorandum 81 (P/PM81)*. My experience as a parent of a child with diabetes provides an entry point for this inquiry. I do not intend to generalize my experience to represent

that of other parents of children with diabetes. Rather, the focus is on discovering the set of ruling relations that draws us all into participation, coordinating our work and grounding our experiences.

Institutional ethnographers pay particular attention to the notion of ‘work’, ‘work knowledge’ and ‘text’ when explicating the social organization of a specific institutional complex. In IE, work refers to what people do that requires some effort and some acquired competence (Smith, 1987). Work knowledge refers to people’s ordinary knowledge of their everyday doings in the institution (Smith, 2005), in this case, my ordinary knowledge of my doings in relation to the safety of my child at school, as well as physicians’, nurses’, and CCAC care coordinators’ ordinary knowledge of their doings. Text refers to words, images, or sounds that exist in a material form that carry messages and can be replicated and circulated in multiple sites (Smith, 2006; Smith & Turner, 2014). The institutional ethnographer investigates the actual practices of people in their actual work settings, including their practices with texts. Special attention is paid to the knowledge people draw on to read a text, how people take up texts and what they do with texts. The possibility of the replicability of a material text in different settings at different times and the “recognizable identity of a text from one site of activation to another is integral to the text’s distinctive form of coordinating ruling relations” (Smith & Turner, 2014, p.5). By mapping the actual sequences of work and texts in people’s accounts, and showing how their work processes and work organization are articulated from one setting to another, social relations can be mapped and explicated (Smith, 1987; Turner, 2003,

2006). This process of paying attention to people's doings, as they are called for by a text, is referred to as the "act-text-act" sequence (Smith, 2006, p.67). Smith (2006) uses the "act-text-act" (p.67) (work-text-work) sequence to illustrate the coordination of work activities from one site to the next through the competent activation of a text (for example, from the physician at the diabetes clinic to a CCAC care coordinator through the CCAC referral form). The text is embedded in a sequence of action: the work that went on before provides for the condition of work called for in the moment, and then what is going on in the moment is carried forward, and lays the ground for what happens next. In taking up texts and textual practices, the institutional ethnographer is looking at how texts draw people into relations and organize the work and activities they do for the institution.

I will begin by explaining from my experiential knowledge the actualities of caring for a child with diabetes. Then I outline some basic features of the SHSS program. I explicate how the competent activation of the *CCAC Referral Form*, and the *CCAC Medical Orders for Services at School* by the physician at the clinic and the CCAC care coordinator subordinates a mother's knowledge of the care her child needs at school, and draws her to participate in work that complements, and yet is subordinated to the institutional practices of the SHSS program.

Parent's experiential knowledge and work of caring for a child with diabetes

According to the *Clinical Practice Guidelines* of the Canadian Diabetes Association (2013), diabetes management for children involves blood glucose (BG) monitoring, BG and ketone testing, insulin administration and dosage adjustment, carbohydrate counting and nutrition, exercise, as well as prevention, detection, and treatment of hypoglycemia (Wherrett, Huot, Mitchell, & Pacaud, 2013). The treatment goal is to keep the child's blood glucose level within a normal range as much of the time as possible. To do so, I was instructed by the physician at the clinic to check my child's blood sugar level at least 6 times a day, and more as needed. The purpose is to avoid hyperglycemia and its well-documented long-term complications (including heart attack, stroke, kidney failure, blindness, amputation) while minimizing hypoglycemia to prevent seizures, poorer cognitive function in young children, and potential death (Wherrett et al, 2013; Yewchuk, Morrison, & Yewchuk, 2012).

What is listed above is what I was given and learned at the pediatric diabetes clinic at the time of my child's diagnosis at age 2 years and 4 months. However, the actual activities involved in monitoring and managing this illness is not nearly captured by such lists. The actual activities are more complex and require considerable flexibility. Caring for my child involves chasing after her and gripping her hand tightly to prick her finger (to draw the drop of blood required for testing her blood sugar levels), begging her to finish her food (so that she'd have adequate carbohydrates), and poking her with the insulin needle (in order to sustain the level of insulin in her body required for her health).

On average, I check her blood sugar level 7 to 10 times (every two hours) during the day using a glucometer that analyzes the drop of blood on a disposable test strip. I record these levels and the amount of insulin administered in a daily log book (that health professionals at the pediatric diabetes clinic examine during each follow up visit). While I developed a diabetes care routine specific to my child, the number of times and timing of checking her blood sugar varies depending on the activities she is involved in, and my knowledge of her embodied and emotional signals. I am constantly alert and attentive to her because I know from experience that she can be doing the same things, eating exactly the same food, receiving the same amount of insulin, but her blood sugar reading is 10mmol/L one day and 3mmol/L on another (checked at the same time of day). So, I puzzle constantly over the blood sugar readings in my daily log book, looking for patterns and associations of blood sugar levels with insulin dose, physical activities, sickness, stress, growth spurts, the temperature of the environment, amount, types, and timing of carbohydrate intake, and whatever else happening inside and around her body that will affect her blood sugar, much of which is not visible and cannot be monitored directly. I engage in this constant juggling in order to keep her blood sugar level within range to protect her current and future health and well-being. But even with very constant attention, my child still experiences fluctuating high and low blood sugar levels. Often (especially when I have made an insulin dose change, and/ or my child has had physical activity during late afternoon) I will check her blood sugar throughout the night to ensure her blood sugar level is within range. If her blood sugar level is low in the night, I can treat it (before she goes unconscious) and when it is too high, I can correct it with insulin.

In a nutshell, this complex intensive daily routine demands that I do the work of a pancreas and “think like a pancreas” all day and night, every day and night (Scheiner, 2004). The disjuncture between official accounts of diabetes management and the actualities of caring for a child with diabetes is illustrated in this quote at a parent’s blog:

[the blood sugar numbers] don’t tell the full story; they don’t even begin to tell the story of my sleepless nights. My perpetual brain fuzz from calculating carbs to insulin to activity to emotional state, 24/7 endlessly. The numbers don’t reflect the hours I spend trying to understand the complex relationship of type 1 diabetes and emotional health. The hours I spend connecting, reading, listening and social media’ing to understand, to learn learn learn. My guilt over having never achieved perfection. My tears over watching seizures from insulin shock or vomiting from ketones. (LuvLeaDlife, 2013, paras. 3-4)

Here, as in my own account, the numbers measuring a child’s blood sugar level stand in for how well the parent is performing diabetes management (from the perspective of the physician). These numbers abstract the work parents engage in to attempt to maintain a blood sugar level that is within range. I will return to this number/s and how it is worked up in an official account in the CCAC assessment to determine what type of care a child needs at school.

The School Health Support Services program in Ontario

The movements of deinstitutionalization, community integration and mainstreaming have resulted in an increasing number of children with chronic health conditions and/ or disabilities attending mainstream schools (Shiu, 2001; Thies, 1999). In response to the concern regarding the lack of health support services to school-age children, the Ontario government issued an *Intersectoral Policy/ Program Memorandum*

81 (P/PM 81) titled: Provision of Health Support Services in School Settings in 1984.

This is a Tri-ministry (Ministry of Health and Long-Term Care, Ministry of Education, and Ministry of Community and Social Services) agreement governing the health support services for school-aged children during school hours (Ontario Ministry of Education, 1984). The stated purpose for the implementation of this policy is to “ensure that, by 1985, no school-aged child should be denied access to education because of special health support needs during school hours” (Ontario Ministry of Education, 1984, para.8). Within the *P/PM 81*, it clearly states, “Responsibility for the direct provision of these services at the local level will be shared by the school boards, the Home Care Program (*the former CCAC*) of the Ministry of Health, and agencies operating under the Ministry of Community and Social Services” (Ontario Ministry of Education, 1984, p. 2, italics added).

The *P/PM81* is what Smith (2006) refers to as a “regulatory text” (p.79).

Regulatory texts are higher-order texts that “regulate and standardize texts that enter directly into the organization of work in multiple local settings” (Smith 2006, p.79). But for any text to be recognized as authoritative, it must have authorization from somebody, and this is shown at the beginning of the text: “Issued under the authority of the Deputy Minister of Education” (Ontario Ministry of Education, 1984, p.1). This tri-ministry agreement is situated in the Ministry of Education.

The regulatory text formulates an institutional process and a sequence of action for how health support services at school will be provided.

The Home Care Program (*the former CCAC*) of the Ministry of Health, at the request of a school board, will be responsible for assessing pupil needs, and for providing such services as injection of medication, catheterization, manual expression of the bladder, stoma care, postural drainage, suctioning and tube feeding. The Ministry of Health will also be responsible for intensive physio-occupational and speech therapy, and for assisting school boards in the training and direction of school board staff performing certain other support services The school boards will be responsible for the administration of oral medication where such medication has been prescribed for use during school hours. (Ontario Ministry of Education, 1984, italics added, p. 1).

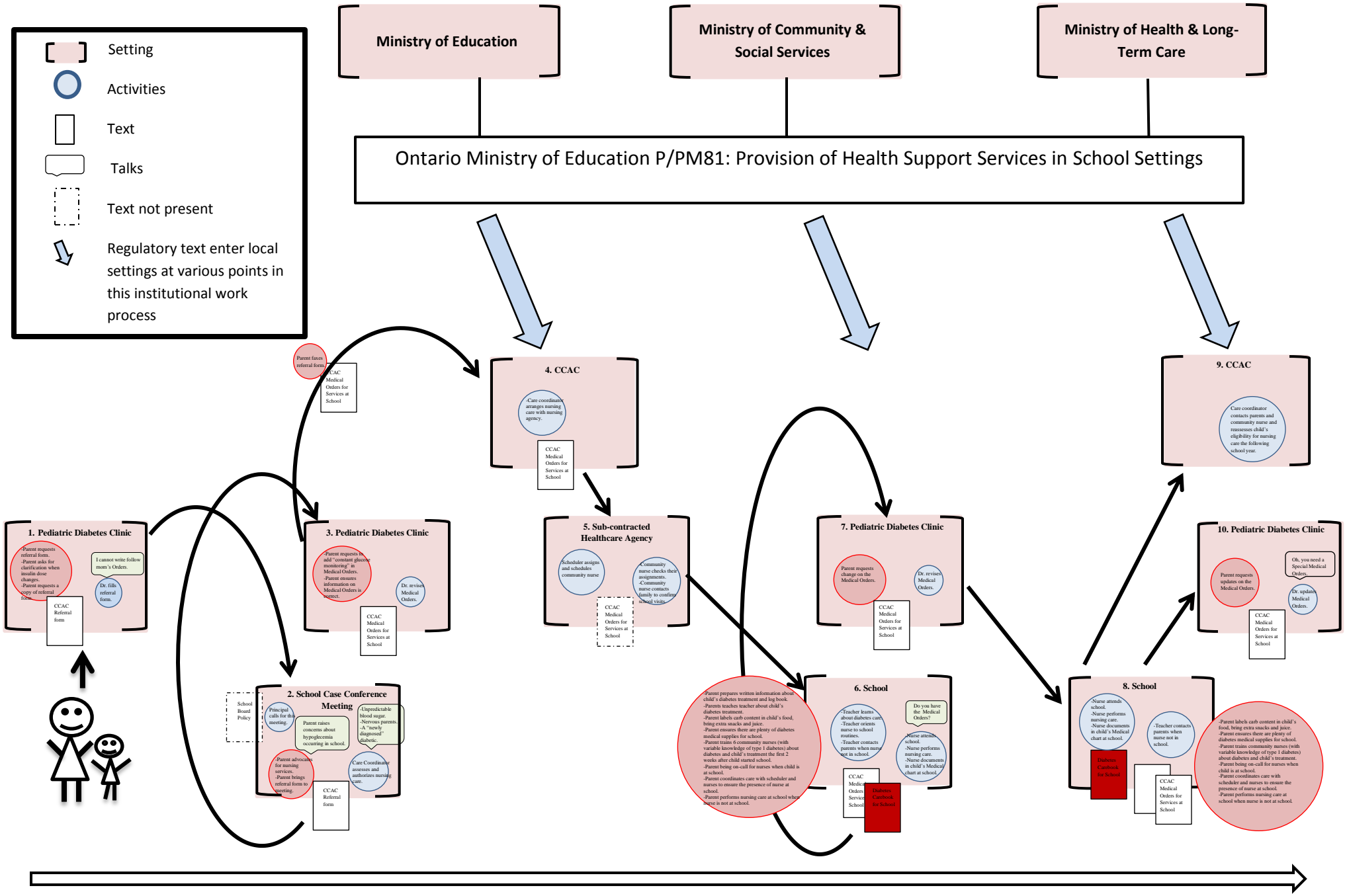
Locally, the school staff is responsible for making a request for service to administer oral medications when such medication is prescribed. In activating the request from school, the CCAC staff, specifically the CCAC care coordinator, will arrange to conduct an assessment of the student's needs at school. The exact way this assessment will be conducted or the criteria for eligibility for services are not clear from this text. Here, the work of the CCAC staff in conducting an assessment can be recognized as an expression or instance of a textually authorized procedure from a higher source of organization, independent of particular people (Smith, 2006). Within the CCAC SHSS program which is funded provincially by the Ministry of Health and Long-term Care through Local Health Integration Network (LHIN) (CCAC, 2014), the CCAC care coordinator is also responsible for coordinating the actual delivery of services provided by healthcare professionals hired by sub-contracted private healthcare agencies.

The organization of parent's work: Securing School Health Support Services, advocating for their adequacy, and supporting their delivery

Adopting Turner's (2003, 2006) approach to mapping institutional sequences, figure 1 is a map showing my work as a parent entering into the institutional complex of the organization of the SHSS policy and practices. I first offer an overview of this map, and then I elaborate each step in the sequence of action.

I entered the institutional complex at the site of the pediatric diabetes clinic (See site 1 in figure 1) when I requested health support services for my child at school. The services initially activated were significantly mismatched with both my own knowledge of what my child needed and the instruction I had received at the diabetes clinic. I was thus drawn into work that attempted to bring the school support services into alignment with my own (unauthorized) knowledge, and with knowledge embedded in diabetes care guidelines. The school case conference (See site 2 in figure 1) turned out to be a site where a parent can advocate for more nursing support, which I did. I learned here that a Medical Order for 'constant glucose monitoring' would activate 'shift nursing' at school. Even after securing this higher level of care I continued to be drawn into monitoring, supporting, and providing care for my child at school (See site 6 in figure 1). The red circles indicate my doings, without which the intended outcomes of the SHSS policy could not be accomplished. The black arrow looping back from site 2 to site 3 in figure 1 (as well as site 6 to site 7 in figure 1) indicates my return to a previous step in this institutional complex, a return that would not have been necessary had the directions on the Medical Orders had been matched with my own knowledge of my child's needs.

Figure 1: The organization of parent's work: Securing, Advocating and supporting the delivery of School Health Support Services



Time's arrow

In the following, my focus is on the work-text-work sequence coordinated through the *CCAC Referral Form* and the *CCAC Medical Orders for Services at School*, and explicates how the competent activation of these two texts formulates a distinctive relation between the physician at the clinic and the parent who is requesting services, and between the CCAC care coordinator and the parent. These two texts that the physician at the clinic filled out carry the intention of the policy at a particular CCAC, and enter into the local setting and mediate the activities of the physician, parent, and CCAC care coordinator. These texts are standardized for use for all students that will receive health support services in this CCAC. Standardization appears to be more efficient and fair in carrying out the work of the institution, but as I will show it leaves out some of the necessary diabetes care children need to stay safe at school. It is this objectification of diabetes carework that draws parents into doing work that will keep their children safe at school.

Parent is drawn into institutional processes to secure health support services

Returning to the point (see site 1 in figure 1 and figure 2) at which I approached the diabetes clinic for a referral for services at school for my child with diabetes who was about to start kindergarten, the following is an excerpt of the exchanges that occurred during that clinic visit:

Physician: How much insulin does she take now at lunchtime (without lifting his head, he flips through the medical file).

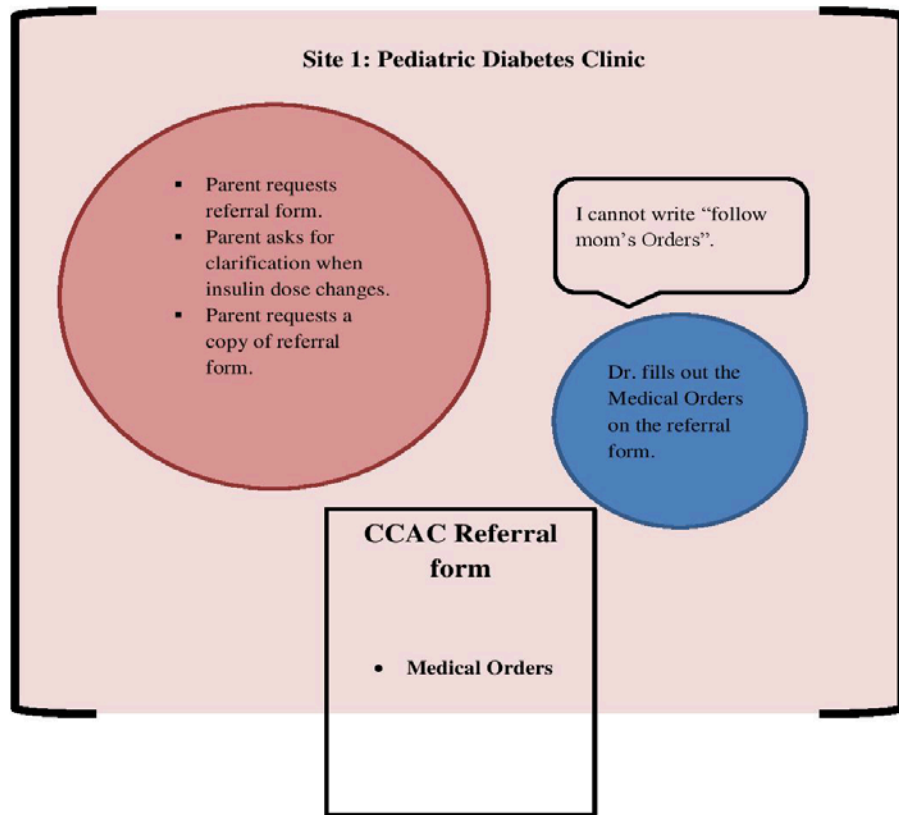
Mom: She takes 4 units of Humalog.

(Physician flipped through the file, and then he started writing on the referral form under the section: "Medical Orders". Noticing he wrote fixed dosages of insulin, the mother interjected).

Mom: But her insulin need changes, what happens when there is a need to change her insulin dose?

Physician: You have to come back and update the Medical Orders. I just can't write 'FOLLOW MOM'S ORDERS'.

Figure 2: Parent's Work at the Pediatric Diabetes Clinic



The physician filled out a copy of the CCAC referral form of “Standardized” Medical Orders during this visit. In the section Medical Orders, it reads,

(1) treat hypoglycemia (BG less than 4 mmol/L) as per Standard Guideline of Canadian Diabetes Association. (2) check BG at lunch. If BG less than 12.0, give 4 u of Humalog SC. If BG 12.1-17.0, give 4.5 u of Humalog SC. If BG > 17, give 5.0 u Humalog SC.

To many readers these Medical Orders likely appear well in keeping with standard care guidelines. Yet these Orders are very different from what parents are taught to do at the diabetes clinic, and different as well from parents' daily knowledge of how to ensure the health of their children with diabetes. Here is a line of fault, a disjuncture between two contradictory ways of knowing about the health support needed for a child with diabetes to stay safe at school: a parent's embodied experiential way of knowing, and the objective, institutionalized way of knowing taken up by the physician at the clinic through the *CCAC Referral Form*. In IE terms, this is the problematic, and the entry point to the inquiry.

Examining this work-text-work sequence we can see how the competent activation of this text by the physician subordinates both the mother's and the physician's knowledge of the type of supports a child needs to be safe at school. In activating this text that makes a referral for health support services at school, the physician is organized to write what is institutionally actionable under the CCAC SHSS program. The individual physician, of course, can include more nursing instructions on the Orders. However whether or not these additional instructions are actionable is already pre-determined by *P/PM81*, and it is the CACC care coordinator who is ultimately authorized to assess the needs of the student. Here, we see how the regulatory text enters into the local setting and organizes what happens there.

The Medical Orders written on this *CCAC Referral Form* warrants one community nursing visit during lunch hour. The Medical Orders make no mention of blood sugar checks during the day (except one, prior to lunch) and there is no mention of checking before and after physical activities (as parents know from experience that they must do, and is recommended by the clinic). There are no nursing instructions related to preventing low blood sugar levels occurring over the course of the school day. In addition, the ‘prior to lunch’ insulin injection is especially troubling for children who are not eager eaters. If children have not consumed sufficient carbohydrates and they are given insulin that is calculated based on the carbohydrate target of the meal, their blood sugar can drop rapidly; it is, thus, best to give insulin after lunch based on the amount of carbohydrates the child has actually eaten. These Medical Orders, in the timing of blood sugar checks and insulin injections, are not oriented to the shifting and particular bodily needs of children with diabetes. It does not carry the child’s best interests, rather it carries the interests of the SHSS program.

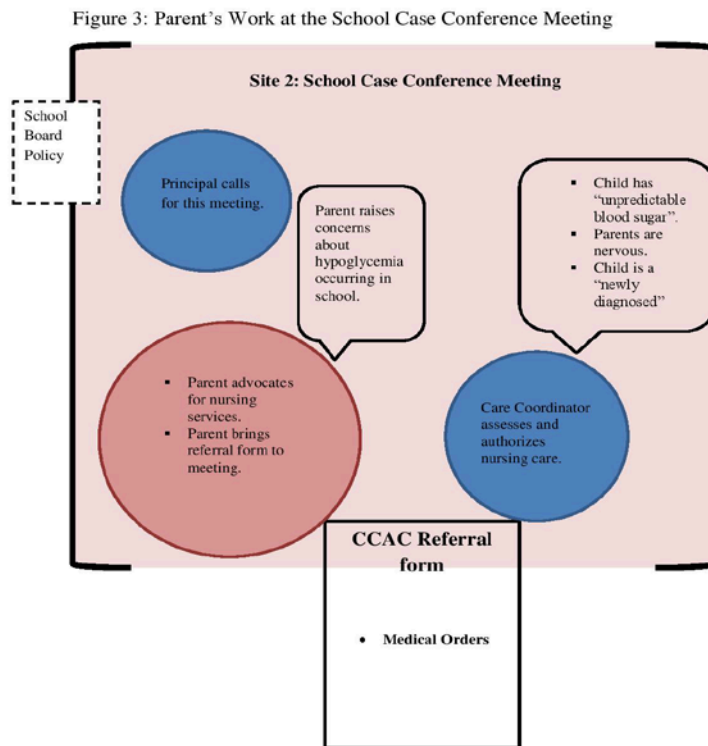
These Medical Orders also authorize a fixed amount of insulin. Yet parents are taught by the physician at the clinic to adjust the insulin dosage daily and know in an intimate way what amount of insulin is best for their children. However neither the mother, nor the nurse who actually provides the nursing care at school, are authorized to change the insulin dosage that the nurse would administer at school. Under the Regulated Health Professions Act (1991) and Nursing Act (1991) (as cited in College of Nurses of

Ontario, 2014), the community nurses (who are likely Registered Practical Nurses) can only initiate a controlled act (in this case, the administration of a substance by injection) when ordered through a physician. If the parent determines that a dosage change is needed, the parent needs to set up an appointment with the clinic (likely not able to have it on the day of phone call). The physician updates the Medical Orders, and then it will be faxed to the CCAC; a CCAC staff receives the Orders, and then faxes them to the sub-contracted nursing agency; the nursing agency staff receives the Orders and then faxes them to the community nurse at school. If the community nurse does not receive the updated Orders in time (which is very likely), the child will either receive the dosage from the old Medical Orders (which is the incorrect dosage for that day) or the parent must go to the school to give the new correct dosage. Here, what child needs does not align with the institutional processes of the SHSS program, and parent's complementary work must be incorporated if child is to be cared for well.

The complexity of this sequence of action raises important questions about the social circumstances of parents. The way this sequence of action is organized assumes that all parents have time and financial resources to make arrangements to attend clinic visits to update the Medical Orders and to be at school to monitor and facilitate care processes.

To secure adequate services, parent attempts to have her knowledge incorporated into the school-based care routines

Upon receiving a CCAC referral form from the diabetes clinic and/ or a request from a school staff, the CCAC care coordinator conducts an assessment of the student's needs. As mentioned previously, *P/PM 81* does not prescribe what an assessment entails, different experiences can be recognized as “assessing pupil needs”, for example, it can be a phone call to the parent. In my case, it was a meeting in the school (see site 2 in figure 1 and figure 3) involving school staff, CCAC care coordinators and the parents. This meeting recognized as “assessing pupil needs” in a course of action pre-determined by *P/PM 81* is crucial for the development of a care plan which specifies the type and amount of ‘nursing care’ a child will receive in school.



During this meeting, I raised my concerns about the high possibility of my child's blood sugar level dropping due to physical activities at school. I then described my usual diabetes care routine, which includes blood sugar checks a couple of times throughout the night to prevent hypoglycemia.

In activating the eligibility criteria for a particular service (which is unknown to parents), the CCAC care coordinator competently selected from the mother's talk what fits in the eligibility criteria, and assessed my child's blood sugar levels as "unpredictable" and the "child lacks awareness of hypoglycemia", and noted that "parents are nervous" with a "newly diagnosed diabetic."

With this assessment, and after reading my copy of the Medical Orders, the CCAC care coordinator instructed me to go back to the clinic to have the Medical Orders updated to include an instruction for 'constant glucose monitoring'. I later came to understand that the Order for 'constant glucose monitoring' would activate a particular arrangement of nursing services - 'shift nursing' - whereby a community nurse is present for the whole time the child is at school (a 'shift' from 9am to 3pm).

Inquiring into this instruction from the CCAC care coordinator, it starts to become clear that CCAC's authorization shapes what is institutionally actionable in a specific way. It is only with CCAC's authorization that the physician at the clinic can include 'constant glucose monitoring' on the Medical Orders. In turn, 'constant glucose

monitoring’ written on the Medical Order organizes what the community nurses can do at school. Without ‘constant glucose monitoring’ on the Medical Orders, the CCAC care coordinator could not move to the next step in the sequence of action of arranging for ‘shift nursing’ and provide the instructions whereby the community nurse can actually perform this ‘nursing task’.

Here is an instance of a routine work organization between the physician at the clinic and CCAC care coordinator through the work of the mother. We can see how the parents’ knowledge and practices are subordinated to the institutional requirements through the work of the CCAC care coordinator. Usual fluctuations in blood sugar level from parents’ knowledge have to be constructed as ‘unpredictable’ and worked up to fit into the official categories of the eligibility criteria in the CCAC assessment to secure ‘shift nursing’. Moreover, it shows the nature of the services a child can receive is not determined by the physician; rather, the CCAC has pre-defined actionable care plans. The CCAC (and not the physician) is authorized by the SHSS to determine the care plan. The ‘default’ plan is the standardized Medical Orders that I first received. It was through my advocacy and the CCAC care coordinator’s work in ‘assessment’ that my child received the ‘Special’ Medical Orders that included ‘constant glucose monitoring’ described above. Even though it is not unusual for children with diabetes to have fluctuating blood sugar levels, and the services I advocated for is what every child with diabetes needs to stay alive and well in school, yet not every child can get this level of service without someone doing the advocacy work. Here, what I do routinely to care for my child has to

be re-conceptualized administratively as ‘special’ care to warrant the allocation of adequate services. The Medical Orders, then, do not represent what a child needs to stay well at school, rather it represents what CCAC is able to authorize.

The SHSS policies and practices depend on parent's text-mediated voluntary work

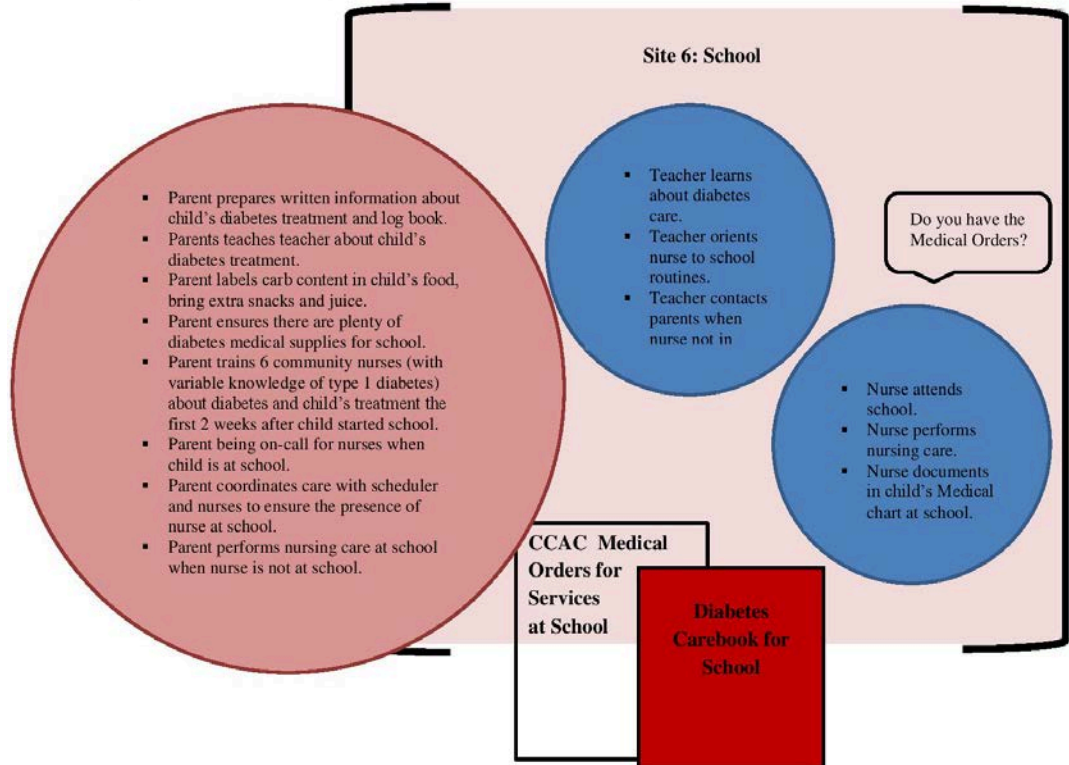
Once the CCAC care coordinator received the Medical Orders for ‘constant glucose monitoring’, ‘shift nursing’ can be arranged. Yet certain aspects of necessary diabetes care are still missing. For example, these Medical Orders do not specify the time in which the child needs a blood sugar check, or when she needs a snack. Moreover, it made no mention of glucagon, a life-saving hormone to be injected if the child becomes unconscious due to hypoglycemia (and that can save a child’s life or prevent any potential cognitive damage). Nor is there any mention of ketone testing and how to correct the dosage of insulin if the child has ketones.

From this mother’s standpoint, then, the Medical orders are inadequate to ensure the child’s safety at school. The problem for the mother becomes how to get her unauthorized knowledge included with respect to the child’s wellbeing. I resolved this problem by engaging in what I call ‘preparation work’ and ‘teaching work’. The preparation work involves assembling a binder of written information about diabetes and its treatment, such as, information on signs, symptoms and treatment of hyperglycemia and hypoglycemia, how to administer insulin, emergency glucagon administration, carbohydrates contents in food, parents’ contact information, a daily log for recording

blood sugar levels. I also include a daily care schedule (with timing of food, blood sugar checks and insulin injections). I have not however merely replicated the care schedule my child and I follow at home. Rather, I have sought out from the teacher a copy of the classroom timetable, and coordinated my child's daily diabetes care with the classroom schedules and routines. For example, I coordinated my child's snack time to match the nutrition break in school. I did this by modifying our usual home breakfast routine (changing the amount of carbohydrates she eats and the amount of her insulin dosage). My actions here make visible how local settings are organized and coordinated: my daily activities in my own home, the way I feed and care for my child, are coordinated by the extra-local relations of the SHSS policy and the institutional routine of the school.

Teaching work is conducted in the school (see site 6 in figure 1 and figure 4), I reviewed my child's diabetes routine with every community nurse, again in an effort to ensure that my own knowledge of how to care for her is incorporated into the institutional practices. Even though all the nurses are trained professionally as registered nurses or registered practical nurses (and thus possess the skills to perform a blood sugar test and to administer insulin), it is not necessary that every one of them are trained specifically about diabetes management for children. I've noted earlier the Medical Orders lack sufficient detail to guide adequate care in the local setting. I continue to be on-call for the community nurses' phone calls from school if they have any questions regarding my child's care.

Figure 4: Parent’s Everyday Diabetes Care Work at the School



The teaching work becomes more burdensome when there are multiple nurses involved in caring for the child. My child had six different community nurses during the first four weeks of school. The constant changes in nurses meant that I took time away from work to be available to provide training, and my child needed to get used to multiple different strangers performing intrusive nursing procedures on her. Here, one can see the way community nurses are scheduled to children assumes that the work, my child and the nurses are the same in the world of everyday experiences as it is known textually, that any nurse can be scheduled to do the ‘assignment’. In actuality, a new nurse does not have the knowledge of a particular child’s needs, and it takes a while to get used to the child and

their diabetes routine. And with a new nurse, I received more phone calls with inquiries about my child's care. There were times there was no community nurse at school due to scheduling issues, and I have to leave whatever I was doing and get to my child's school to perform the diabetes care my child needs to stay safe at school. The other option, of course, is for my child to stay home. Yet when my child stays at home, the mandate of the SHSS to ensure the full participation of students with health conditions is not met. I have shown it is my voluntary work and commitment as a parent that keeps the SHSS policy and practices working as they are supposed to operate.

Conclusion

Drawing on my experience as a mother whose child with diabetes is starting kindergarten, this paper explicates how the SHSS policy, and in particular its authorization of the CCAC to assess and coordinate care in schools for students with health conditions, enters into and organizes the work of the physician at the diabetes clinic and the work of parents. My experience is not unique. Rather, my experience as a parent is shaped by routine textual mediated practices of the CCAC SHSS program.

Figure 1 is the map showing the organization of a parent's work of securing, advocating and supporting the delivery of health support services necessary for a child with diabetes to stay safe at school, and is mediated by the *CCAC Referral Form* and the *CCAC Medical Orders for Services at School*. The official account from the CCAC SHSS program website claims that, "many students with complex health problems and

disabilities would not be able to attend school without the health supports that CCACs provide” (CCAC, 2014, para. 2). What I have shown here is the kind of work required of parents, and without the incorporation of parent’s voluntary complementary work and ‘unauthorized’ knowledge, the SHSS policy and practices will not ‘work’ in ensuring children with diabetes is safe at school. All of these efforts were intended to make sure that my own institutionally unauthorized knowledge of my child’s needs become effective for the organization of the delivery of services for her.

Not all parents can do this work like I did. The work of parenting for health at the school setting is coordinated with the work of the community nurses, and the work of teachers. The conditions and quality of the nurses’ work is partly dependent on the mother’s voluntary complementary work and knowledge, and when the nurse is not present in school, the teacher relies on the parent to be present at school to care for the child. However, this organization of work does not take into consideration the material conditions, practical skills and resources of parents’ lives, that is, whether or not their employment spares them the frequent absences or interruptions due to the need to train new nurses, or answering nurses’ phone calls when the nurse needs to clarify information about child’s care, whether or not it is feasible for parents to attend school every time there is a change in insulin dosage or when the nurse is not present at school. Even though the SHSS policy intends to ensure equity, it is actually only able to ‘work’ when parents’ voluntary supplementary work is incorporated into its service delivery practices and sites.

In this paper, I have identified the regulatory text, and explored what parents do to request and secure adequate services at school. Questions for further ethnographical inquiry are raised from here, for example how is nurses' work organized? How are teachers' work organized? And how are these coordinated with the work of parents to understand how support services for children with diabetes actually happen in the classroom.

CHAPTER SIX

The textual account of ‘quality’: Institutional technologies that coordinate the scheduling of community nursing for students with diabetes in Ontario schools

Abstract

Using institutional ethnography, this article explores the social organization of the scheduling of community nursing for students with diabetes in Ontario Schools. The entry points of inquiry are my experiences of having several different and differently qualified community nurses delivering care for my child with diabetes at school, and of being routinely drawn in myself to provide supplementary healthcare work. Exploration begins thus as problems arise in situations where ‘inconsistent’ community nursing care is being delivered. The exploration moves beyond the local setting of the school to the office of a community healthcare agency where service coordinators are working competently to ensure each *nursing visit* is fulfilled by a community nurse. The article shows how their scheduling work is coordinated extra-locally via the Community Care Access Centre (CCAC). In particular it brings into view how an institutional technology, the Client Health Related Information System (CHRIS), mediates the routine work of service coordinators in community healthcare agencies, and shapes the conditions for community nursing and the experience of students with diabetes and their families. Further, information gathered by CHRIS about *service offers* accepted and rejected by the agency, is taken up by the CCAC quality and financial officers to monitor, evaluate and determine the allocation of ‘market share’ to the agency. Managers at healthcare agencies are thus organized to accept service commitments for which they cannot always provide a

consistent nurse – directly affecting the quality of nursing care and the daily lives of children and families who rely on this care.

Introduction

Health Information technology or electronic health information systems are integrated, computer-assisted systems designed to enable the collection, storage, organization and sharing of comprehensive patient information among various healthcare providers across multiple settings (World Health Organization, 2005). These technologies are increasingly used in various health care settings and hold considerable promise to streamline the delivery of services and improve the efficiency and quality of healthcare (Stolee, Steeves, Glenny, & Filsinger, 2010). Despite its potential contributions, its implementation in various clinical settings is not without controversy (Aarts, Ash, & Berg, 2007). While they appear to be tools to simply manage information, researchers found the implementation of these technologies ascribes value to particular ways of knowing and privileges certain ways of representing what is to be known (Bar-Lev, 2015; Melon, White, & Rankin, 2013; Rankin, 2004; Rankin & Campbell, 2006). In turn, it mediates how healthcare professionals practice patient care, resulting in lower quality of care. In this article, I will examine an institutional technology used in the home care setting in Ontario, Canada. Even though, this tool is designed to enable the CCACs to administer integrated, quality, and continuity of care (Zvaniga, 2011), and my investigation shows the use of this technology mediates the routine work of healthcare

staff across various settings directly affecting the continuity and quality of care for children with diabetes.

Two incidents in the school

Arriving home, the phone was ringing as I enter the door. It is around 12:55pm. I rushed in to see who is calling. An unfamiliar name was shown on the caller display. By the time I reached the phone, it already hung up. The timing of the call alerted me to the likelihood of a nurse calling from my daughter's school. Another new nurse again I thought, there are so many new nurses I have lost count of the number of nurses that came to the school to provide care for my daughter. I hurriedly called back,

"Hello, this is Lok-Yi's mom."

"I am XXX, the nurse at school. Her blood sugar was 2.8, I gave her 2 dex tabs, and she is now at 4.1. I am NOW giving her insulin."

"Okay." (Thinking the nurse will now give insulin to match the carbohydrates for her lunch since her blood sugar level is now within normal range).

The same day after school, I checked her blood sugar level. It was 19.6mmol/L, which is extremely high. Confused, I took the pink binder (Lok-Yi's diabetes care book for school I created with all the necessary instructions to keep her alive and well at school), I read "hold insulin" written by the visiting nurse on the daily logbook. That explains why her blood sugar is high, but I thought the nurse said she is NOW giving her insulin. Moreover, it is clearly written in the Medical Orders which are in the binder and to be read by every visiting nurse to "administer 3.5 units of Humalog insulin subcutaneous at second nutrition break." Thus, "hold insulin" means the visiting nurse did not follow the Medical Orders and Lok-Yi was given the 'wrong' dose.

In the above story, the community nurse newly assigned to my child attends the nursing visit, has access to the Medical Orders, but apparently lacks the knowledge of how to care for my child and miscommunicates over the phone, so that the necessary nursing care to ensure my child's well-being and safety at school did not happen. From a parent's standpoint, the quality of nursing care is far from optimal. In another incident, a community nurse confirmed by phone she will provide care for my child the next day, then texted me on the following day that she has been "*scheduled to provide care for another patient.*" I've been frustrated by the unpredictability and uncertainty of the

quality of care caused by the frequent change of community nurses over the past five years since my child with diabetes started school. This change in community nurses and their unfamiliarity with my child's care results in frequent phone calls to me during nursing visits. 'Scheduling,' that prevents the community nurse from providing care to my child confirmed one day and changed the next, carries a clue for where to trace the incident's institutional organization. These experiences of community nursing for my child at school provided an entry point to explore the organization of the work of scheduling nursing visits, how this coordination provides the conditions for community nursing work, and, I suspect, what my child and I experience as 'inconsistent' and 'sub-optimal' care.

Conducting research using institutional ethnography

Institutional ethnography (IE) is an alternative way of conducting sociological research that is committed to discovering "how things are actually put together" and "how it works" (Smith, 2006, p. 1). IE differs from traditional sociological research in that the inquiry does not begin in theory: the abstract, conceptual organizations or relevances of institutional discourse, but from people's experiences, a standpoint outside of institutionalized discourses (Smith, 1987).

Positing an ontology that viewed the social as the concerting of people's activities, institutional ethnographers start the inquiry from where people are as bodies in the actualities of their lives in actual situations and everyday activities (Smith, 1999, 2005).

The inquiry does not stop at the local setting, rather it moves beyond the local setting to explicate the extra-local relations that enters into and shapes people's lives and their activities in the local setting (Smith, 1999, p. 96). Smith refers to this extra-local relations of large-scale coordination as "relations of ruling" (2005, p. 13). Texts, and what people do with texts are material forms of social relations (Smith, 2005). It is through paying attention to actual people's ongoing activities, their talk of how they go about doing their work, what knowledge they draw on, what texts are used to coordinate this work in relation to others across multiple sites within the institutional complex under study that provides traces where institutional ethnographers can map out the generalizing sets of ruling relations embedded in particular local experiences and practices.

This knowledge of how institutions are put together is invaluable as it expands people's knowledge of their everyday world and has the ability to empirically illustrate how people's everyday experiences are hooked into institutional relations and organizations such that people experience it as they do. It is a sociology that creates knowledge *for* people, rather than one that is merely *about* them (Smith, 2005). The ability to track back to how things are socially organized and how things work can make visible the inner workings of the institutional work processes and the consequences of such organization on people. Knowledge produced this way provides more concrete direction to assist in social change and social activism (G. Smith, 1990, 1995).

This article draws on data in personal journals documenting my experiences, seven formal interviews conducted with staff who are involved in different sequences of the institutional process in which community nursing is delivered to students with diabetes in the school setting (two interviews with community nurses, one interview with a scheduling supervisor, and one interview with a manager at a healthcare agency; two interviews with CCAC care coordinators and one interview with a CCAC manager), and examination of two institutional texts used by community nurses during nursing visits: the *CCAC Medical Orders for Services at School* and *Physician's Orders Record*. Ethical approval was obtained from the University Research Ethics Board and the interviews were conducted from September 2013 to June 2014.

The conditions and organization of community nursing work

In Ontario, the CCACs authorize and coordinate the provision of community nursing. Community nursing or 'Home Care' nurses deliver nursing care in people's homes, at school, in the workplace or in other community settings (Canadian Nurses Association, 2015). The majority of students with diabetes receive visiting nursing at school. My exploration of the organization of scheduling begins with visiting nurses' work. Here, a visiting nurse describes her work routine:

We get our work list the night before and I can see a list of who I am going to see, and if I don't know the person, then I will ask the other nurses [within our team] for report.....I will just say can I have a report on so and so, and then, if someone knows them, they will give me a brief little update, if it's a new admit, the office will tell me you have a new admission tomorrow, this is the information, I will get a copy of the referral from CCAC, I will get a copy of all the doctor's orders, hopefully they are filled out which sometimes they are not, sometimes you have to go chasing them down a little bit.

This visiting nurse's work day starts with checking the 'work list' on her Blackberry phone the night before. She explains the 'work list' is composed of nursing visits for adult and children patients in their homes and at school. The number of visits assigned to her varies each day depending on the existing patient *caseload* and new referrals from CCAC. The *caseload* can range from 7 to 14 visits. In the above quote, the visiting nurse pays attention to the familiarity of the patients' names when she receives the list, and the necessity of getting information about the care (including the doctor's orders) for the patient with an unrecognizable name. Here, she talks about asking for reports from other nurses on the team. Elsewhere, she tells me that she can review brief notes about a patient on her Blackberry and if reviewing the notes is sufficient, she might not need a *report*. And there are times a patient is put on her list last minute that she might not even have time to ask for a *report*.

The community nurse will also pay attention to whether or not she will have a 'new admit', that is, a new patient, on her list. With a new patient, the visiting nurse will have to conduct an initial assessment and will have to factor in more time when planning her work day. She will also need to ensure all the paper work is present to provide her details about what she will need to do during the visit, particularly the doctor's order, without which she cannot perform the actual tasks and duties that comprise the actualities of her *nursing care*.

From this nurse's description, the agency office will notify the nurse of a 'new admit', and also schedules the nursing visits whose specific tasks she must attend and perform. I later learned from this nurse that it is an administrative staff person, the service coordinator, in the office that is responsible for this work as well as for scheduling the nursing visits, and that the service coordinator does not require any nursing training as their main responsibility is to ensure all the patient visits are 'covered' by a visiting nurse.

Currently, this nurse has a school visit for a child with diabetes on her 'caseload' and she is the 'primary nurse'. This means that she is the primary person who will conduct the assessment and deliver the nursing visit for this child. The agency's care coordinator will also arrange for one or two 'secondary' nurses in case the primary nurse is off during the week or on vacation or sick. She added that "ideally" these are the nurses that will provide care for this child. However, in actuality, it doesn't always happen this way. The visiting nurse explains below that she is not always aware of the reasons behind how service coordinators schedule her 'work list' and there are times she will be scheduled by the service coordinator to provide care for another patient instead of her primary patients even though she preferred 'continuity'.

It's her [service coordinator] job to be consistent and to make sure that there's continuity in the staffing. Sometimes they don't. Sometimes, they just kind of pick; and it's unfortunate. And they will tell us one thing and they will tell the family another, that's the other thing. It's difficult. But it is preferable to have continuity.

Incident three

This next incident shows how I am drawn in to provide voluntary healthcare work when a new nurse is scheduled for my child. Here, my child is also drawn into participate in monitoring her own care.

Driving in my car to a meeting, my phone rang. I pulled over to the side of the road.

“Hello”

“Hi, this is AAA.” “I am the nurse at school. Your daughter’s blood sugar is 11.7, I want to give her 5 units more to correct it but she says no, don’t change it, my mommy will be very upset. The Doctor’s Order says to give her a correction dose.” (Did she just say 5 units? Oh gosh, I felt so glad that I had a conversation with my daughter about paying attention to what the nurses are doing and she is able to say something.)

“Yes, 11.7 is higher than her normal range, she does need a correction dose, but it is not 5 units. It’s 0.5 units more. 5 units will bring her blood sugar down by 50mmol/L. Her correction factor is 1 units per 10mmol/L.” (Fearing she didn’t understand me.) “That means you will give her a total of 4 units of Humalog.”

The nurse confirmed the dose, and hung up.

As I continued to drive to my meeting, I can’t help thinking whether or not she really did say 5 units. Did I mishear her? I can’t imagine what will happen to my child if she was given 5 extra units of insulin.

That night when I got home, my husband showed me the text the nurse send him that day, “Hi, Lok-Yi’s BS is 11.7 but she said not to give extra insulin. The sliding scale reads to admin an extra 5 units, is that ok?” This text confirmed that indeed she did say 5 units. But I still feel puzzled as to where she got that number. So I reviewed the nursing chart in school the next day and discovered that she got the number from the ‘Physician’s Orders Record’.

Had the nurse not called to confirm the insulin dosage, she might have given 5 extra units of insulin to my child and she likely would lose consciousness due to severe hypoglycemia. We might be tempted to understand the situation by blaming the visiting nurse for her individual carelessness in misreading the Doctor’s Order. Indeed, I later discovered the primary nurse wrote the nursing instructions by hand onto the ‘Physician’s Orders Record’ in the nursing chart at school [a chart separate from the binder I’d produced and in which the Doctor’s Orders are included]. The school’s chart reads, “*If BS is 10.1 – 15 Give extra .5u, If BS is 15.1 – 20 Give an extra 1u As per DrXXXXX.*” and the

new visiting nurse had mistaken .5 for 5 units. We can also understand these disturbing incidents as the effects of scheduling. If the primary nurse who conducted the admission assessment, with knowledge of my child's care was scheduled to provide care, I suspect the above incidents would not have happened. The nurse would know the accurate correction dose.

For the delivery of 'quality' nursing care – care that comes from knowing how to read the sensuous actualities of the patient and the finely tuned medical responses to her state – the visiting nurse needs to be familiar with the patients' care needs and the setting where care takes place. As the primary visiting nurse described above, she relies on the service coordinators to schedule her 'primary patients' onto her 'work list'.

The work of Agency service coordinators in scheduling nursing visits

When a referral comes over from CCAC, it just basically has the school that they go to, and the approximate times that they are requiring service. So at that time, base on geography and the number of staff we have in the area, we [service coordinators] look to see if we can accommodate that request, sometimes the outlying areas such as [rural location 1] [rural location 2] are a little bit more difficult to service.....Typically for pediatrics, we don't have a problem accommodating, so when the referral comes over, we accept it. At that time, we put the schedule in place in our system, we contact the school board as well as the parents to say this is what's happening, we are going to servicing. Typically we go out to do a home visit first and meet with the parents, just to go over policies and what we do. And obtain any medical orders and then services.....And then, at that point, we choose a nurse that, we assign a primary care nurse so our nurses don't necessarily work Monday to Friday, they have, they work alternate weekends, so they do get a day off during the week. Usually one per week, so that day, they have a partner that will see that student, so typically we try not to get anymore than two staff in there. When there are vacations, sometimes it is difficult, we do have to introduce another worker. Depending on the age of the child as well, especially the younger ones getting them comfortable with a nurse is really important, we do our best there.

From this scheduling supervisor of a healthcare agency, we see how service coordinators assemble the work list of visiting nurses, and what knowledge they draw on

to put together the scheduling of nursing visits. Above, she explains how the process of scheduling starts with a request/ referral for service from CCAC. She describes how, upon receiving the request, the service coordinator will decide whether or not to accept the request for service base on the timing of the visit, the location of the visit and the availability of nursing staff. Once the service request is accepted, the service coordinator will assign a primary nurse to the patient. 'Ideally' the primary nurse will conduct the 'admission' - gather all the information and paper work and assess the nature of the nursing care from the patient or parents in the case of children with diabetes, and the primary nurse will 'ideally' be the main person delivering the care. The service coordinator will also schedule another one or two nurses to the same patient (who will become familiar with the patient's care) to form a 'care team' who will as a team ensure 'continuity of care' for the patient.

With school visits for children with diabetes, the scheduling supervisor explains below how the service coordinator conducts the scheduling using the healthcare agency's computer system.

In our system we have a list of nurses, and it kind of, you can look at their day view, so it shows you what they have for the day. So, because pediatrics is so time specific, they take priority. So, what would happen is the pediatrics is scheduled first, and then, the other coordinator, so we stay ahead of our schedules, and typically with pediatric schedules, they don't change. Whereas adult clients, you know, if maybe they have wound care, they are not time specific, they can be seen at any time throughout the day.

The service coordinators will normally schedule the pediatric patients first since school visits for pediatric patients are 'time specific visits' meaning it has to happen at a specified time, and are considered a priority. In addition, she mentioned that in order to

maintain consistency of nursing staff for the pediatric patients, the service coordinators for pediatric patients need to ‘stay ahead’ on the scheduling, before the service coordinators for adult patients put in the adult nursing visits. Once the pediatric and adult patient visits are scheduled with a visiting nurse, their work is done. Then, the scheduled ‘work list’ will be accessed by the visiting nurses.

The visiting nurses and the scheduling supervisor I interviewed used the term “ideally” often. They know their work should or some sequence should happen in a particular way, however in actuality, their work happens differently. When I pointed out my observation of the use of the term “ideally”, the scheduling supervisor explained that ensuring each patient’s visits are “covered” by the same visiting nurse every time is not often achievable, since “there are many variables interfering with the schedules.”

The scheduling supervisor provided some reasons why nursing schedules change, for example, there may be an unpredictable influx of large numbers of requests for services from CCAC. The service coordinators will inform her and she will have to bring in contract staff and move around nursing staff to cover the influx of requests. Other times, a family or the school may request a change of nursing staff for a school visit, since all school visits happen more or less the same time, depending on how many school visits are in the area, there are limited staff to cover all the school visits. If there is a request to change nursing staff, another nurse with another child, regardless of their satisfaction with the care, will need to be pulled to cover the other school visit. And then, the school

schedules change from year to year, the nurse that was available last year at an earlier time may no longer be available to conduct the school visit this year at a different time.

As I listened to the scheduling supervisor explain the reasons behind how care coordinators schedule nursing visits, I could see that they are being pulled from different directions and how it will be challenging to schedule consistent nursing staff for any particular patient. Thinking it through afterwards and reviewing the interviews, the reasons given somehow still didn't answer how there comes to be *so many* different nurses providing care for my child, where 4 out of 5 days, it can be a new nurse every single day.

Again reviewing the interview transcripts, I discovered an intriguing exchange with the scheduling supervisor in the following portion of the transcript:

Scheduling supervisor: I'm always assuming it's going to be an hour visit. So I assume that first, and if I can't accommodate that, I would call CCAC at this point, sometimes they will call the mom and speak with the mother and call us back. Other times, they have permission from the parents to give us the contact information and I have to call the parents and have a conversation to say: what is it exactly we are doing in there, is she self-sufficient when it comes to eating her meal, and at that point, make a decision as far as whether we can accept or not, and sometimes we have to say no, I don't [accept the service request]. I can't say the last time when she [service coordinator] said a no to a pediatric referral.

Interviewer: Even though there might be a possibility [of saying 'no'], but it doesn't sound like it happens.

Scheduling supervisor: No, cause we do have casual staff as well. So for example, if maybe, we look at it, we can accept it, but every Thursday is really going to be a struggle just because of timed visits. We can say to a casual nurse, "would you commit to this client every Thursday?" And so, we are again, moving puzzle pieces and trying to figure it out.

Above, the scheduling supervisor was explaining how she and the service coordinators decide whether or not a request for service from CCAC will be accepted. At

times, this is not a straightforward process since the request for service contains limited information, the service coordinators need to find out more about the nature of the visit and what the nurse is required to do (which provides clues to how long the visit may be) in order to decide whether or not they can accommodate that visit (that is, can the nurse physically do the job requested and get to the next patient, and so on).

What was relevant to my concerns about ‘consistent’ care in this conversation is that the scheduling supervisor does not remember a pediatric referral being *declined*. While the healthcare agency has the option of *declining* a request for service, in the case of pediatric requests, in practice this rarely happens. The healthcare agency will accept the request for service and *cover* the care, even if it means calling on casual staff. Also, even if a casual nurse commits to being available for a particular nursing visit every Thursday, as in the above supervisor's example, it is understandable that the supervisor is “moving the (staff) puzzle pieces around and trying to figure it out” to get all the visits ‘covered’.

Later, I learned how rarely declining service requests is due to the particular contract arrangement the agency has made with the CCAC (my next trail to follow). Here, the scheduling supervisor provides clues and traces of how CCAC contracts enter into and textually mediate the scheduling work of service coordinators at the healthcare agency so that they are visibly accountable to the CCAC.

Client care and marketization in community healthcare

Community nursing in Ontario is currently provided by non-profit and private for-profit healthcare agencies that have contracts with the CCACs. While the delivery of community nursing has always been provided by non-profit agencies, the introduction of the “managed competition” model by the Ontario Progressive Conservative government in the 1990s opened up the delivery of home care to private for-profit organizations and brought in market and economic principles to organize community healthcare (Heitlinger, 2003). I learned from the healthcare agency manager that most of their business is from the contract they have with CCAC, with just a small percentage of clients that pay out of pocket. Before the managed competition model was shelved in 2008, there were huge turnovers both in nursing staff and healthcare agencies. When a healthcare agency loses out on a bid to provide services through the CCAC through the Request for Proposal (RFP) process, the agency would likely be unable to sustain its operation. In response to the outcry from these healthcare agencies, the RFP process was put to a halt. From then on, a healthcare agency that has contracts in place with CCAC continues to keep their contracts. Even though the managed competition model is no longer in use, the market and economic principles that were introduced at the time did not disappear. Here’s how the manager explains the current agency relation with CCAC:

The competitive model, I don’t think necessarily ensures quality at the end of the day. So now the model is, I am not sure whether they’ll ever go back to RFPs, but those that have contracts have contracts. They watch our metrics in terms of missed visits, events, the client satisfaction surveys. They make decisions, so in some areas where a provider hasn’t been doing well in all those metrics, it may affect their market share. So that’s how the CCAC kind of manages us going forward now, in terms of quality.

Having an existing contract with CCAC however, does not automatically guarantee stability of business for the agency. The CCACs have contracts with several healthcare agencies in a particular geographical region to deliver specific services. Each agency will have a particular percentage of ‘market share’ for that geographical area. Depending on the ‘quality’ of service the agency is providing, a healthcare agency can increase, decrease, or maintain its share of the market for that particular area. This is based on the result of that evaluation that measures agencies performance according to the specific ‘metrics’ used by the CCAC. The manager lists some of the items on the metric used by CCACs to evaluate ‘quality’: missed visits, decline of request for services, satisfaction of patients, and incident reports.

She also describes how the metrics produce a constant managerial dilemma faced by the healthcare agency:

So they measure us on that metric. So in terms of the amount of referrals we’re offered, how many we reject, so it is a metric for us. We try and say “no” very few times, right? But we also don’t want to say “yes” and not be able to provide the service. Like, if I say “yes” to a rural client and we don’t have anybody we can send out there, then we leave that client at risk. So that’s the challenge. That’s the push and the pull of it.

Two imperatives – to accept service offers, and to ensure that no nursing visit is missed – must be met if the agency desires to keep a higher score on the evaluation of the metrics, and consequently either keep or increase its ‘market share’. The solution is to accept the referral for service from CCAC and call upon the causal nursing staff to fill the nursing visits. However, from this analysis, we can see the organized practices of accepting requests for service that produce a solution for the healthcare agency will also produce the problems of ‘inconsistent nurses’ that I encountered with my daughter’s care

in school. Here, you can see how the managerial interests of the healthcare agency, their orientation to the ‘market share’ and the well-being of the agency’s business concert the work of the service coordinators into accepting service requests, employing casual workers, and scheduling nursing visits. This then shapes the kind and quality of care received by patients and their families. This is not to say that service coordinators only have money or profit on their mind when scheduling. They are still doing their central task of matching the most suitable nurse to the patient and trying to keep the primary nurse or primary team with the client as much as possible. But in times of high demand for nursing visits but low supply of nursing staff, when “push comes to shove,” ensuring that *all the nursing visits accepted are “covered”* by a visiting nurse, regardless of which nurse, takes precedence. It is not only good business for the healthcare agency to cover all the service offers it has accepted. This manager shows her orientation to the practical matter of producing the agency’s performance given the metrics. The metrics - as technologies of market ideology - mediate her work of overseeing the business of ‘doing client care’ at this healthcare agency via the directions she will give to the scheduling supervisor and service coordinators who provide community nurses’ visits:

Yes, it is all about client care, but at some point, we are not making any money doing this care. We are going to go out of business.....They [CCAC] have to understand the reality that, yes, we are in the business of caring for people, but we also can’t go out of business caring for people too, it’s that balance.

CHRIS: The institutional technology accounting for ‘quality’ and ‘performance’

We see from the healthcare agency manager’s description, how economic ideologies and measurement technologies enter into the everyday practicalities of her work managing the agency. In her talk, she emphasizes the consequences that arise for her

in her managerial role, of the tensions between maintaining the business of the agency by accepting referrals from CCAC for fear of losing market share, and putting clients at risk by not having enough nursing staff to deliver care. An aspect of this tension arises from different ways of knowing about “quality of care.” For this manager, what is “good client care” as she knows it as a professional nurse and “good client care” as she knows it as a manager who knows an external way of producing it from the evaluation measuring the agency’s work through the CCAC metrics for ‘quality’ and ‘performance’. Her everyday work knowledge includes how the evaluation of the healthcare agency through production of the metrics for the CCAC is key to whether or not her agency’s ‘market share’ will be maintained, increased or decreased. While the CCAC is watching the agency’s metrics, she, too, must be vigilant. She pays attention to her accountability to the CCAC. She keeps watch on how her healthcare agency fares on those metrics. She is careful not to “say no” too many times to CCAC requests for services.

From the standpoint of the CCAC, the contractual relation with agencies includes assessing and overseeing their work providing community care, and the client information system assists with those functions. In an interview with a CCAC manager, I learned how the CCAC does the ‘watching’ and comes to know the performance of the sub-contracted healthcare agencies. In the excerpt below, the CCAC manager describes how the Client Health Related Information system (CHRIS) used by the CCAC, allows them to automatically organize and manage referrals and contracts with sub-contracted healthcare agencies:

In our CHRIS program, our data base, when the care coordinator puts in a service offer it's sent to the agencies as an offer and it's up to them to accept it or reject it. They say yes I can take this service, no we can't provide that service. Right? That's all tracked as well as the number of times that they reject an offer. When the offer goes out, it is usually done by market share. Right because say in [city] here we have you know 2 agencies and they each get 50% right. So that means every other referral they would keep switching back and forth. CHRIS does that all automatically. In some areas we'll have one agency that has a 30% market share, another agency may have 60%, you know, and so it automatically keeps track of that and make sure that, "Okay, I sent this referral to [healthcare agency] last time, I'm sending it to [healthcare agency 2] this time. [Healthcare agency] has a higher contract so they get the one after that and [healthcare agency 3], you get the one after that because you have a lower thing [contract]. So CHRIS does all that according to market share. And it's up to the agencies you know if they accept it or reject it. And that is tracked, that is logged and if we end up with an agency that, you know, rejects 90% of the offers we're sending over, yep the quality people will say let's have a talk about this. What's going on here?"

The CHRIS program is a province-wide Web-based business and patient management system designed and built by the Ontario Association of Community Care Access Centres (OACCAC) in consultation with the 14 CCACs and deployed in 2010. The OACCAC hired a consultant with a background in enterprise-wide Web-based business application to create a "combined Enterprise Resource Planning system and Customer Relation Management system" (Zvaniga, 2011, p.23) to introduce and implement a business model into CCACs. The application of this system enables CCACs to efficiently and easily gather, coordinate, store, share, and access client health records, as well as connect them with diverse healthcare providers. The developers of the CHRIS system made a commitment to build a software that would "drive productivity and success, and enable Ontario CCACs to deliver quality, streamlined, safe and timely patient care" (OACCAC, n.d.) with the least possible cost, as well as facilitate unity and standardization of community healthcare (Zvaniga, 2011). There are four core components in CHRIS: Case management, service provisioning, financial management and reporting (Zvaniga, 2011).

In the above interview excerpt, the CCAC manager describes how the CHRIS program is used to automatically coordinate the work of the CCAC care coordinators with the work of the healthcare agency service coordinators, and subsequently with the work of the CCAC quality and financial officers. The CCAC care coordinator conducts the assessment of each new patient or ‘client’. In the case of a child with diabetes this included a meeting with the family and information obtained at the meeting is put in the database at that time using the case management component (Zvaniga, 2011). Once the assessment is complete, the CHRIS program will automatically and electronically choose the provider of care based on the assessment and the matching algorithm (already pre-set in the system with information about the contracts and market shares of the different healthcare agencies, the region they serve, and the services they provide), and sends out a request for services to the provider. This is the ‘service provisioning’ component of the system. The service coordinator at the healthcare agency connected to the service provisioning component of the CHRIS system will receive the request on their end, and will either accept or decline the request. The CHRIS program automatically tracks the number of offered, accepted and declined visits of the healthcare agency. In turn, this information will be connected to the ‘financial management’ component of the system to facilitate payment to the healthcare agencies. It is also connected to the ‘reporting’ component of the CHRIS program and generates reports about the ‘quality’ and ‘performance’ of the healthcare agency which, as this CCAC manager points out, is used by the CCACs’ quality and financial officers to discuss and determine a rating and the

market share assigned to the agency. As well, CHRIS also fits the Ministry of Health financial and statistical reporting requirements, and can efficiently generate reports in an automatic fashion for the ministry. As such, the ministry has all the statistics they need “to know exactly what’s going on with the funds and more importantly with the health of Ontarians” at their fingertips (Zvaniga, 2011, p.54).

Here, we see the development of the CHRIS program made possible the coordination of different people’s work in multiple sites – at the healthcare agency, the CCACs, and various sites of care (in this case, my daughter’s school). We also see how people’s work is ruled electronically. A person in need of care is assessed and different dimensions of their needs are written up by the CCAC care coordinator as a number in a particular type of service visit and entered into the CHRIS program by the same CCAC care coordinator or her administrative staff at CCAC. Once entered, the individual and all their particular and unique human needs are translated into a standardized form of client information, and the coordinator creates an offer (of an opportunity to work) for the healthcare agency. Under the CHRIS software, the matching work the agency needs to do is done. But, what matters when the information recorded is used by the CCAC to see ‘what’s going on,’ is simply whether or not the service offer sent to the healthcare agency is being accepted or not. The acceptance or rejection ‘move’ by the agency manager itself that is part of her matching client to nurse, is automatically recorded in the CHRIS program and later used to assess the healthcare agency’s ‘performance’ and ‘quality’ of service. The CHRIS does not record why an offer for a visit is declined. It does not have

the capacity to recognize the local conditions of managers who are matching clients to nurses and putting together ‘good client care’. It cannot see where there are inadequate nursing resources and the kind of managerial effort that try to sustain ‘quality’ nursing care. Even though it is up to the healthcare agency whether they accept or reject the service offer, it is clear from the interview with the healthcare agency manager that in actuality it is unlikely that she will decline offers given the very real consequential loss of the local market share of CCAC contracts for the agency.

While the healthcare agency manager described other measures on the metrics such as incident reports (events) and client satisfaction surveys, it is unclear from this manager if or how these would be entered into the CHRIS program; if indeed the information is entered, it is not assigned as much significance by managers who orient primarily to the quality metrics of accepting clients. The CHRIS program introduces specific criteria for a measure of ‘quality’ - accepting service offers - into how CCACs conduct their business with healthcare agencies. This version of ‘quality’ generated by the CHRIS program has an entirely different empirical ground from a version of quality that would operate among families, parents, patients. For example, this latter version would involve expectations of the local agency taking stock and doing a responsible assessment of the agency’s capacity to provide the service to the individual patient well. In the case of providing a “consistent” nurse who has knowledge on how to care for the individual – young child, diabetic, with fluctuating blood sugar levels during school hours – this would mean a regular nurse who knows the patient and can adequately make judgements

about what is needed right at the point of care. The marketization of community health care, however, with its institutional CHRIS technology produces adverse coordinating effects in the everyday work and lives of staff in local agencies, and on my child and me. While the CHRIS program promises to facilitate efficient, quality care with the least possible cost, what is not accounted for in this accounting system is the worry, time and labour costs involved in how the responsibility for ‘quality care’ is assigned to parents (as in the case of children needing care at school), and other family caregivers and patients in the community.

Conclusion

This paper examines the social organization of nursing work via close examination of the scheduling of nursing visits for students with diabetes requiring nursing care at school. The inquiry starts with my experience of the lack of a consistent nurse for my daughter in school, and how that draws me in to provide supplementary voluntary healthcare work and the need for me to have increasingly skilled knowledge of diabetes care for children, without which adequate, life-ensuring care will often not be delivered to my child. From my puzzlement over the frequent changes in visiting nurses, we explored from three incidents how my child’s care at school is shaped by the organization of the work of community nurses. We learned how visiting nurses' work in the community is coordinated with the scheduling work done by service coordinators at the healthcare agencies, and then, how this scheduling work and the work of CCAC care coordinators and financial officers is organized through the “core components” of the

CHRIS program. The CHRIS, the institutional technology that mediates the work of all these workers in the institution of community nursing and connects it to ‘clients’, carries the economic and financial interests of the institution and mediates the work of the service coordinators through measuring the quality of care as the number of visits being accepted and delivered by the healthcare agency. The knowledge built in CHRIS, in particular of the number of visits accepted by an agency, is used to determine the market share of each individual community healthcare agency. This way of knowing ‘quality’ contrasts with my knowledge of quality of care known experientially. My analysis shows that what I experienced, as the ‘suboptimal’ care received by my child, is a property of the marketization of community healthcare enacted by using this institutional technology of ruling.

It is no wonder that my daughter (who was seven at the time) decided to put her health in her own hands. In our discussion of her transition to using insulin pump therapy, she expressed her own grasp of the situation:

“Mommy, if I practiced how to use the insulin pump, maybe I don’t need a nurse next year.”

“Why don’t you want a nurse?” I asked.

“I don’t trust them. I only trust [name of primary nurse]. When it is the other nurses, I feel scared, I feel that they are going to do something wrong.”

Her desire to learn to use the pump is a result of her own experiences of the nursing care she receives at school. She wants to avoid having to depend on a care provider who cannot be counted on to keep her safe and to release herself from the worry of mistakes being made and the potentially dangerous, even fatal, consequences. While

the CHRIS technology may indeed, assist CCACs to deliver efficient, quality care with the least possible cost, what we see here is how the everyday conditions for agencies who must produce those efficiencies and ‘cover’ care by scheduling nursing visits, in the actuality of my child’s life what is also produced is the costs she and I bear on a daily basis to maintain her health.

CHAPTER SEVEN

‘Teach, reduce and discharge’: Community nurses’ textual production of ‘independence’ and the coordination of discharge from home care services

Abstract

Over the past three decades, the Canadian healthcare system has undergone significant reform and restructuring. As a result, healthcare and healthcare costs are relocated from hospitals to the community (McGregor, 2001). Text-based technology is increasingly used to standardize care and contain healthcare spending. This paper examines an example of a text-based technology used in the School Health Support Services programme for students with diabetes in Ontario, Canada. Using institutional ethnography, the inquiry starts with parents’ concerns regarding the premature termination of nursing care for their children with diabetes at school. The exploration shows how these parents’ concerns are hooked into the institutional work of assessment for service discharge conducted by the Community Care Access Centre (CCAC) care coordinators. The analysis shows how the institutional category of ‘independence’ coordinates the service discharge work of the CCAC care coordinators with that of the nursing work of community nurses at school. The activation of the category of ‘independence’ by the nurses mediates their work, orienting their focus away from providing direct nursing care, and towards transferring primary care to children with diabetes. Children doing diabetes self-care work at school is then written up in nursing texts to stand in for children’s ability to manage diabetes ‘independently’. The textual production of ‘independence’ enables the next institutional course of action, that is, the

discharge of children from nursing services at school. In this process, children with diabetes are drawn into doing the discharge work that ultimately serves the cost-containment interests of the institution. This institutional process also functions to obscure important actualities: It obscures how children's 'independence' is co-created on a daily basis with their parents and relies on their parents' work, and it discounts the significance of children with diabetes coming to their own embodied and emotional readiness for diabetes self-care.

Introduction: The Reorganization of Home Care

Over the past three decades, the Canadian healthcare system has undergone significant reform and restructuring. Private-sector business strategies and management ideologies were introduced into the Canadian public healthcare system in the mid-1990s in the name of cost-containment, efficiency and productivity (Browne, 2000). In a separate but related trend, text-based technology has been increasingly used to standardize care and manage healthcare expenditures. In addition, through advancements in medical technology, the movement of deinstitutionalization and community integration, more and more children and adults with chronic health conditions are being cared for in the community, which has further increased the demand for home-based care.

Unlike hospital and physician care that is universal under the Canadian Health Care Act, home care has never been mandated as part of universally insured health services. In 1996, after the passage of the Canadian Health and Social Transfer, the

federal government withdrew from the former federal/ provincial role of cost-sharing and monitoring (Aronson & Neysmith, 2006; Aronson, Denton, & Zeytinoglu, 2004), and because home care is not protected by the Canada Health Care Act (1984), it is often an easy target for funding cutbacks.

In Ontario, a series of reforms were implemented in home care under the conservative government. The Community Care Access Centres (CCACs), which are autonomous non-profit incorporated organizations, were introduced. Their mandate is to provide a single point of access to manage and coordinate long-term care and home care services. Unlike the previous home care programme, the CCACs have no direct responsibility to provide services; instead, they are assigned the role to assess and determine clients' eligibility for services and to monitor clients' progress. In effect, the CCACs became the purchasers and administrators of care, instead of providers of care. At the same time, the 'managed competition' model, a market-based system of selecting service providers and allocating funds, was introduced to better manage the cost, quality and efficiency of home care (Browne, 2000). To further control healthcare costs, the government imposed a capped budget on the CCACs' home care spending, establishing eligibility and the maximum amount of nursing, home-making and personal support services an individual could access (Abelson, Tedford Gold, Woodward, O'Connor, & Hutchison, 2004; Randall & Williams, 2006). Instead of containing costs, these reforms relocated healthcare and healthcare costs from hospitals to the community (McGregor, 2001). Costs were also shifted from the public sphere to private households, with women

providing significant unpaid labour (Armstrong, Amaratunga, Bernier, Grant, Pederson, & Willson, 2001). Since 2006, CCAC programmes have been funded through the regional Local Health Integration Networks (LHINs), instead of directly by the Ontario Ministry of Health and Long-term Care.

Little is known about the effects of home care restructuring on the lives of children with disabilities and complex chronic health conditions and their families (Peter, Spalding, Kenny, Conrad, McKeever, & Macfarlane, 2007), and there are no studies specific to children with diabetes. This paper draws on data from an institutional ethnography that examines the social organization of the CCAC School Health Support Services (SHSS) programme for children with diabetes in Ontario Schools. This inquiry starts with parents' concerns regarding the premature termination of nursing care at school for their children with diabetes, and traces these concerns to text-based technology used in the CCAC SHSS programme. The exploration makes visible how parents' concerns are articulated to the policy of the SHSS, particularly to the budget, and hooked into the institutional work of assessment for service discharge conducted by CCAC care coordinators. This paper shows how a specific text, *Diabetes Checklist for Independence*, provides the conceptual categories that coordinate the service discharge work of CCAC care coordinators with the nursing work of community nurses at schools. In this inquiry, I show how the everyday stresses and actualities of parents' work of supporting their children's ability and readiness to do diabetes self-care is subordinated to the textual account of 'independence' within the institutional discourse. A manager at healthcare

agency A articulates the discourse succinctly: ‘Our goal is to teach and reduce and discharge patients and encourage them to be as independent as possible.’

Institutional Ethnography

Drawing on Smith’s (1990, 2005), Smith and Turner’s (2014) and Griffiths and Smith’s (2014) work on the social organization of knowledge and institutional ethnography, this paper explicates how the CCAC assessment for service discharge is socially organized such that children with diabetes become their own primary carers at school, and parents are left, as one mother said, ‘panic stricken’ about their children’s safety. The inquiry starts with the experiences of parents of children with diabetes, and explores the social relations that enter into- and shape their experiences and the experiences of their children in the local setting of the school. Since the social relations are not simply located in the local setting, they are not entirely discoverable within the local site (Smith, 2005). The inquiry thus moves beyond the local setting to extra-local settings (the healthcare agency and the CCAC) to discover what shapes and coordinates parents’ and children’s local experiences and practices (Smith, 2005).

Smith (1987) defines social relations as the “concerted sequences or courses of action”, both in and across multiple sites, involving the activities of people who do not necessarily know each other (p. 155). She contends that the form of social organization in contemporary society is made possible through texts. Text-based

technologies are the essential coordinator of institutional processes, and it is through investigating people's actual practices with texts in their actual work settings, as well as tracing how their work processes and work organization are articulated from one setting to those of others, that social relations can be mapped and explicated (Smith, 1987; Smith & Turner, 2014; Turner, 2003, 2006).

This paper draws on my personal experience as a mother of a child with diabetes, my journals (documenting my conversations with community nurses, CCAC care coordinators, teachers, in addition to what I did and continue to do to ensure my child is safe and well while at school), interviews with seven parents of children with diabetes recruited from a parent support group, and 11 interviews with staff from four healthcare agencies (three community nurses, one clinical educator, two nursing supervisors, one scheduling supervisor and one manager) and staff from one CCAC (two care coordinators and one CCAC manager).

The parent interviews were conducted first to refine the focus of the research project. The parents (five mothers and two fathers) were from seven two-parent middle-class families; two of the families had more than one child with diabetes. They were asked general questions about their caregiving experiences, such as daily routines of diabetes care, rewards, challenges, and what they found helpful and unhelpful in the process. While they expressed how caring for a child with diabetes was demanding, all parents described that it was most challenging when their child

was left in the care of someone else, particularly when they were at school for an extended period of time. Joy, a parent of a five-year-old child with diabetes explains: “You can’t just, ‘I’m off to school, see you [in a lighthearted voice].’ The diabetes follows him to school, it’s not just in our home.” This is especially challenging for parents of young children when their children have many years away from mastering the knowledge and practical skills of the complex regimen of diabetes self-care.

I developed the focus of this research based on my own extensive experience and what I was learning from talking with doctors, nurses, teachers and other parents. In-depth interviews with parents helped to develop and refine the research problematic. I interviewed one of the parents a second time to further explore her experiences of negotiating and advocating for adequate nursing care for her children at school. The interviews quoted below were chosen because the children were diagnosed at a young age (before age nine), and parents were drawn to participate in the concrete institutional processes to request and secure nursing care for their children. The experiences in the parent interviews are not used to generalize a representation of the experiences of all parents of children with diabetes. Rather, their experiences, like mine, provide an entry point for inquiry. Their experiences interface with the institutional complex of school health support services and point to the social relations to be explored, as well as a variety of agents differently located in the institutional work process that I needed to talk to in order to

understand the complex of relations embedded in local practices. I then interviewed the nurses and the CCAC care coordinators. After that, I traced upwards and talked to the managers of healthcare agencies and of the CCAC. The experiences of the other four parents were not included in this paper because they had a limited encounter with the CCAC. Their children were diagnosed at an older age and were able to perform the diabetes self-care routines; additionally, these parents have the financial security to make themselves available to care for their children at school by seeking part-time- or no employment.

While the social organization of service discharge was not entirely discoverable in the interviews with parents, it became clear in the interviews with CCAC and healthcare agency staff that the institutional category, ‘independence’, and the CCAC mandate, ‘to teach, reduce and discharge’, are essential in coordinating the work of assessment for service discharge between nurses and CCAC care coordinators. The specific institutional texts, *Diabetes Checklist for Independence*, *Diabetes Independence Assessment Tool*, *Nursing Update*, referenced in the interviews with staff at the CCAC and healthcare agency, are also incorporated into this research. Categories and concepts carried in institutional texts are central to the coordinative practices of all the workers in the social relations of the institution. Institutional texts are authoritative, and govern what is institutionally actionable. Here, the notion of an ‘institutional circuit’ (Griffiths & Smith, 2014, p. 12) is useful as an investigative device. It orients the researcher’s attention to

sequences of action where people are at work producing a textual representation from the actualities that fits into an authoritative text, thus enabling the next course of action mandated by the governing institutional text. In what follows, I will show how events in the ordinary world of parents and children with diabetes are reconceptualized within the institutional category of ‘independence’, and worked up into a documentary reality that accomplishes service discharge.

Research Problematic

In Ontario, under the SHSS programme, CCAC care coordinators assess the ‘eligibility’ of children with diabetes for nursing services at school. However, the services for which children are initially deemed eligible do not remain constant throughout the child’s schooling. In periodic reassessments, parents whose children receive nursing supports at school are faced with the possibility that nursing care might be terminated, which can generate tremendous worry for parents. For example, in my interviews, Brenda, the mother of a six-year-old child with diabetes, describes herself as ‘panic stricken’ at the possibility that her child would not have nursing support for the next school year. Brenda explains:

When we brought the nurse in, I was really, really worried about how we were going to manage at school. Just panic stricken. How is this going to work, [sigh] so we had the nurse come out, and she would watch [name of child] take her blood sugar and add up her food because still that’s the biggest problem, she’s six years old. So, I, she can’t reliably say that sandwich is 34 grams [carbs] and that strawberries are 8 grams [carbs] and she can’t add it up. And, be accurate [laughed] and that’s very important, so the nurse adds up for her. She does her button pushing, and boluses for herself. I don’t know, I don’t think we are going to have a nurse next year, because besides from the adding, she doesn’t need any support, she reliably does all the other, all the other parts. We need somebody to, like I said, do that adding, and somebody to make sure that what she’s pushing in matches the number that is just added up.

At the time of the interview, Brenda's daughter was attending grade 1. She had been diagnosed with diabetes 10 months prior. The child has a nurse visit the school during lunchtime to monitor the child's administration of insulin through the insulin pump, and to ensure that the amount of carbohydrates taken matches the insulin dose given. It is essential that these match: If the child enters an incorrect carbohydrate amount, she will receive an incorrect dosage of insulin. If she receives too much insulin, she will be at risk of fainting due to severe low blood sugar levels; if she receives too little, she will experience extreme thirst (dehydration) and the possibility of future health complications due to severe high blood sugar levels. The presence of a nurse to double check the amount of carbohydrates the child is entering into the pump has assured the mother that her child's health will be protected. The possibility that the nurse will not be present in the upcoming year has made Brenda afraid that something might go horribly wrong.

From Brenda's standpoint and knowledge, nursing support is necessary to keep her child safe while at school. After all, having the ability to literally read what is on the insulin pump and the skills to press buttons on the pump does not automatically mean the child will also have the level of mathematical skills and diabetes knowledge required to read the number on the pump, and to be able to add up all of the carbohydrates in the lunch accurately so as to deliver the correct amount of insulin. Here, reading the number is a complex skill (Darville, 2014; Turner, 2014). Pushing buttons is a fine motor skill, while the calculating is a cognitive skill. In addition, there is the skill of being careful,

focused and unhurried in the process of entering the numbers, which perhaps falls into the realm of maturity. We can see that even though this child can ‘reliably’ do all the other parts of diabetes self-care (such as blood sugar testing and pushing buttons on the pump) which require fine motor skills, this mother knows her child is lacking the cognitive skills and maturity due to her age and perhaps also simply due to the sort of child she is, as she still needs some sort of supervision or support to care for her health well at school. Also, and perhaps crucial to the mother’s assessment, is her knowledge that both high and low blood sugar levels can affect the child’s judgement in reading the screen of the insulin pump correctly, and her ability to actually carry out the necessary diabetes self-care tasks.

In another interview, Kylie, the mother of a teenager with diabetes, shares a similar concern regarding the premature termination of nursing care at school and the troubles she experienced when the CCAC staff attempted to discharge her child when he was not yet capable of managing his diabetes care on his own. At the time of the interview, her son was 14 and had not received nursing services at school for the previous three years. He was diagnosed with diabetes at the age of two years. When he started kindergarten at age four, he received three nursing visits per day during school hours. The mother describes these nursing visits as “a bottom line for safety”. Her conviction that the visits were necessary rested on an incident when her child was in kindergarten. She received a call from the nurse that her child had fallen into a coma due to an extremely low blood sugar level. The mother later learned that the nurse arrived at the school to find the child slumped over in a chair in the principal’s office. He had been there for an hour.

His lethargic behaviour, a sign of low blood sugar, was mistaken as misbehaviour. He continued to have three nursing visits until the age of eight or nine. As the boy grew older, his need for nursing was brought into question:

Probably around, it could have been grade 1, but probably the really big push to us (from CCAC) that you need this was around nine years old. Probably around, it could have been grade 1, but probably the really big push to us that 'you need this' was around nine years old. So he would have been in grade 2 or 3. Yea grade 3 I think. And he was nowhere near ready because given the chance he will not do any diabetes care. In fact, yesterday he didn't check his blood once at school, and he's like 14.

In the above excerpt, Kylie describes the CCAC's staff's certainty that nursing care should end as being at odds with her knowledge of her child's (lack of) readiness to take on this responsibility alone at school. She knows her child will not perform the necessary life-saving diabetes self-care tasks reliably, and requires adult supervision to be safe at school. Kylie faces a different challenge; her child has the skills to manage the pump, but he resists performing diabetes self-care. To ensure her child is safe at school, she describes that she had to fight really hard to sustain nursing visits to ensure her son performs the necessary diabetes self-care. In grade 4, the nursing visits were reduced to once a day. The next school year, Kylie recounts the same conversation with the CCAC:

Grade 5, they (CCAC) said 'you can't have the nurse anymore.' And then the teacher brought in the teachers' union 'cause she was saying, 'I'm an educator, I'm not a nurse and I don't do diabetes care.' So and I was saying, 'Ok well I can't have him in school without somebody taking some level of responsibility for what's happening with him.' And again, the principal and the teachers' union came in and advocated that the CCAC needed to continue nursing. So they continued.

With the advocacy of the teacher, the child continued to have one nursing visit a day for grade 5. The next year, despite the endocrinologist at the pediatric diabetes clinic insisting that the child needed nursing care due to his often out of range blood sugar

levels, the CCAC declined to make nursing visits available. By this time, Kylie was tired of advocating, and the child expressed being more ready to manage diabetes with the help of a new school principal who was willing to supervise him. Kylie suspects that it is not the child's medical needs, but rather the intentions of the CCAC, that determines whether or not a child is deemed eligible for nursing care:

I was like, 'How can you pull the nursing when the doctor is saying you have to have nursing?' [The CCAC care coordinator said], 'Well, what they don't know they don't need to know,' or something like that and also, 'You know the hospital doctor is not responsible or doesn't make the decisions for the CCAC. He's not in charge of who I authorize nursing for and I'm not authorizing nursing.' I was like oh. To me it was like a lot of what was going on behind the scenes with the restructuring of CCAC.

In the different parents' comments, we see traces of the social relations that shape their concerns about adequate nursing care. We also see how institutional rationales insert themselves into parents' talk and understandings. For example, Brenda says: "*I don't think we are going to have a nurse next year, because besides from the adding, she doesn't need any support, she reliably does all the other, all the other parts...*" Here, Brenda's own knowledge of what supports her child's needs is erased by the institutional knowing that the child "does not need any support". Appearing to be more aware of the CCAC's imperative, Kylie engages with the institutional process differently, as she is drawn into participating in the service discharge work sequence by performing advocacy work. From both of their experiences, a disjuncture between two contradictory ways of knowing about children's ability and readiness to care for their health at school is identified: the parents' way of knowing, and the institutionalized way of knowing taken up by the CCAC care coordinators.

Parent's Knowledge of the Child's Ability and Readiness to Engage in Diabetes

Self-care

Diabetes is a very complicated chronic health condition. As a parent with a child with diabetes, I consider the treatment regimen for keeping my child alive (medically known as 'managing' diabetes) equally complicated. I have written elsewhere (Watt, 2015) that there is a disjuncture between official accounts of diabetes management and the actualities of my experience of caring for my child with diabetes. According to the *Clinical Practice Guidelines* of the Canadian Diabetes Association, the official account of diabetes management involves blood glucose (BG) monitoring, BG and ketone testing, insulin administration and dosage adjustment, carbohydrate counting and nutrition and exercise, as well as the prevention, detection and treatment of hypoglycemia (Wherrett, Huot, Mitchell, & Pacaud, 2013). The actual activities involved in 'monitoring' and 'managing' this illness are far more complex and not nearly captured on this list. The actual activities involved in caring for my child and keeping her alive and well require advanced mathematic, analytic, data collection, trouble-shooting, tracking and time management skills, the ability to focus, anticipate, plan ahead and lots of 'hoping for the best'. Dr. Stephen Ponder (2015), a physician and diabetic, notes that even though diabetes self-care routines are taught as constants, they are at best only estimates (p. 63). Unfortunately, nothing is predictable about diabetes management. It is not the type of treatment that guarantees good results if you follow a standard procedure; you can do the same thing on two separate days and the blood sugar readings will be different. There are a myriad of factors that interfere with the management of diabetes, from the temperature

of the skin when insulin is injected to how the body breaks down and absorbs food, the level of physical activities, sickness, stress and growth spurts (Ponder, 2015).

Parents interviewed in this study share similar experiences in managing their children's diabetes. All of them describe learning the diabetes management regimen as stated in the *Clinical Practice Guidelines* at the pediatric diabetes clinic. Even though the initial learning was steep and overwhelming, they eventually established diabetes management routines and became more at ease with 'managing' diabetes. Yet as parents consistently point out, strictly following the diabetes management regimen as prescribed at the clinic is inadequate to keep their children's blood sugar levels within range. Achieving this optimal glycemic control decreases the risks of the development and severity of future microvascular and neurological complications (Diabetes Control and Complications Trial Research Group, 1994). Parents describe seeking other information on how to manage their children's diabetes through reading books, reading information from selective reliable websites, attending support groups and talking with other more experienced parents of children with diabetes. They learn to adjust the regimen based on how the child responds to the treatment changes as indicated by the blood sugar reading.

Brenda explains:

A lot is just mothering. If it's too high, if it's too low, you know you need to fix it, and we did that really quickly. Almost as soon as we're not going to get into trouble [laugh] for doing it when she's safe again. We just sort of took over.....we change bolus rates, we change, like carb ratio, we change her basal rates based on what her numbers are telling us, we don't wait for our three-month appointment to resolve things. I'm not going to have a doctor telling me that, 'Oh no, you have to wait for this.' If I am not sure what I am doing, then I am going to wait, but when you know how to adjust your basal, we know how to test to see if it's working, we know how to check to see if it's her boluses that are off, so we can do that. If I am having trouble, I'll ask, but in most cases, I go to books or the internet and that's my main source.

The above excerpt shows that Brenda is knowledgeable in ‘managing’ her child’s diabetes. Here, she reflects on the importance of learning how to do diabetes management for her child. She wants to prevent her child from experiencing extensive periods of high or low blood sugar levels that can have detrimental short- and long-term health implications, so she takes it upon herself to learn a more sophisticated set of skills for responding to the specific conditions her child faces. While healthcare professionals have medical knowledge about diabetes and diabetes management, they do not know how a particular child responds to diabetes treatment. On the other hand, parents who manage their child’s diabetes every day know from repeated experience and embodied watchful attention the effects of diabetes treatment on their child, and have become experts in ‘managing’ their particular child’s diabetes. Kylie explains:

He would still have seizures and that he had a lot of lows or he would have these like highs or at a certain point I caught on to the fact that the more aggressive I was with trying to get his blood sugar low the more we would bounce back and forth from really low to really high. And so I had decided, they told me to do this, but I’m not going to do it that fast I’m going to do it a lot slower, so I increased the insulin a lot more slowly than they had asked me to do at the clinic. But what I was getting was yea an overall too high number, but I wasn’t going like this ping ponging kind of. Now once I explained myself about why I had chosen to do that it did feel like there was some understanding and not like, ‘Oh that’s really wrong.’

Here, she describes how she uses her knowledge obtained from day-to-day care and attention to decide on the best treatment option for her child. The clinic aims for the treatment goal of a tighter A1C, also known as “glycosylated hemoglobin”, which is an indicator for optimal glycemic control. It is a test that provides results for an overall blood sugar average for approximately the past two or three months, and is associated with better long-term health outcomes (Scheiner, 2004). She is well aware of the clinic’s goal,

and it is also her goal, but her management routine also takes into account her child's emotional well-being (compromised by sharp fluctuations in BG levels), as well as the risk of seizures that she knows is also linked with a sudden sharp drop in BG and severe hypoglycemia. She has learned from experience that one of the challenges in 'managing' her child's diabetes is linked with his anxiety and anger. Like Kylie, Brenda emphasizes the importance of paying attention to the emotional aspects of living with diabetes:

Not only the medical decisions but the messages that I am giving her, what's sort of not, what am I telling her, am I making her ashamed, am I making her feel like it's something she needs to hide, do I make her embarrassed when she has to do things in public, what sort of body images am I creating for her, those I worry about that too. Yeah, I struggle with how much information do I give her, obviously if she's old enough I'll give her any sort of information about possible consequences down the road, but it's that, you know, at what point do we start talking about, 'If you don't do these things, this is what could happen.'

As is apparent from the parents' accounts, there is much more involved in 'managing' diabetes than simply poking fingers, inserting needles or pressing buttons on a pump. Parents interviewed in this study draw on the knowledge they learned from the clinic, books, the internet and parent support groups, as well as their daily work of tracking, data collecting and experiential knowledge, to decide the best treatment for the overall well-being of their children. In addition to their children's medical needs and immediate well-being, parents are mindful of their children's emotions and the long-term effects of living with a chronic condition. They are cautious about how much information to share with their children and when to share it. Their understandings of whether their child is ready to take on diabetes self-care take into account not only the child's ability to understand and perform diabetes self-care in a technical sense. Parents also orient themselves to the child's personalities and social needs. For example, my daughter who is

eight years old, living in the moment and fitting in with her peers, often takes precedence over ‘required’ tasks. Even though my daughter knows how to check her blood sugar and knows she needs to finish all the food in her lunch, and does finish all her food most of the time, there are times (not often, thank goodness!) that she will throw out her food in order to go out for recess at the same time as her friends, or she just does not feel like checking her blood sugar levels. Sometimes, she will not check her blood sugar, even when she feels weak (and she knows this is a sign that she might be experiencing low blood sugar levels), because she does not want to feel different or miss out on having fun with friends. Or she simply forgets because she is pre-occupied with whatever interests her at the moment, as children and young people (and adults) often are. Just as importantly, the child’s maturity and emotional readiness is crucial, not only in the present, but also to lessen the possibility of the child’s future emotional problems and resistance to diabetes self-care (a significant and well-established problem) (Delamater, 2009; Follansbee, 1989; Helgeson, Reynolds, Siminerio, Escobar, & Becker, 2008). Each child is unique, so from the different parents’ standpoints it is not possible to pre-determine or standardize when children *should* take on the responsibility for diabetes self-care.

The Textual Production of ‘Independence’

Taking up the institutional perspective, the CCAC and nursing staff orient themselves to a different way of understanding when a child can ‘manage’ their diabetes. In my interviews with the CCAC care coordinators, I learned that ‘service discharge’ or

‘discharge planning’ is integral to their work of assessment. This is how one CCAC care coordinator I interviewed describes this routine work process:

In the summertime, I go over all of the children who are diabetic and have nursing in school and look at whether or not they have progressed. And sometimes by the age of eight, a child is pretty well able to do things on their own with someone just looking over their shoulder to make sure they’re doing it ok. It is a process. And if they’re not ready that’s fine, but by about eight maybe nine they’re able to do it on their own and so they don’t need nursing.

Here, this CCAC care coordinator describes how her work entails paying attention to when the school year begins, as this is when she will review the list of children with diabetes requiring nursing. The age of the child, eight, orients this CCAC care coordinator to activate a work sequence that prompts her to consider service discharge. Even though she initially indicates that it is ‘fine’ if a child is not ready at age eight, her awareness of the actuality that some children might not be ready at age eight is very quickly subordinated to the institutional imperative and pre-determined timeline to conduct a timely discharge: by the age of eight or ‘maybe nine’, as she says that children are “able to do it on their own.” Another CCAC care coordinator I interviewed explains her understanding of the mandate of the CCAC as it relates to school supports for children with diabetes:

The budget doesn’t influence our decisions, but we do have to be aware that if a child has three visits a day, we are looking at \$150 a day everyday five days a week maybe till that child is in grade 3 or 4 cause our goal is independence, our goal isn’t stability. That is the goal of the parent to work with the clinic and the physician, and then, you know, do the best they can with the information that they have, to have that child do well. Our goal is to have them do well, but also to be able to check their own blood sugar and to be able to give themselves insulin using the insulin pen, or to be able to operate their pump.

Even though this CCAC care coordinator does not directly speak of service discharge, we can see how the ‘goal of independence’ stands in for a discharge process:

The goal is not for the child to be independent ‘as a person’, but rather to be independent of these specific nursing services. Even though she emphasizes that the budget does not influence decisions, we can see how an awareness of the costs of the service is built into the rejection of stability (that is, ongoing services), a clarity that ongoing services are in violation of the institutional mandate. The goal of ‘independence’ carries the intention of the institution to ensure children are independent of nursing services by grade 3 or 4, which is around the age of eight and nine. Both CCAC care coordinators see a sequence of work ending with the termination of services at a pre-determined timeline.

The care coordinator went on to explain how she comes to know whether the child is ‘independent’:

I would expect also that the nurse will keep me up to date, we do have a checklist for independence, it’s not a standardized form but it’s a form that the nursing agency can change, and they can tick off..... that is the *Diabetes Checklist for Independence*.

The above accounts reflect the work these workers do in a sequence of action in the institutional course of action of conducting an assessment for service discharge. The *Diabetes Checklist for Independence* is the operating text, and the category, ‘independence’ within this text organizes how the CCAC care coordinator monitors whether or not a child can be discharged from services. As stated on the *Diabetes Checklist for Independence*, meeting the ‘criteria for independence’ enables service discharge to occur:

Once the student has successfully completed the Checklist, meeting the criteria for independence, the nurse is to contact the PDEC (Pediatric Diabetes Education Centre) and case manager to review the service plan and outcomes. If the student is independent, he will be discharged from the CCAC.

This document provides the institutional conceptualization of ‘independence’: It involves the capacity to perform specific diabetes management tasks, such as blood sugar checking, recognizing low blood sugar and administering insulin (see Appendix C). In addition, we see the coordination of the work of the nurse from the healthcare agency at the local level of the school with the service discharge work of the CCAC care coordinator at the CCAC office through this specific text, the *Diabetes Checklist for Independence*. The CCAC care coordinator is not present at the school. She does not come into direct contact with the child with diabetes; rather, she relies on the nurse at the front-line to report on the child’s progress. The *nursing update* (in an oral and/or written format) produced by the front-line nurse at school stands in for whether or not the child is actually able to care for his or her diabetes independently at school. The CCAC care coordinator knows the child through the *nursing update*. When the *nursing update* indicates the child is ‘independent’, then the CCAC care coordinator can move on to discharging the child from the CCAC services.

Although the *Diabetes Checklist for Independence* is not a standardized form across Ontario, I have discovered during this research that the discourse of ‘independence’ is widely circulated among healthcare agencies. A nursing manager I interviewed at Healthcare Agency A uses another version of the checklist, the *Diabetes Independence Assessment Tool*, among her team. The manager of Healthcare Agency B reveals the shared understanding of the work of promoting ‘independence’:

But really, we should be teaching kids to be as independent as possible as early as possible. Any child over grade 3 that's still getting nursing in, what does that say to the child? 'I am sick, I need a nurse, I can't manage this on my own,' so it's a whole philosophy I am a nurse by background, and from a philosophical integrity point of view, I don't feel right putting service in where we should be promoting independence.

In this passage, another form of knowledge about independence is brought to bear.

Whereas earlier, the child's independence hooks into an institutional discourse of cost containment, here the child's independence is linked with discourses about well-being and autonomy for people with chronic illness. Yet much of the nursing knowledge about chronic illness relates to working with adults with chronic illness, and places a considerable emphasis on the embodied and emotional process of people with chronic illness coming to readiness to handle the often complex medical regimens of their own illness. Here, a specific chronological marker – grade 3 – appears again. We can see, then, how nursing knowledge about the subjective actualities of chronic illness is subsumed to institutional benchmarks.

The following quote spoken by the same healthcare agency manager shows how the necessity for children with diabetes to build lifelong responsibly patterned self-care behaviours is also hooked into- and shaped by the institutional conditions of tight nursing resources:

I've seen young adults in their 20s and still not managing their diabetes well and then, now they are going to get into health issues because, maybe they have social issues at home, and this is a great way to get, play those social issues off. Or to get attention or you know, all of those other things where people do things to harm themselves right. So you see that if you don't do it early, and give them the correct messages early on, that they can lead to lifelong pattern behaviours that aren't healthy for the child. The other piece is nursing is fairly, they are tight resources in the community, so I know our scheduler you talked to, she will get frustrated. I have got to send this nurse every day to this child and he should be independent, and now I've got this child, now I've got to find somebody else for her, we could switch the

resources over, right. Move, you're independent, you are now discharged to self-care, you know, congratulations, fantastic, if you ever need us in the future, we can come back in, but *you should be discharged to self-care, so we can now use our resources over here.* (emphasis added)

We see above how the institutionally pre-determined timeline, and the knowledge of tight nursing resources, mediates what this manager knows regarding when children *should* manage their diabetes on their own and end nursing services. She takes up her nursing knowledge to underscore the importance of giving children correct messages about diabetes self-management to justify the service cut-off timeline. Here, the language used in promoting well-being and autonomy for people with chronic illness merges with the managerial discourse about the responsible use of limited nursing resources. My interviews with the nurses also showed the prevalence of the institutional imperative to help promote 'independence'.

A nurse from Healthcare Agency B describes more generally how her role is to guide, teach, watch and help, and eventually to get clients/families to be 'independent' in doing their own care. When I asked what informs her approach in working with children with diabetes, she explains:

It's actually the CCAC's mandate that the visiting nursing role in the home is to teach and reduce visits, to reduce nursing visits. We teach the client as much as we can and decrease the frequency of nursing visits. Say for wound care, it's easier if the dressing is required to be changed every day. Maybe for the first three, four, five days, the nurse may come and do it for that many days, and then, the patient or family members or somebody should be learning how to do that wound care, so instead of the nurse coming in every day, we will come every two days With the kids, with the diabetes at school, it doesn't quite work out that way where the nurses reduce the frequency of visits, you know, you are not going to say we are going to come on Monday but not on Tuesday, but then we will come on Wednesday. For the school visits, we're more reducing what we are actually doing for the child. So we will still be going to come from September to June every day, but maybe in September I was checking your blood sugar and telling you to record in your logbook, and I was drawing up your insulin for you, but hopefully by June you know how to check your own blood sugar now. And you'll

remember that you have to write it in your logbook, and you know that you need to eat your carbs and you know that you have to draw up your insulin and this is where I am going to give it. So our role is to teach them to be independent with doing this.

She explains at agency staff meetings that the senior staff asserts time and time again that their role is to ‘teach and reduce visits’. Indeed, our interview was saturated with language about her routine everyday work of transferring the primary care of children with diabetes to the children themselves. In activating the CCAC’s mandate and the category, ‘independence’, her work of providing direct nursing care to children with diabetes is reorganized to doing work to reduce the child’s dependence on nursing care. A related part of her role is to collect data that will construct her *nursing update* on the child’s ‘independence’ level to the CCAC. Once the nurse sees that a child can successfully check her blood sugar, record the number in the logbook, treat hypoglycemia, draw and give themselves the right amount of insulin and eat all the carbohydrates in the meals, the nurse can competently select from the actuality of the child’s doings to fit into the criteria for ‘independence’, and produce a textual representation via a checklist of the child as ‘independent’ in doing all the diabetes self-management routines at school. The textual production of a child as ‘independent’ in the *nursing update* and *Checklist* to the CCAC enables the next institutional course of action to follow. Upon receiving such an *update*, the CCAC care coordinator can deem this child to no longer be in need of nursing supports, and can terminate nursing services. This completes the ‘institutional circuit’ (Griffiths & Smith, 2014, p. 12) and an institutional sequence of action (Smith, 2006; Turner, 2003, 2006).

The following account shows the work this nurse does in producing a textual account of the child as ‘independent’. We see how both the child and the parent are drawn into a pre-determined timeline to accomplish ‘service discharge’ for this particular child. When I asked this nurse if she makes the decision or recommendation to discharge the child from the services, she insisted that it is a joint decision with the parent:

It’s a *joint* decision, usually for myself; I will say to the parents, ‘He is doing really great with doing all of this diabetes management, you know, just wanted to prepare you for maybe you know discharging the nurses.’ Usually, *we sort of pick at Christmas break or at the end of June. I like to start that discussion with the parents usually a few months in advance* and say how do you feel about that, you know eventually the nurses will stop coming when do you feel that that is appropriate for your child, and this is what your child is doing at school, and they don’t need me, they don’t even talk to me hardly anymore, I walk in, they do everything and then they are done. So, it’s not something that I will ever just say to the parents like we are not coming. (emphasis added)

In the nurse’s explanation, we can see how she engages parents in a conversation to plan for discharge and how it would be exactly in a conversation like this that Brenda would become ‘panic stricken’. Brenda’s concern with respect to the termination of nursing care emerges in the context of the ongoing coordinated work sequence between the nurse and the CCAC care coordinator in accomplishing a timely service discharge. From the moment she opens a discussion with the parents about the child’s future nursing supports at school, the nurse draws parents and children into doing work that enables a service reduction and discharge. Thinking of her daughter’s safety at school, Brenda told me she plans to work on teaching her daughter to count and add up carbs more accurately. Still feeling uncertain of her daughter’s mathematical skills, and unable to rely on the teaching staff at school to provide support, she says she will resort to adding up all the

carbs in her daughter's lunch, write the number representing the amount of carbs on a piece of paper, attach it inside the lunch box and hope nothing will go wrong.

Kylie, the mother of the teenage boy, also has a nine-year-old daughter with diabetes. She describes how the conversation with the CCAC about ending nursing care when her child was eight prompted her to urge her daughter to learn to do diabetes care on her own. Unlike her son who refuses to perform diabetes self-care routines, she feels thankful and relieved that her daughter is not resistant to diabetes care work; her daughter was able to learn quickly and she dependably performs diabetes self-care routines. Kylie works full-time outside the home, and cannot regularly leave her place of employment to attend to her children's healthcare needs at school. Both Brenda and Kylie need to continue to work outside the home, as their employment insurance pays for the expensive but necessary medical supplies that sustain their children's diabetes care.

Joy, the mother of a five-year-old child works at home to care for her children. At the time of the interview, her child was in a half-day kindergarten class and received one nursing visit per day. Joy decided to not seek paid employment, so that she could be available to attend to her child's healthcare needs at school. Knowing that her child will have diabetes for the rest of his life, she opted to avoid pressuring him to do diabetes care. She told me that living with diabetes and being pricked by a needle 10 to 12 times a day is enough of a burden for him, and she wants to do everything she can to support his transition to doing his own diabetes care work, and avoid him becoming resistant to it. So,

for example, when her son initiates the finger pricking himself, she readily supports this, and this is how she intends to proceed, following his lead with respect to his own readiness. Unlike Brenda, Kylie and perhaps other parents, Joy is in a rare position of having financial security, which allows her to engage in a process that is actually responsive to her child's readiness.

In this section, I showed how the concept of 'independence' enters into and organizes the nurses' attention. The nurse selects particular aspects of what she witnesses children doing to produce a text that represents the child as 'independent' in their diabetes self-care. This textual production of 'independence' (the *Update* and *Checklist*) is then taken up by the CCAC care coordinator as an indicator that the child is no longer in need of nursing services at school. The child's 'independence' is hooked into an institutional discourse of cost containment, as the CCAC manager confirms that the school health budget has been frozen at the 2007 level despite an increasing number of children with complex medical needs, and the CCACs had to come up with ways to manage their budget. It is under these actual conditions that the work of the assessment and service discharge has been intensified and shifted to families: "It's always been teach, reduce and discharge. You've got to try to make the client as independent as possible. It's their healthcare; they need to manage their healthcare" (CCAC manager).

However, what is left out of this discourse of 'independence' is the emotional readiness and maturity required to perform these complex skills with care and accuracy

on a daily basis, and that children may not be mature enough to engage in on their own, yet it is crucial for their health and well-being at school. The way the SHSS programme is currently organized also discounts the need of children with diabetes, who are living with this lifelong chronic health condition, to take a ‘vacation’ from doing diabetes self-care routines themselves (which parents know intimately and orient themselves to), and is also documented in research as a strategy that improves children’s adherence to diabetes self-care routines (Follansbee, 1989). The way the institutional processes is organized also does not take into account how the category of ‘independence’ mediates parents’ relationship and work with their children differently, thereby depending on the different socio-economic locations of the family. Not every family has the time, knowledge and resources to attend to the healthcare needs of children while they are at school. Indeed, the textual production of ‘independence’ obscures much of what is happening in the child’s lived reality, their parents’ work in supporting their ability and readiness (physically, cognitively and emotionally) to take on diabetes self-care and the inter-dependent nature of chronic health management. As Piette (2010) states (p. 4), “‘self’ management is a misnomer”; disease care is actually shared by family members and broader social networks. Research highlights that parental support and shared responsibility in diabetes care results in better glycemic control and better self-care behaviours in children (Helgeson et al., 2008). Furthermore, as we hear how the CCAC care coordinators and healthcare agency manager speak of the timeline for discharge and what eight year olds *should know and do*, the discourse pathologizes those who are

understood as ‘dependent’ within the institutional way of knowing informed by the pre-determined timeline to accomplish service discharge.

Conclusion: Institutional knowledge of timelines versus knowledge of complex diabetes care work

In this paper, I have shown how people differently positioned in social relations know and understand diabetes self-care work at school differently. CCAC care coordinators, healthcare agency managers and nurses orient to both the restructured context of home care service delivery, and the standardized timelines for service termination. From their very different standpoint, parents orient to the daily practices of caring for their child’s diabetes, as well as their knowledge of the unique characteristics, personalities, abilities, capabilities and maturity of their individual child, including their forms of ‘resistance’ to doing their own diabetes self-care. Parents are also oriented to carefully developing a lasting lifelong diabetes self-care routine with their children. This paper makes visible how parents’ knowledge that their children are not ready to take on their own diabetes care, and their efforts to support and enable their children’s lifelong work of diabetes self-care, comes up against a pre-determined timeline for terminating nursing services in school.

Starting from the concerns of parents regarding the premature termination of nursing care for their children at school, this exploration revealed how the institutional framework of ‘independence’, and the CCAC mandate to teach, reduce and discharge

clients at a pre-determined service termination timeline, coordinates the work of parents and children with diabetes, front-line nurses and the CCAC care coordinators. The activation of the concept of ‘independence’ by the nurse mediates the nurses’, parents’ and children’s work and relations, and draws the nurses’ attention to focus on the institutional work of transferring primary care to children with diabetes. Once children engage in diabetes self-care, the nurse can competently select specific actualities of the child’s doings to fit the criteria of ‘independence’ and write up into the operating text (the *Checklist*) and a form of Update to the CCAC care coordinator a representation of the child as ‘independent’ in managing their diabetes. The nurse’s textual production of the child’s ‘independence’ will be taken up by the CCAC care coordinator, who can then proceed to the next institutional course of action, that is, to discharge the child from nursing services at school. This textual production of ‘independence’ obscures the actualities of children’s every moment-to-moment ability and readiness to take on diabetes self-care, in addition to parents’ concerns about their children’s future well-being and ‘resistance’ to doing diabetes self-care if pressured to take on the responsibility prematurely. What becomes visible is that in the organization of children’s work to do diabetes self-care ‘independently’, they and their parents are drawn into doing institutional work that accomplishes their ‘independence’ of these specific nursing services. The necessity for children with diabetes to come to their own embodied and emotional readiness for diabetes self-care is discounted.

CONCLUSION

This study began with a practical question I was faced with when my child with diabetes was about to start kindergarten: Who will care for my child's health and well-being at school when she is not (cognitively, emotionally, and physically) mature enough to do so on her own, and I am not there to do it? This question of how children with diabetes are cared for at school is of concern to me and other parents of children with diabetes, particularly those of us whose children have yet to acquire the knowledge, practical skills, maturity and stability to conduct the necessary self-care routines. These diabetes self-care routines are necessary to keep the child alive and well, and include blood sugar testing, carbohydrate counting, administering insulin, interpreting the number representing the child's blood sugar level, and managing the blood sugar level by monitoring and balancing the blood glucose level with the amount of insulin dose, food, exercise, sickness, and the timing of these activities etc. Parents' concerns are informed by their knowledge and experience of actually caring and doing these diabetes self-care routines for and with their children with diabetes on a minute to minute and day to day basis. They know through doing these complex, well-coordinated and intensive daily and nightly diabetes self-care routines that diabetes is a complicated illness and the results of care are not completely predictable even when they strictly follow these self-care routines. There are countless factors that can affect the child's blood sugar levels, and in turn affect the child's health and well-being. The management of diabetes is like chasing after a moving target and parents are required to make many 'medical' decisions on behalf of their children every single day. They are astutely aware that the failure to take

into account these factors and to be responsive to the changing conditions of the child's environment and body can have dire immediate and/ or long-term consequences for the child's health. Parents know that it is crucial to have a knowledgeable adult at school to assist, support and supervise children to ensure that these intensive diabetes self-care routines are actually performed while the child is at school.

My interest in studying how diabetes care for children is organized in Ontario schools arose from the difficulties I experienced in getting the care I deemed necessary to keep my child safe at school, and from the interviews I conducted with parents of children with diabetes in which they described in very compelling terms some of the worry they experienced and hardships they encountered. I wanted to figure out how this world in which parents of children with diabetes, including myself, act and suffer is put together such that these hardships come into being (Smith, 1987). Taking the standpoint of parents of children with diabetes, our experiences provided a starting place to investigate how diabetes care in Ontario schools is organized socially and institutionally. Opening up a material interrogation of our experiences reveals the social relations that organize the health supports in the school setting and shows how parents' work around their child's health care in school is connected to and incorporated into the institutional policies, processes, and knowledge of the Community Care Access Centre School Health Support Services program to secure the safety of children with diabetes at school.

During the course of doing this research, there have been many moments when I have second guessed myself and wondered if this research is a form of self-indulgence, if I am making a mountain out of a molehill. After all, when I advocated for services closer to our ‘normal’ care at home, my child received more adequate nursing; the teaching staff at her school are more than accommodating and caring; and my child is now receiving care from a team of consistent nurses. Things are finally going well. Yet as was clear from this thesis, the ‘finally going well’ was brought about by my advocacy work, and repeated complaints to a range of care providers and managers. The mountain only became a molehill because of how persistent I was in making it smaller, and because of the resources I had in that effort.

At times I also worried that parents, like myself, that know how to advocate for their children and have social and material resources to do so, are being unfair to those who ‘really’ need the services such as parents who simply cannot take time from their paid work to engage in this level of advocacy and supplementary care. Yet reading over and over again similar stories written on the on-line diabetes community of the challenges and difficulties parents encounter in securing an adult (either from the school or from CCAC) to supervise their children in doing the diabetes self-care routines and monitoring their blood sugar levels at school, or being called upon frequently by the school to provide guidance or to get to the school immediately to attend to the child’s health struck a chord in me, and reminded me that parents’ concerns and the challenges they experience are real. I have known parents who decided to leave paid employment,

delayed returning to work or changed from full-time employment to part-time employment so as to be available to care for their children, but not every parent of children with diabetes can afford to do so. Although our children don't always look medically sick, they undoubtedly need the necessary care and support to stay alive. Indeed, whose standpoint is taken matters to what is known. Now I have come to see both my self-doubt and the nurses' perceptions as organized by social relations originating outside of this local setting of the school (as I have discussed in the section about discourses of (in)dependence).

In this concluding chapter, I will use an article that was published on July 30, 2015 in the Hamilton Spectators, a local newspaper, where I was being interviewed to draw some concluding thoughts about what I discovered through doing this research. The title of this newspaper article reads: "Parents scared over gaps in diabetes care at Hamilton school", and it was a part of a series of activities put forth by the Canadian Diabetes Association to campaign for the rights of children with diabetes to have the necessary care and supports so that children can attend school in a safe and supportive environment. The newspaper article preceded the launch of the Diabetes Charter for Canada and aimed to draw the public's attention to the everyday world of parents and children with diabetes, and point to the discrepancy and inadequacy of the school and health system in meeting the needs of children with diabetes. It is clear from this newspaper article that knowing from different standpoints results in different understanding and experience of the issue: parents' concerns over their child's health and

the need to find a knowledgeable adult to support a child's care in school, school board's understanding of diabetes care as medical support and thus not within the realm of work of teaching staff, and CCACs' institutional ways of knowing about care being available to those who need it. The problematic of my study was developed from this disjuncture, these contested ways of knowing, about what is the care needed for children with diabetes at school and who will be providing it.

Objectified ways of knowing: the myth that care provision is dependent on the child's needs

Standardization as a form of textual knowledge

In this newspaper article, the vice-president of patient care and chief of professional practice of a particular CCAC claimed that the care provided for children with diabetes is not dependent on a budget, but "it's dependent on a child's needs" (Hamilton Spectator, Parent Scared Over, n.d.) Indeed, in my investigation, I have identified an instance of a textually authorized procedure within the institutional work process of CCAC SHSS that is referred to as the assessment of the student's needs at school. The CCAC care coordinator is authorized under the *P/PM81* legislation to conduct the assessment and determine the student's eligibility for services (Ontario Ministry of Education, 1984). Once deemed eligible and 'in need' of services, the CCAC care coordinator will coordinate with the for-profit or non-profit healthcare agencies to actually deliver the care, and the CCAC can officially claim that the provision of diabetes care for children is dependent on a child's needs. However, the presence of this seemingly

objective assessment procedure within this institutional work process obscures the knowledge drawn on to conduct the assessment and thus not brought into question. It is unclear how a child's needs are being assessed, and what knowledge is drawn on to determine the eligibility.

My investigation shows that a child's needs are already pre-determined even before I, as a parent of a child with diabetes, requested a referral for health supports in school at the pediatric diabetes clinic. It is pre-determined by the CCAC SHSS, and thus the intentions of the CCAC SHSS enter into the local setting of the clinic and organize the physicians at the clinic to write what is institutionally actionable within the CCAC SHSS policies. What is institutionally actionable is standardized and links with the relevancies of the CCAC SHSS eligibility and fiscal policies. As an institutional text, the standardized *CCAC Medical Orders for Services at School* stands in for what every child with diabetes needs at school. The standardization of needs assumes each child with diabetes has the same needs, and the unique needs and the complexities of the care of each individual child are obscured. What was written on the initial *Medical Order* directs the CCAC care coordinator to the list of 'service categories' within the SHSS program and organizes her to set up one community nursing visit for my child. 'Nursing' as a service category orients the CCAC care coordinator to understand the child as needing nursing care, and pre-sets the parameter of the assessment and directs the CCAC care coordinator's attention to assess the eligibility for 'nursing' services, whatever else the student with diabetes needs that fall outside of this service category or the other service

categories have nowhere to be included in the form. Indeed in my conversations with CCAC care coordinators and community nurses, the ‘nursing’ services provided for students with diabetes are understood to be blood glucose testing and administration of insulin. The more social aspects of diabetes care such as supervision of food intake, and double-checking child’s completion of the diabetes self-care routines are not explicitly defined as part of nursing care, and thus cannot be taken up to warrant nursing services. As I have shown in Chapter five, the initial standardized *Medical Order* that was written for my child did not serve her interests. It did not align with what she needs in terms of the frequency of care and the timing of care to ensure her well-being. While care that was more in alignment with what my child needs was eventually authorized, it was made possible through my advocacy efforts and in turn, what I had to say had to fall within the relevancies of the CCAC SHSS eligibility policies in order for it to be actionable. This is one instance that shows standardization practices do not serve the interests of my child, and likely other children given the complexity of diabetes care and the unique needs of each individual child.

In addition to the standardization of the needs of children with diabetes through the Standard *CCAC Medical Orders for Services at School*, the termination of services (the decision that children no longer need this care in school) is also pre-determined and standardized. Of course, children’s chronic illness does not change as diabetes continues to be an incurable chronic health condition and thus children with diabetes continue to need diabetes care in school to stay alive. What is determined by the CCAC as ‘not

needed' is nursing services. I discovered in my research that once a child reaches the age of 8, the CCAC care coordinator will activate an institutional work sequence that accomplishes 'service discharge'. It is expected that by age 8, the child with diabetes should no longer be in need of nursing services as they should be able to care for their own diabetes independently of nursing services. We see the work of the CCAC care coordinator is organized by a standardized work sequence ending with the termination of services at a pre-determined timeline, rather than what child actually needs. The needs of children with diabetes are subordinated to the institutional mandate of CCAC, and serve the interests of the institution.

One of the CCAC care coordinators I spoke with in this research mentioned the setting up of a 'care pathway' for children with diabetes in school to standard services. From this CCAC care coordinator's standpoint, the development of a scientific and evidence-based care pathway will improve the accountability and efficiency of services for children with diabetes in school. This text will also solve the problem of unequal access to services with some children staying on service until an older age than others. The reliance on 'evidence-based' knowledge to manage the allocation of resources and to reform the health care sector is not new. As early as the 1980s, Campbell (1988) studied the introduction of a particular management technique, the "patient classification" systems in organizing nursing work to become more 'productive' in the context of increasing government financial restraint. Campbell (1988), Rankin (2004), and Mykhalovskiy (2001) studied the use of text-mediated standardization practices in

hospital reform. They offered an analysis that shows how the activation of these seemingly objective institutional texts (patient classification systems, care-maps for post-surgery patients, and care pathway for cardiac care respectively) reshape the work of health care professionals and subordinate the complex needs and the actuality of patient's embodied conditions to serve the managerial interests of hospital efficiency and the effective use of hospital resources. The use of texts and information technology to standardize practices in health care is increasingly prevalent; Ringham is studying how a particular computer information system (including electronic health records, forms, flowsheets) organizes the work of nurses in the neonatal intensive care unit, pulling nurses away from attending to the immediate feeding work that is necessary for the severely ill infants to succumbing to the institutional pressure of filling out the fields on a computer screen (C. Ringham, personal communication, September 13, 2016). Even though these standardized institutional practices may claim to make nursing work more efficient, they also override nurses' professional and experiential knowledge and pull the nurses' attention away from the body care of patients. What I discovered in my research adds to this body of literature to make visible the standardization of knowing and practices in health care based on scientific knowledge do not serve the interests of those most in need of care.

Information technology as a form of textual knowledge

In addition to standardization practices, increasingly quantitative data and electronic health information systems are used to reform the management of health care.

In this study, I have identified the use of an electronic health information system, CHRIS, at the CCACs. The introduction of this institutional technology in 2008 aims to improve the collection, coordination, sharing and access of client information between the CCACs and the service providers so as to better the delivery of services and improve the quality of care for patients. While this institutional technology appears to be a neutral tool to manage and share information, and coordinate the delivery of services, I discovered the way in which the fields and the internal rules for the software is set up re-organizes how quality of care is being understood. When the acceptance of *service offers* by a healthcare agency is automatically calculated by the software to represent the quality of services of that agency and linked up to the work of the CCAC quality and financial officers to monitor, evaluate and determine the allocation of ‘market share’ to the agency, the survival of the agency is at stake. For the survival of the agency, managers of healthcare agencies are organized to accept service commitments for which they cannot always provide a consistent nurse. My research shows that this institutional technology is far from neutral. Not only does it not necessarily improve the delivery of services and quality of care for patients and professional front-line staff, it actively re-organizes the work of service coordinators and directly affects the conditions for community nursing and the quality of nursing services for children with diabetes and their families. With the lack of consistent nurses, parents are called upon to monitor, and provide guidance to ensure the safety and the quality of services for their children.

Rankin (2004) investigated how an electronic institutional technology, the admission, discharge, and transfer (ADT) software, works in the hospital where her study took place. She studied how a specific bed utilization software subordinates the professional knowledge and values of a nurse who activates this software, and organizes her work of patient care to accomplish a timely discharge, which is necessary for the next patient who is about to go into surgery and will need a bed for the purpose of ‘admission’ upon the completion of the surgery. The nurse’s work of patient discharge is recorded in the software, and the data collected will generate statistics about the efficiency of the hospital. This information will be used by hospital managers and directors to inform policy decisions and to negotiate with the Ministry of Health for future funding. Rankin (2004) discovered that not only is this data used to organize practices within the hospital, this virtual reality produced by this information-based technologies is also taken up by the Ministry of Health to pursue further ‘improvement’ on the performance and efficiency across all the hospitals within the province, resulting in a leaner management of hospital resources. What is troubling is that this ongoing ‘improvement’ project has no end in sight.

The CHRIS program has been in use across all the CCACs in the province since 2010. At the time when I conducted this study in 2013 and 2014, the CHRIS program was mainly used to coordinate client information between the CCACs and the provider organizations and facilitate the delivery of services and the management of contracts. It is unclear to me and the CCAC manager I interviewed how the data generated through

CHRIS is used by the Ministry of Health to inform policy decisions. However, when reading how the developer of this software designed the CHRIS program, it is clear the system is built in such a way that the Ministry can automatically generate reports “to know exactly what’s going on with the funds and more importantly with the health of Ontarians” (Zvaniga, 2011, p.54). What can this software tell us about the health of Ontarians and how the Ministry will use this data needs further exploration. One thing is clear: the embodied actuality of the health of Ontarians, such as the complex life of parents and children with diabetes and their experiences of care, are not captured by this software, and thus it is hard to believe that if this data is used to inform policy decisions, it will serve the interests of those receiving care.

I have discussed in Chapters five, six and seven how the text-mediated objectified way of knowing the care children with diabetes need in school through a pre-determined standardized *Medical Order*, CHRIS, the information-based technology, and a pre-determined service discharge timeline, and they are used to organize care for children with diabetes in school. This institutional coordination does not align with what parents know as needed for their children and thus is insufficient to ensure the well-being and quality of care for children with diabetes at school and produces ‘gap’ in care for these children. This ‘gap’ draws parents in to doing voluntary health care work at school, without which the child’s safety and continuity of care is not possible. Some parents are more able to do this work than others. In the next section, I will discuss how the relations of health care reform and restructuring shape the public discourse around who should be

responsible to care for children with diabetes in school, and further normalize parents' responsibility in their children's care at school, and re-organize what ought to be public responsibility to the private domain of individuals and families.

The discourse of (in)dependence obscures parents' voluntary health care work

The reform and restructuring of the home care sector had gone on for three decades at the time when I undertook this research. The three decades of reform and restructuring not only reorganized how home care services are allocated and delivered through the setting up of the autonomous non-profit incorporated organization that we have come to know as the CCACs, it changed how the public come to know who has the right to access these community-based services. The need for reform and restructuring was constructed on a discourse of the rising costs of health care and the unsustainability of a universal health care system with an aging population; the health care system was said to be in 'crisis'. The cause of this 'crisis' was in part due to increasing demands and rise of costs, however it was largely attributed to the lack of an efficient and cost-effective public bureaucracy which resulted in poor management of funds and services, encouragement of dependency on services, and a lack of choice of services (Browne, 2000; Armstrong et al, 2001). Framed as mainly a management issue, market relations and for-profit business sector ideology and practices were taken up by the provincial government to better manage the system. It was believed that competition would induce incentives on the provider organizations to be more creative and productive, and in turn

would improve their quality of services by nature of having to maintain their competitiveness.

The introduction of market relations and ideologies mediated the relations between the ‘state’ and its citizens. Under the model of ‘managed competition’, the ‘state’ became the purchaser of services and began ‘governing at a distance’, while at the same time, its citizens were constructed as rational ‘consumers’ and were expected to make responsible choices about their access and use of health services. Responsible citizens will actively engage in maintaining their health and be independent of services so as not to drain the already limited public resources. Those that access services when they are not in need are deemed ‘irresponsible’, ‘dependent’, and a ‘burden’ to the already burdened health care system. But, as I have pointed out in the previous section, the assessment of need is neither neutral nor objective, it depends on whose standpoint and what knowledge is taken up to assess what is needed. Under conditions of fiscal restraint and the shrinking of the public sector, what is needed comes to be more and more narrowly defined by those who are authorized to make that definition as they take up the standpoint and interest of the institution.

I want to emphasize that this discourse has been prevalent for more than three decades and the public (particularly those who do not have experience or know of anyone in need of these community-based services) are also organized to believe people should be responsible users of services and not over-burden the system, making small sacrifices

to save the health care system. It is not immediately apparent from the newspaper article that this is the position taken up by some members of the public, but when you look through the comments section, it becomes clear that parents are portrayed as “self-righteous,” “irresponsible,” and “entitled” when they point out the insufficiency of the current level of services and request services that match with what children with diabetes actually need to ensure their well-being and safety in school. I have also heard the same discourse spoken by some of the nurses, nursing managers and the CCAC care coordinators I interviewed. This discourse of ‘dependency’ and ‘burden’ to the system is what led a friend to say it’s not a wise way to use public resources when she found out my child has a shift nurse at school and wondered what the nurse does all day. This is also the reason why I feel guilty having a shift nurse for my child. Did my child get more services because I squeaked loud enough? My speaking about what I routinely do to care for my child to the CCAC care coordinator and her competent selection from my talk of what fits into the eligibility criteria is part of the institutional process of assessment. What are normal routine fluctuations in blood sugar levels have to be constructed as “unpredictable”, my child has to be constructed as “lacking of hypoglycemia awareness” and a “newly diagnosed diabetic”, and my husband and I have to be constructed as “nervous parents” in the assessment in order to move onto the next step of concluding that the child needs “shift nursing”. Even with the level of services that my child received, I was frequently called upon to provide guidance, coordinate the nurse’s presence in the school, and to be at the school to actually do the care. Although some members of the public deem parents as ‘irresponsible’, my investigation makes visible the

fact that it is parents' voluntary labour and knowledge that enables the public institution of schooling to operate as it does and enable children with diabetes to attend school safely. While it is in parents' interest to ensure their children's safety and well-being, not every parent has the material conditions, flexibility and literacy level to engage in this voluntary health care work. A policy that relies on parents' voluntary work to sustain its official ideal to provide an inclusive and equitable education is in effect reproducing inequality and exclusion.

Should 'special' health supports be an essential feature of an equitable and inclusive education?

As I have noted earlier, my study did not extend to address the school as an institutional complex. However, in this brief section I offer some reflections on the role and responsibilities of teaching staff. I have identified that *P/PM 81 titled: Provision of Health Support Services in School Settings* is the policy that governs how health support services in school will be provided, and it is issued under the authority of the Deputy Minister of Education (Ontario Ministry of Education, 1984). Situating the policy in the Ministry of Education indicates that it is the Ministry of Education that has the authority and responsibility to implement and change this policy. The way this policy is currently written outlines that it is the responsibility of the school boards and the local CCACs to ensure children have access to the health support services needed in order to attend school. It also outlines an institutional process and a sequence of action whereby the CCACs will assess students' needs and will provide health support services once a

student is deemed in need of it. However, what is unclear and not explicitly written in the policy is what happens if a student is deemed not in need of such services after the CCACs' assessment.

I have previously alluded that the CCACs' assessment may not always align with the actualities of the child's need, particularly when the CCACs are assessing the child's need for nursing services. While a child may not need nursing care, he/she may still need support to actually perform the diabetes care routines accurately, such as adding the numbers of carbs in the food she eats as in the case of Brenda's daughter, or Kylie's son who will not reliably perform the care because he dislikes diabetes and disassociate himself with it, or as in my child's situation where she is easily distracted, she needs constant reminders to stay on task and to double check she actually completed all of the necessary diabetes care routines. There have been many occasions where she checked her blood sugar at lunch time but forgot to give herself insulin because she was distracted and starving; the desire to solve the problem of her hunger trumps giving insulin. The presence of an adult to remind her and ensure she does all the necessary diabetes care routines is necessary in those occasions.

Difficulties arise for parents when the school their children with diabetes attend cannot provide services that are considered more social or 'soft services' such as making sure the child is adding up the numbers correctly, that they actually perform all of the diabetes care tasks and that they finish all their food. These are not currently defined as

nursing services, though a broad definition of nursing would certainly include these tasks as attending to and monitoring patient care. From the school's standpoint, diabetes is a medical condition and thus any work that pertains to the care of diabetes may be strictly defined by some school boards as medical support, work that is performed by the medical profession, not the teaching profession. While some school staff do engage in some of the 'non' medical aspects of this work, like my child's teachers (classroom teacher, learning resource teacher, and education assistants) who will remind her to do her blood sugar checks at the assigned times, monitor her blood sugar, and contact the parents when needed, it is not clear to what extent they are mandated to do this work.

Based on my observations, the teaching staff will never engage in the medical aspects of care such as doing blood sugar checks and administering insulin through insulin pen or pump (even if it means just pushing buttons), the non-medical aspect of care is up for debate. I suspect it depends on whether these tasks are defined as medical or social, and it seems that how they are defined is up to the individual discretion of some school boards, and schools as there are no higher level regulatory texts explicitly stating what is and what is not the school's responsibility. It also depends on whether the school will have a dedicated staff at dedicated times to conduct this work. It is not possible to simply add this onto the lap of the regular classroom teacher because it is not feasible to stay and attend to the needs of a child with diabetes when the child is experiencing low blood sugar, and when the classroom teacher needs to attend to the learning needs of the rest of the students in the class on an ongoing basis. Whether or not there is a dedicated

staff will depend on the school staffing which cannot be pre-determined as staffing is dependent on the actual number of students registered for that school in that particular academic year, and students with diabetes, as far as I know, do not warrant the support of one education assistant staff. What this possibly means is that the available teaching staff changes from one academic year to next based on the number of student registration. What I am proposing here are speculative accounts based on my observations, conversations I overheard, and conversations I have with my child's teachers. How the non-medical diabetes care work of teaching staff is organized or not requires further empirical exploration.

Final thoughts

Knowledge is not neutral and neither are the institutional processes that underpin and regulate our everyday lives. Throughout this dissertation, I have highlighted the contested ways in which diabetes care for children is known in Ontario schools. What parents know is needed for their children with diabetes to stay well and safe at school differs significantly from how the schools and the CCACs (the two institutional complexes authorized to ensure the education rights of children with 'special' needs are fulfilled) know the diabetes care needed in school. Tracing the institutional relations organizing how health support services for children with diabetes actually happen in the classroom, I am able to develop a map (see Figure 1 on p. 160) illuminating how the institutional process of health support services in school is put together, and how it works. More importantly, through this map, I am able to show the kind of work expected of

parents, and that the CCAC SHSS policy and practices will only ‘work’ as they should with the incorporation of parents’ ‘unauthorized’ knowledge and their ongoing voluntary complementary healthcare work. Even with parents’ ongoing work of teaching, monitoring, coordinating, advocating for and doing the actual diabetes care at school, children with diabetes are still exposed to risks to their well-being and life. In making parents’ work visible, I hope to talk back to the official claim that students with complex health problems and disabilities can attend school because of the health supports offered by the CCACs, as well as the public discourses that pathologize children as ‘dependent’ and parents as ‘nervous’ or ‘irresponsible’ and ‘entitled’. More importantly, I hope a different coordinated system of care and supports for students with complex health problems and disabilities in school can be re-designed whereby parents’ knowledge is authorized and aligns with the institutional ways of knowing about children’s needs, the inter-dependent nature of human existence is recognized, and parents do not have to rely on someone taking action ‘above and beyond’ the institutional mandate for their children to be safe and well cared for at school.

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APPENDICES

Appendix A: Community Care Access Centre (CACC) referral form: ‘Standardized’ Medical Orders

Community Care Access Centre CCAC CASC Centre d'accès aux soins communautaires		Name:
REFERRAL FORM DAY SURGERY & CLINICS		PHONE:
		HIN#:
Regular Hours: Monday-Friday 8:30am-4:30pm Extended Hours: Monday-Friday 4:30pm-8:30pm Weekends & Stat Holidays 8:30am-8:30pm		UNIT NUMBER:
Phone: [redacted] Fax: [redacted]		DOB:
Primary Diagnosis: <i>Type 1 diabetes.</i>		FP:
Secondary Diagnosis:		FP PHONE:
MEDICAL INFORMATION		PCP:
DAY SURGERY & CLINIC Unit/WD		
DATE:		
SURGICAL OR OTHER PROCEDURE(S)		D/ M/ Y/
MEDICATIONS/RELEVANT MEDICAL INFORMATION		
MEDICAL ORDERS A physician's signed medical order is required in specified circumstances such as wound care and fractures.		
(1) Treat hypo glycaemia at 12.0 (BG less than 4.0 mmol/L) as per standard guideline of Canadian Diabetes Assoc. (2) check BG ac lunch. If BG at 12.0 less than 12.0, give 4u Humalog SC. If BG 12.1-17.0 give 4.5u Humalog SC. If BG > 17.0 give 5.0 u ⁿ Humalog SC		
FRACTURE INFORMATION	Site:	Type:
WEIGHT BEARING STATUS	Full: <input type="checkbox"/>	Partial: <input type="checkbox"/>
		Feather: <input type="checkbox"/>
		Non wt bearing: <input type="checkbox"/>
MEDICAL SUPERVISION		
Family Physician:	Referring Physician: (please print)	
	Signature: [redacted]	
	Date: [redacted]	
Form #103 Jan. 12, 2007	Faxed by:	

Appendix B: School Health Support Services Application Form

	APPLICATION FOR SCHOOL HEALTH SUPPORT SERVICES
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A. STUDENT INFORMATION *(please print)*

Surname: _____ **First Name:** _____
Date of Birth (dd/mm/yy): _____ **Gender:** M F
Address: _____ **City:** _____ **Postal Code:** _____
Health Card Number (HCN): _____ **VC:** _____
Mandatory: HCN is required by [redacted] CCAC in accordance with the Long-Term Care Act, 1994 to determine student's eligibility for CCAC

Parent/Guardian: Legal Guardian Yes No **Living with:** Yes No
Name: _____ **Relationship:** _____
Home Phone #: () _____ **Work #:** () _____ **Cell #:** () _____
Parent/Guardian: Legal Guardian Yes No **Living with:** Yes No
Name: _____ **Relationship:** _____
Home Phone #: () _____ **Work #:** () _____ **Cell #:** () _____
Family Physician: _____ **Phone:** () _____
Other Medical / Professional Personnel: _____
Medical Diagnosis: _____
Language Spoken in Home (if other than English): _____

B. SCHOOL INFORMATION

Public Separate Private Home **Specify Board:** _____
School: _____ **City:** _____
Resource Teacher: _____ **Phone:** () _____ **Fax:** () _____

C. SERVICES REQUESTED

Nursing Occupational Therapy** Safety / Accessibility
 Physiotherapy** Equipment
 Nutrition Re - referral
 Speech Therapy**

For 'Private and Home School' only: Personal support Equipment

***Mandatory – Supporting documentation must accompany referral*

D. RELEASE OF INFORMATION & CONSENT TO ASSESSMENT

I do hereby give consent to the school to release/share information including Third Party records, relevant to the care and status of my child to the Community Care Access Centre (CCAC) as deemed necessary for assessment of School Health Support Services. I consent to the following:

- CCAC will enter the referral information into its database;
- CCAC will share referral information with their contracted Service Providers;
- CCAC will exchange and share information with school / school will exchange and share information with [redacted] CCAC

Parent/Guardian or Student (16 years+): _____ **Date:** _____
(dd/mm/yy)
Print Name: _____
Principal/Designate Signature: _____

As a CCAC client, or as a guardian acting on behalf of a client, you have the right to refuse to provide personal information for the purposes explained above. Refusal to provide this information may impact on CCAC's ability to provide services. No information is released for any other purpose without your consent, unless required by law.

Fax to: [redacted]
Mail to: [redacted]

CS: CH: Form 99 Approved 02.10 Version 13.01

Appendix C: Conceptual categories in the Diabetes Checklist for Independence

Task	Skill/ knowledge level	Student Outcomes (initial & date)			
Glucose Monitoring	Student will be able to:	Requires Assistance	Requires Supervision	Perform Independently	Date Accomplished / comments
	Wash hands/ ensure hands are clean				
	Locate glucose meter				
Prepare lancing device	1.Cock the handle of the lancing device				
Prepare meter	1.Insert strip into meter				
	2.Check correct code (if required)*				
Perform the test	1.Choose a finger to “poke”				
	2.”Poke” finger and put blood on strip				
Record test result	Record result in log book*				
	Return test kit to usual place				
Hypoglycemia	Student will be able to:				
	State their symptoms of mild hypoglycemia-if able				
	Notify teacher/ adult that they are feeling low				
	Test blood glucose with meter if able				
Take appropriate action	Treat with the appropriate fast acting sugar				
	*If no meter available then treat with appropriate fast acting sugar				
	Recheck after 15 minutes if still feeling unwell				
	Eat a snack with some carb and protein if next nutrition break is > 60 minutes *				
	Understand reason for low reaction*				
	Anticipate a low and take extra carb to prevent it*				
Snacks / Meals	Student will be able to:				
	Understand the importance of eating all of snack/ meal as planned				
*Advanced					