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# (Un)safe at School: Parents' Work of Securing Nursing Care and Coordinating School Health Support Services Delivery for Children with Diabetes in Ontario Schools

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*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 between how and whether parents can deliver their knowledge and resources.*

*Key words: institutional ethnography, diabetes, school health support services, children, healthcare work*

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 for delivering 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 well-coordinated and intensive daily 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 settings 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*. 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 groundwork 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 are 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 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 from 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 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 (PPM 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). Within the PPM 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 PPM 81 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

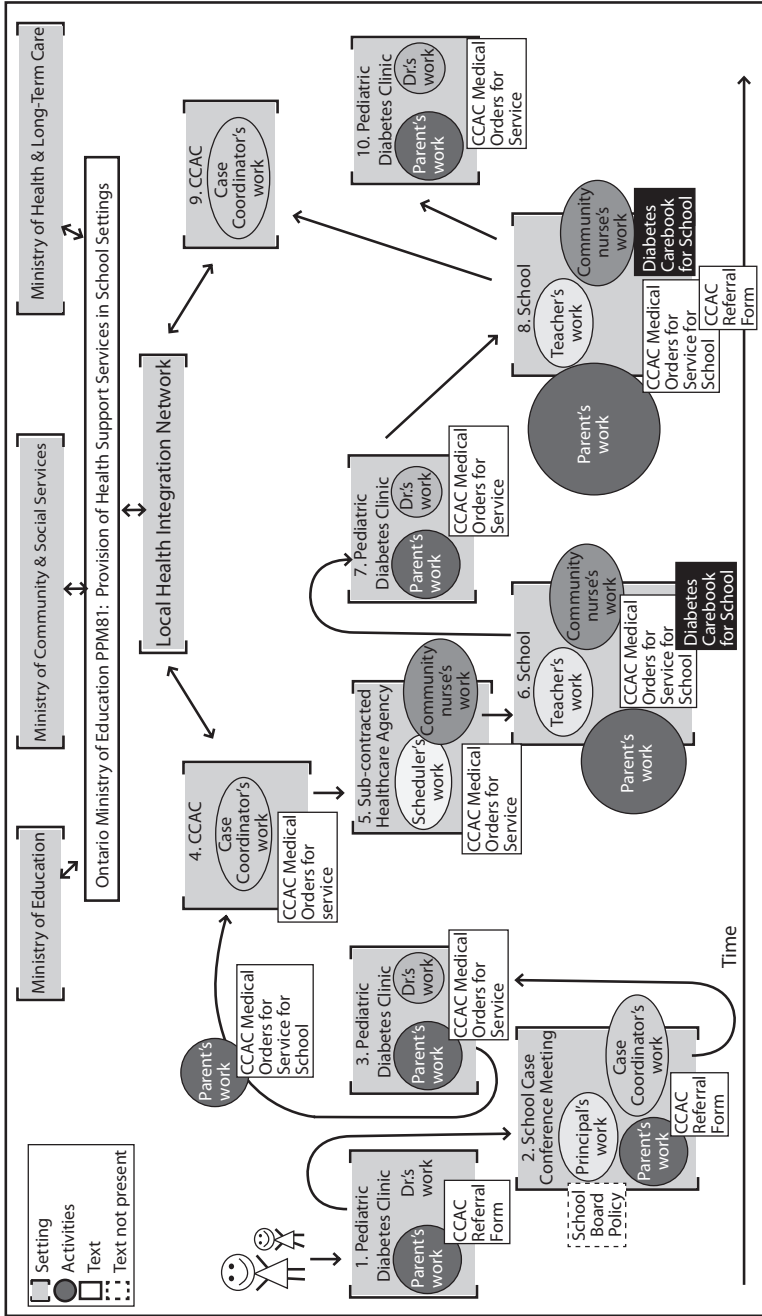
of the text: "Issued under the authority of the Deputy Minister of Education" (Ontario Ministry of Education, 1984, p. 1). This tri-ministry agreement is situated in the Ministry of Education.

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 injections 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 and 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.

Figure 1. The Organization of Parent's Work: Securing, Advocating, and Supporting the Delivery of School Health Support Services



*The Organization of Parents' 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 Parent's work circles indicate my doings, without which the intended outcomes of the SHSS policy could not be accomplished. Transitions from site 2 to site 3 and from site 6 to site 7 in figure 1 required me to 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.

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 who 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.'

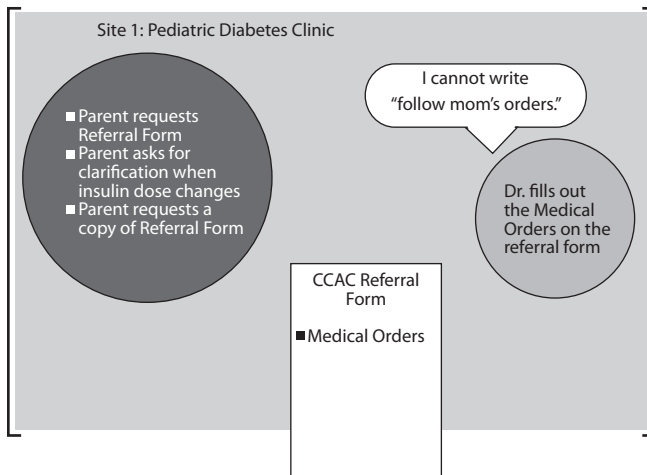
The physician filled out a copy of the CCAC referral form of "Standardized" Medical Orders during this visit. In the section "Medical Orders," it reads:

(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.

These Medical Orders 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.

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



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 PPM 81, and it is the CACC care coordinator who is ultimately authorized to assess the needs of the student.

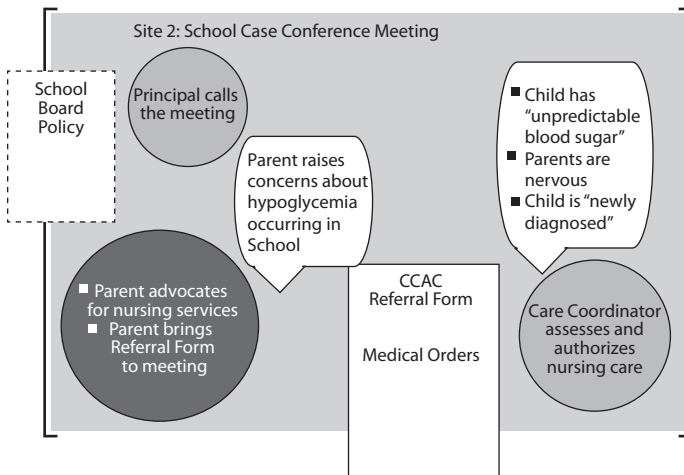
The Medical Orders written on this *CCAC Referral Form* warrant one community nursing visit during lunch hour. The Medical Orders make no mention of blood sugar checks during the day (except one, prior to lunch) and there is no mention of checking before and after physical activities (as parents know from experience that they must do, and as 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. The document does not address the child's best interests; rather, it addresses 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 (unlikely on the day of the phone call). The physician updates the

Medical Orders, and then the document 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 the child needs does not align with the institutional processes of the SHSS program, and parents' complementary work must be incorporated if the 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.

Figure 3. Parent's Work at the School Case Conference Meeting



*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, PPM 81 does not prescribe what an assessment entails, and different experiences can be recognized as “assessing pupil needs.” For example, an assessment 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 predetermined by PPM 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 fit in the eligibility criteria, and assessed my child’s blood sugar levels as “unpredictable,” stating that the “child lacks awareness of hypoglycemia,” and noting 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 about 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 are 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, the document represents what CCAC is able to authorize in terms of care.

#### *The SHSS Policies and Practices Depend on Parents' Text-mediated Voluntary Work*

Once the CCAC care coordinator received the Medical Orders for 'constant glucose monitoring,' 'shift nursing' could be arranged. Yet, certain aspects of necessary diabetes care are still missing. For example, these Medical Orders do not specify the time at 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.

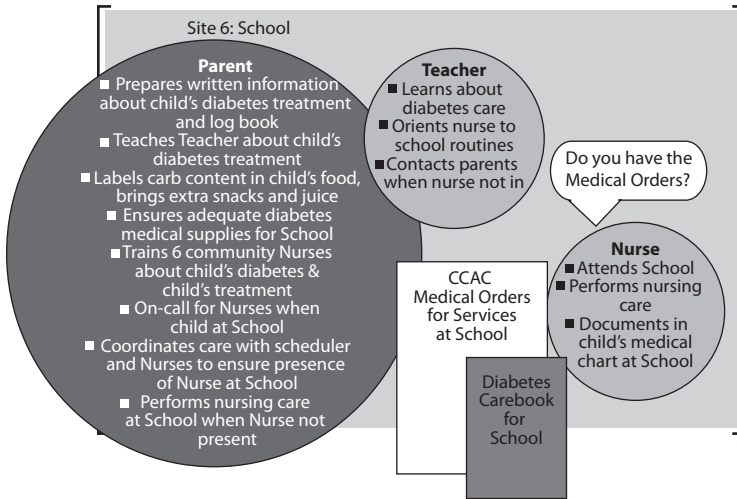
From this mother's standpoint, then, the Medical orders are inadequate to ensure the child's safety at school. The problem for the mother becomes how to get her unauthorized knowledge included with respect to the child's well-being. I resolved this problem by engaging in what I call 'preparation work' 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, carbohydrate contents in food, parents' contact information, and 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 concerning 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 necessarily true that

every one of them is trained specifically on diabetes management for children. I noted earlier that the Medical Orders lack sufficient detail to guide adequate care in the local setting, and 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 that my child needed to get used to multiple 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 is, 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 his or her 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 had to leave whatever I was doing and

get to my child's school to perform the diabetes care my child needed to stay safe at school.

The other option, of course, was 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 that 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 textually-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. Without the incorporation of a parent's voluntary complementary work and 'unauthorized' knowledge, the SHSS policy and practices will not 'work' in ensuring children with diabetes are safe at school. All of these efforts were intended to make sure that my own institutionally unauthorized knowledge of my child's needs became 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 allows them the frequent absences or interruptions due to the need to train new nurses, or answer nurses' phone calls when the nurse needs to clarify information about a 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 is teachers' work organized? And, how are these coordinated with the work of parents to understand how support services for children with diabetes actually take place in the classroom?

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