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

by

Lisa Watt  
PhD Candidate,  
School of Social Work, McMaster University  
KTH-319, 1280 Main Street West  
Hamilton, Ontario L8S 4M4  
Tel: 905-923-1527  
E-mail: wattlh@mcmaster.ca

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## **Keywords:**

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## **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.

*Keywords:* school health supports, children with diabetes, institutional ethnography, home care, healthcare restructuring

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## **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 (Randalla & Williams, 2006; Abelson et al., 2004). 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 et al., 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 et al., 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; Turner, 2003, 2006; Smith & Turner, 2014).

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 (Turner, 2014; Darville, 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 et al., 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; Helgeson et al., 2008; Follansbee, 1989). 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 A). 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 (Turner, 2003, 2006, Smith, 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.

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## Appendix A: Conceptual categories in the *Diabetes Checklist for Independence*

Task	Skill/ knowledge level	Student Outcomes (initial and date)			
		Requires Assistance	Requires Supervision	Perform Independently	Date Accomplished/ comments
<b>Glucose Monitoring</b>	Student will be able to:				
	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 logbook* Return test kit to usual place				
<b>Hypoglycemia</b>	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					