A Child's "Terminal Illness:" An Analysis of Text Mediated Knowing

by

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ABSTRACT

Several years ago a ten year child with a disability died from "severe malnutrition" according to a Coroners Service inquest jury. The inquest evidence shows that approximately one week prior to this child's death three health care providers conducted individual assessments of the child. Using institutional ethnography as a theoretical and methodological framework, the author conducts a textual analysis of the health care providers' documents generated during their provision of service to this child. Obtained as public documents from the Coroners Service, this data includes: the hospital form, the hospice society records and home care nursing records.

In this inquiry, the author argues that health care providers' texts, as constituents of individual and collective action, mediated the health care providers' actions in relation to their professional and organizational agendas. The inquiry shows how this mediated textual activity led to an official and authoritative view of this child as dying from a "terminal illness". It also demonstrates how this official view subordinated alternative views about this child that might have directed professional intervention in a different way.

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Acknowledgments

My inquiry began when I learned about the death of a small child, who had touched the hearts of many individuals. Throughout my inquiry process, the people I connected with who had learned about her circumstances continued to be touched by her story. In its final form, therefore, my inquiry represents the efforts and support of those many individuals who expressed their heartfelt empathy for this child and who made invaluable contributions to my work as it unfolded. Any shortcomings in this inquiry, however, are strictly my own.

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CHAPTER ONE: INTRODUCTION

> There can be no doubt that children are amongst the most vulnerable and powerless members of our societies to-day (Freeman, 1992, p. 29).

A few years ago, Nina, a child with a disability, lived at home with her mother and siblings in a small, rural community. Together with her child care worker, Nina attended school on a full time basis where she participated in school programs, interacted with her peers, and received therapeutic services. According to an inquest jury's findings, Nina died from "severe malnutrition" approximately one month after her tenth birthday while absent from third grade due to her child care worker's illness. At the time of her death, it wasn't readily apparent to people who had known Nina 'what happened' to cause such a tragic end to her life under circumstances where she had not exhibited any health problems requiring medical intervention in the weeks and months prior to her death.

My connection to the events surrounding Nina's death began in the years before I formally engaged in my inquiry process as a graduate student. At the initial time I learned about Nina, I discovered she had died from "severe malnutrition" despite the involvement of many service providers, including physicians, social workers, and educators, all of whom became aware of Nina's circumstances in the weeks preceding her death. Throughout my ensuing years in graduate school, I wondered 'what happened' to Nina; I wondered how Nina died from "severe malnutrition" when so many adults responsible for ensuring her well-being and safety knew about her critical need for professional intervention. At the time of Nina's death, and today, it is a highly unusual occurrence for any person in the developed world, particularly a child, to die under circumstances where basic necessities such as food and medical care should be readily available.

Due to the uncertainty about 'what happened' to cause Nina's death, the provincial Coroners Service held a seven week inquest in which, pursuant to their legislated authority under the Coroners Act, five jury members determined "who the deceased was and how, when, where and by what means [she] died" (Coroners Act, 1979). This jury, participating under conditions set out in the provincial legislation, confirmed the date Nina died, arrived at a classification of "homicide," and concluded that the medical cause of Nina's death was:

> Severe malnutrition as a result of inadequate nutritional intake over a period of time caused directly or indirectly by the actions of other persons (Coroners Service Inquest Jury Recommendations, 1997, p. 1).

At the inquest's conclusion, the jury made numerous recommendations in conjunction with the death classification and findings and directed their recommendations at those agencies responsible for implementing the jury's proposed changes. Although the jury classified Nina's death as a "homicide," there was no legal responsibility attached to this finding which distinguished the Coroners Service classification from the definition that existed under the federal Criminal Code. In other words, the consequences that typically arise from a Criminal Code homicide conviction did not apply within the context of the Coroners Service inquest. A RCMP investigation into possible criminal wrongdoing proceeded as a separate process and concluded several years after Nina's death when the provincial Regional Crown Counsel decided not to lay criminal charges.

The inquest's jury based their classification, findings, and recommendations upon evidence presented during the inquest proceeding. This evidence showed, for example, that two weeks prior to Nina's death, a community person contacted the Ministry for Social Services to express concern about Nina's emaciated appearance. In response to this allegation, the Ministry for Social Services designated the contact a "child protection report" and initiated a child protection investigation into Nina's possible neglect. Two days after the investigation began, the Ministry of Social Service's social worker required Nina's mother to take Nina to the local hospital's emergency department, where an emergency physician assessed her medical condition for approximately five to ten minutes. A hospice volunteer, home care nurse, and social worker made one home visit on separate occasions to conduct an assessment during the first week subsequent to the child protection report. At the time of these sole visits, each service provider talked to Nina's mother and briefly observed Nina.

During the first week the child protection investigation took place, child care worker involvement, by persons familiar and unfamiliar to Nina, was sporadic. In the two week period prior to Nina's death approximately 20 professional service providers (not including two local physicians who each referred Nina to another physician) became aware of Nina's emaciated condition and her need for professional attention. These professionals included: child care workers; the Ministry for Social Services social workers, district supervisors, area managers and a child protection consultant; several physicians including an emergency physician, a pediatrician, medical specialists and a medical child protection specialist; a hospice volunteer; a home care nurse; and school educators. Despite this awareness, no professional person provided social services or medical care to Nina during the week prior to her death. The child protection investigation remained ongoing at the time of Nina's death and social workers had not determined if Nina was a child who required protection. The jury arrived at their conclusions after listening to the evidence of professional workers and other witnesses, including people who had known Nina and 'experts' from various professional fields. In addition, the jury reviewed documentation entered as exhibits during the inquest proceeding.

Several months after Nina died and before the inquest began, the provincial government created a children's commission mandated under provincial legislation to perform a variety of functions including, but not limited to, assessing the adequacy of health, education and social services to all children through various review mechanisms. Under their legislation, the children's commission became responsible for publicly reporting on its work and making systemic recommendations about the way services to children might be improved. One review mechanism within the children's commission that is responsible for identifying systemic flaws is the child fatality investigation process in which child deaths considered "unusual" or "suspicious", according to pre-established organizational criteria, are reviewed. Subsequent to Nina's death, therefore, this children's commission decided to conduct an investigation into the circumstances surrounding her death for the purposes of determining whether Nina's death was preventable and, if so, what recommendations might be made to prevent a similar type of death in the future. As an investigator working for the children's commission at that time, I became responsible for conducting the investigation related to Nina. As investigator, I attended the Coroners Service inquest along with numerous other people who attended as participants or observers during the seven week proceeding.

Throughout my investigation as a children's commission employee, I was perplexed by the circumstances surrounding Nina's death and I continually revisited Nina's story, that is, what I had learned about it, throughout the years I attended graduate school. The words "severe malnutrition", for example, haunted me when I learned that malnutrition usually results from "an imbalance between the body's need for and the intake of essential nutrients" (Berkow, 1997, p. 644):

> Malnutrition develops in stages: First, changes occur in the levels of nutrients in blood and tissues, then changes occur in enzyme levels, next body organs and tissues malfunction, and then symptoms of illness and death occur (Berkow, 1997, p. 644).
>
> Protein-energy malnutrition is caused by an inadequate consumption of calories, resulting in a deficiency of proteins and micronutrients (nutrients required in small quantities, such as vitamins and trace minerals). Rapid growth, an infection, an injury, or a chronic debilitating disease can increase the need for nutrients, particularly in infants and young children who are already malnourished (Berkow, 1997, p. 649).

Nina's autopsy reports, submitted as exhibits at the Coroners Service inquest, did not reveal any evidence of an infection or injury and Nina did not have a "debilitating disease" that would explain the extent of her malnourished condition. I was interested to see, as well, that none of the exhibits entered at the inquest provided any information to show that Nina had received medical treatment for an injury or infection. Furthermore, there was no evidence to indicate that Nina had received the recommended treatment for malnutrition, which often involves a program of re-hydration and feeding with high-energy milk, as described below:

> The milk now recommended for the early stages of therapeutic feeding is enhanced by the addition of both oil and a vitamin and mineral mix, which addresses the special micro-nutrient imbalance that accompanies severe malnutrition. This milk optimizes the chance for rapid weight gain and the

> eventual recovery of a severely malnourished child (United Nations Children's Fund, 1998, p. 79).

According to the literature, there are standard medical procedures for assessing and treating severe malnutrition in children, which often includes inquiries about diet, laboratory testing, a physical examination and the introduction of liquids when food can't be eaten. Appropriate treatment measures may include intravenous feedings or tube feeding through the gastrointestinal tract within a hospital setting. Later, a solid diet of bland food begins and the number of calories gradually increased (Berkow, 1997). In my review of the Coroners Service inquest documents, however, I did not see any evidence these steps had occurred. Rather, Nina became the focus of proposed palliative care.

Nina's experience, I observed, occurred within the context of a provincial commitment to strengthening child welfare and adhering to principles defined in the United Nations Convention on the Rights of the Child (in various chapters throughout my thesis, I attempt to draw attention to these principles by inserting quotations gleaned from the Convention). I noted that Nina did not experience a denial or lack of available health and social services, for example, as many as 20 professional service providers became aware of Nina's need for intervention. And yet for reasons I did not understand Nina did not receive the type of intervention she appeared to require for "severe malnutrition" and no professional person saw her in the week prior to her death. From my perspective as a graduate student, none of the preceding reviews and investigations sufficiently addressed 'how that happened' and 'what happened' to Nina. My desire to explore those questions in a different way is what brought me to my inquiry.

Thesis Structure

For purposes of my inquiry, I obtained those documents, or texts, generated by the three health care providers – the emergency physician, the hospice volunteer and the home care nurse - who saw Nina approximately one week before she died. Upon reading these texts I found myself unsettled by my observation that Nina was constructed, in the texts, as a child whose death was inevitable. For that reason, I was curious about how the health care providers came to "know" Nina and how the health care providers' texts and textual practices constructed an account of their individual interventions. This inquiry, therefore, uses institutional ethnography as a theoretical and methodological approach to explore the process under which Nina became textually represented in the health care providers' official and authoritative documents. From my analysis, I argue that the health care providers' interventions, informed by medical and palliative care discourses, coordinated and accomplished official textual constructs of Nina as a child dying from a "terminal illness." In doing so, I further argue that alternative accounts, which may have led to a different type of professional intervention, became subverted in the process.

Chapter One: Introduction provides an overview and a review of the circumstances surrounding Nina's death that led me to my inquiry. I have provided this information as background to my inquiry's focus and its connection to my personal experience as someone responsible for investigating Nina's death as part of a provincial organization's systemic review.

Chapter Two: The Researcher's Role examines a researcher's role and the challenges researchers, such as myself, encounter when they attempt to make themselves 'visible' in their text. This chapter also explains how I decided to situate myself in my inquiry and describes the problematic arising out of my personal experience.

Chapter Three: Research Methodology broadly discusses institutional ethnography as a theoretical approach and as the method by which I conduct my inquiry. This chapter focuses, in particular, on texts and textual practices. It describes the data and elaborates on textual analysis as the methodological tool used. In addition, this chapter includes a brief discussion about validity, reflexivity, generalizability and ethical considerations as they pertain to this inquiry.

Chapter Four: Joining the Conversation examines the broad topic of professional and organizational relations, with particular emphasis on ideology, "knowing" and "knowledge," texts, textual practices and the role professionals' texts and textual practices play in the construction of knowledge about children.

Chapter Five: Locating the Child attempts to give Nina visibility in my inquiry as a person, living in the broader social world, who had particular likes, dislikes, and needs. It provides 'stories' about Nina told by people who worked closely with her on a daily basis. The chapter also sets out the sequence of major events marking the last weeks of Nina's life.

Chapter Six: Nina as "Terminally Ill" illustrates how the health care providers conducted their work responsibilities in accordance with a professional and organizational agenda informed by medical and palliative care discourses. It shows how the health care providers used administrative forms, provided by the organizations the health care providers were associated with, to demonstrate professional and organizational accountability.

Chapter Seven: Analyzing the Texts argues that the health care providers' administration forms, or textual accounts, existed as a constituent of individual and collective action during their provision of service to Nina. As the analysis shows, the initial concern about Nina's possible neglect shifted, in a textually mediated way, to the notion of Nina as a child dying from a "terminal illness." This textually constructed view of Nina subverted other alternative accounts and possibly led to a different type of intervention.

Chapter Eight: Conclusions and Reflections provides an overview of what I was able to "see" in my inquiry and what I have learned.

In summary, my inquiry attempts to deepen our understanding about 'what happened' to Nina by using the health care providers' texts as an entry point, as a place to begin my inquiry. Through my examinations of these texts, I have explicated how the health care providers' textual practices and texts, as constituents of extended social relations, constructed an official and authoritative view of Nina as a child dying from a "terminal illness." In doing so, my inquiry demonstrates the power of these official and authoritative textual versions of Nina to dominate and subordinate other, alternative views and illustrates how Nina became objectified as a child dying from a "terminal illness." In conclusion, I reflect upon how the health care providers' textually constructed and objectified view of Nina may have directed the actions of the health care providers, who were entrusted with responding to children's needs, and significantly impacted Nina's life and death.

CHAPTER TWO: THE RESEARCHER'S ROLE

> *Bearing in mind* that the need to extend particular care to the child has been stated in the Geneva Declaration of the Rights of the Child of 1924 and in the Declaration of the Rights of the Child adopted by the United Nations on 20 November 1959 and recognized in the Universal Declaration of Human Rights, in the International Covenant on Civil and Political Rights (in particular articles 23 and 24), in the International Covenant on Economic, Social and Cultural Rights (in particular article 10) and in the statutes and relevant instruments of specialized agencies and international organizations concerned with the welfare of children (Preamble, UN Convention on the Rights of the Child).

Nina's story—that is, the pieces I glimpsed while working as a child fatality investigator—haunted me during subsequent years when I was a graduate student. And, as I discovered, Nina's death touched many lives as evidenced by the extensive community response to the news about her death. A meandering stream of reviews, inquiries, and public commentary trickled through the years as people associated with public offices and private agencies struggled, in their own way, to understand how a 10 year-old child died from "severe malnutrition", a rare occurence in western society. Nina, who had lived a very private existence in life, became a very public figure in death. After a considerable amount of personal introspection as a graduate student, I, too, waded into those waters of inquiry and I, too, continued to wonder 'what happened.' Predictably, my historical experiences, my work as an investigator, my emotive reactions to Nina's unseemly death, and my researcher responsibilities raised questions for me as to how I would situate myself as a researcher in this inquiry.

Researcher's Self as Visible

As I examined my own story, in relation to this inquiry, it was apparent to me that researchers do not abandon their prior lived experiences nor do they cease to exist as evolving 'selves' while conducting their inquiry. With this awareness, I searched for ways to locate myself within my inquiry's larger agenda without allowing this pursuit to overshadow my inquiry's objectives. For those people who subscribe to the positivist paradigm, this approach inevitably raises a concern of "researcher bias"—a contradictory notion for the "objective" researcher who attempts to remain silent and invisible in the construction of her/his inquiry text. In the academic world of social research, however, there is increasing advocacy for the position that "there is no neutral place for the researcher to stand" (Campbell & Manicom, 1995, p. 11) and that there is merit in "audible authorship" (Charman & Mitchell, 1997, p. 194). According to DeVault (1999), "feminist epistemologies suggest that personal perspectives are valid and perhaps even essential elements of any systematic attempt to know the social world. This idea comes from the critique of abstract knowledge claims that obscure interest and partiality" (p 105).

In my attempt to reveal myself as "in" my inquiry, as a person bringing her own sense of humanity and subjectivity, I found support in the feminist research approach, which stresses the importance of making knowledge production visible. As DeVault (1999) suggests, "the feminist researcher should find ways of recognizing and revealing to audiences the micropolitics of the research situation" (p. 41) and make herself visible as resource rather than a "contaminant." The "micropolitics," as they apply to my inquiry, relate to my previous role as an investigator working for a provincial commission and the restraints attached to revealing information I learned while working in that position. Micropolitics also concern the delicacy and sensitivity attached to any research situation, like mine, in which peoples' lives may be affected by what is revealed in the research and what conclusions are drawn. Micropolitics, therefore, exist in my inquiry. By knowing that they exist, the reader may also understand that any apparent limitations and constraints in my inquiry's content are possibly due to those factors.

These complexities, and others, surrounded my attempts to locate myself in my research. While DeVault (1999) acknowledges that it remains unresolved as to how to use and locate the self most effectively, the "demand for accountability can be seen as the rationale for experiments with autobiographical and dialogic modes of presenting research...as well as a thread that connects them to projects that are more traditional in format" (p. 41). There are risks, however, in pursuing "audible authorship" insofar as "making personal material more visible often stimulates strongly negative reactions, including trivialization and dismissal" (p. 105) in its departure from standard social science formats that obscure the author's voice. As the author notes, many researchers hesitate to use the first person, as a first step, and avoid providing any biographical and subjective detail.

> Despite these problems feminist social scientists have used personal reflection and testimony in various ways: as wellsprings for scholarly creativity, methods of generating data, touchstones for evaluating knowledge claims, and elements of new formats for reporting research, to name only a few. Their experiments contribute to a growing repertoire of strategies for working with personal material, and also to the development of audiences prepared to read social science texts in new ways (p 105).

It was clear to me that my readers are entitled to know what experiences I bring, as researcher, to my inquiry as a way of making myself, and my work, accountable to them. Less apparent to me was what strategy to employ and how much "personal writing" to incorporate in my inquiry's text.

Challenges to Situating the Researcher

As several authors have noted, whenever a researcher is committed to personal writing the question arises as to how much to place of oneself in the text. Bruner (1993) suggests that the "danger is putting the personal self so deeply back into the text that it completely dominates, so that the work becomes narcissistic and egotistical. No one is advocating ethnographic self-indulgence" (p. 6). According to Denzin and Lincoln (1998b), the goal of personal writing is to place the author in the text openly and in a way that does "not squeeze out the object of study" (p. 413). On the other hand, DeVault (1997) finds herself "impatient with charges that personal writing is 'self-indulgent' or 'narcissistic'" (p. 225) and Mykhalovskiy (1997) suggests these terms are used as "regulatory charges against certain forms of sociology" (p. 229). Smith (1990a), however, is more focused in her analysis on making a distinction between a researcher's "experience" and a researcher's "perspective" when conducting an inquiry.

> When I speak of experience I do not use the term as a synonym for perspective. Nor in proposing a sociology grounded in the sociologist's actual experience am I recommending the self-indulgence of inner exploration or any other enterprise with self as sole focus and object…Rather, sociologists' investigation of our directly experienced world as a problem is a mode of discovering or rediscovering the society from within. We begin from our own original but tacit knowledge and from within the acts by which we bring it into our grasp in making it observable and in understanding how it works. We aim not at a reiteration of what we already (tacitly) know, but at an exploration of what passes

> beyond knowledge and is deeply implicated in how it is (Smith, 1990a, p. 23).

In the process of conducting this inquiry, I worried about becoming ‘self-indulgent’ throughout the inquiry to the extent that my own story, and its articulation, would usurp the inquiry’s original intent and replace my desire to understand who Nina was and ‘what happened’ to her prior to her death. I was concerned about how I would situate myself in my inquiry in such a way that my previous work experience, as an investigator, and other relevant information were apparent and yet did not jeopardize the outcome of this inquiry such that it had no apparent usefulness. As a former investigator, I wondered how I would incorporate my prior work experiences with my inquiry’s objectives; I did want, for example, those experiences to overshadow Nina’s subjectivity. Smith’s (1990a) discussion about a researcher’s role, therefore, helped me to recognize how my prior experienced world served as the impetus to discover and explore a larger societal context. As a result, I concluded I would restrict my personal writing to articulating those experiences directly related to my inquiry’s focus which is an inevitable part, I believe, of the selective, editorial process that always exists whenever a textual account is constructed.

DeVault (1997) describes how a story of “one’s life is a truth that is highly selective and crafted for particular purposes, both conscious and not” (p. 221). In her opinion, “personal writing” brings about a dilemma for researchers as they consider what to reveal in their crafting of their research account. As an illustration, DeVault describes a technique used by one writer that encouraged readers “to recognize the constructed character of her personal writing and to read it more carefully for its analytic significance and connections to the substance of her essays" (p. 222).

> One key to producing useful personal writing seems to be an ability to reflect on experience so that the account does more than simply report the facts. One must consider not only what to write about but also why and how. It is also important to consider what is appropriate and useful-what kinds of everyday accounts move readers beyond the mundane, for example, and what kinds of important material one might be censoring out of shame or fear (p. 222).

There are reasons beyond "fear" and "shame" that explain why important material might be censored out. Many people doing investigative work are subjected to legislative restrictions that ultimately effect what those people may publicly reveal. Ethical and legal considerations may arise in the context of an inquiry which, in turn, may also inhibit the disclosure of certain types of information. As a researcher, I faced some of these challenges. In the end, I found myself assessing what personal writing I could do that would contribute to my larger inquiry and allow the reader to account for my interpretations. I became selective in my writing and chose to include those elements of my story—my experiences—that I felt significantly contributed to my inquiry's intent. By disclosing my historical work experience, as it relates to Nina, I reveal the place from which I looked and from where my "inquiry is 'situated' vis-à-vis other knowers and other ways of knowing" (Campbell & Manicom, 1995, p. 5). According to these authors, "beginning in experience helps the researcher identify 'whose side she is on,' while constructing an account that can be trusted" (p. 5). I begin on Nina's side and on the side of all children who exist as a marginalized, vulnerable group lacking power and voice in all aspects of their lives. My inquiry, therefore, is about the world that many marginalized people live in.

> It is always also about ourselves as inquirers, not just our personal selves, but our selves as participants in the social relations we explore. In discovering dimensions of the social that come into view when we begin inquiry from the actualities of people's lives and experience, we discover the lineaments of social relations in which our own lives are embedded. Writing the social is always from where people are (Smith, 1999, p. 8)

My Self as Inquirer

As a former investigator working for a children's commission, I explored the circumstances relating to Nina's death and, in that capacity, attended the Coroners Service inquest to observe, question, and learn from the direct evidence of all participating witnesses. And while certain information about 'what happened' to Nina prior to her death became apparent to me, I remained unsettled about aspects my investigation at its conclusion. My work as an investigator gradually diminished, however, when I moved to a new position within the children's commission and simultaneously began to attend graduate school. While my position as a child fatality investigator ended, I remained perplexed, for example, about how events unfolded in such a way that a significant number of professionals knew about Nina but did not address her apparent needs in the days preceding her death.

My self as inquirer overlapped my self as a participant in the "social relations" I wanted to explore, that is, the social relations of professionals providing services to children. My new responsibilities at the children's commission, for example, required me to review a provincial ministry's decisions about services to children and possible breaches of the rights of children in government care. In that capacity, I was accountable to the provincial "child serving system," along with other social service, health care, and educational providers. Similar to many professionals providing services to children, I worked within a bureaucratic structure and like them I, too, became textually accountable for work done on behalf of children. My inquiry began, therefore, from my own lived actuality in learning about Nina, as a 'real' child, and in experiencing the professional world of providing services to children while working within an organizational structure. Accordingly, as a researcher I found solace in DeVault's (1999) words when she drew attention to the work of Dorothy Smith.

> Smith's aim is not merely to uncover or give testimony about experience but to make a place for it in analysis that will be focused differently and serve different interests. The feminist sociologist, in her formulation, must refuse to put aside her experience and, indeed, must make her bodily existence and activity a "starting point" for inquiry. From this beginning, the inquiry points toward an analysis of the social context for experience, the relations of ruling that organize daily life and connect all members of a society in systemic interactions" (DeVault, 1999, p. 39).

Beginning in my experience as an investigator, therefore, I moved into my graduate student role where I began to review the public documents available through the Coroners Service. The Coroners Service jury findings and recommendations, in my opinion, did not reveal 'what happened' to Nina during the weeks preceding her death. In reading through other documents, such as the health care providers' texts, I observed that while the texts showed *what* information they had accumulated about her, it was not apparent *how* those health care providers who had personal contact with Nina had constructed knowledge about her. And yet, the knowledge the health care providers accumulated about Nina formed the basis of critical decision-making that ultimately had significant ramifications for this child.

I arrived at my inquiry with a "sensation of disquiet" (Smith, 1999, p. 3) arising from a feeling of uneasiness and my inability to make sense of 'what happened' to Nina.

I found myself questioning how so many professionals failed to identify this child's particular need, that is, the need to receive nourishment, and how it happened that in the week preceding Nina's death, no professional appeared to "extend particular care to the child" (UN Convention of the Rights of the Child, 1989) contrary to numerous international statutes and instruments. From a place of wondering how the professionals who saw Nina – the health care providers, in particular – came to 'know' her and how that 'knowing' impacted their decision-making about services to her, I decided to undertake an inquiry in which I would analyze the health care providers' texts in order to more fully understand 'what happened'.

The Problematic

In my reading of the health care providers' texts, I observed how Nina was described as a child with a "terminal illness" and how she was portrayed as a child whose death was inevitable. This picture, or construction, of Nina did not accord with what I read about her earlier life in the weeks, months and years prior to her death. I started, therefore, with a "sense of a problem, of something going on, some disquiet, and of something there that could be explicated" (Smith, 1999, p 9). I wanted to explore the social organization of knowledge about Nina and, in particular, learn about how she became officially and authoritatively known in the health care providers' texts as a child "dying from a terminal illness."

The focus of my inquiry—its problematic—is situated within the framework of a methodological approach of institutional ethnography. Developed by Dorothy Smith, a sociologist and feminist theorist, institutional ethnography as a research approach is synonymous with the study of the social organization of knowledge. The aim of institutional ethnography is to begin where people are located, in their everyday world, and explore the actual social processes and practices "engaging us in the relations organizing our lives" (Smith, 1990b, p. 10). Institutional ethnography, as a form of inquiry, begins with the identification of a "problematic" in the everyday world that impacts the lives of actual people and explores how those people's experiences are shaped by forces beyond their local and visible world.

> The concept of problematic is used here to direct attention to a possible set of questions that may not have been posed or a set of puzzles that do not yet exist in the form of puzzles but are "latent" in the actualities of the experienced world. The questions themselves, the inquiry, the puzzles, and perhaps the issues are the means of developing the problematic as an inquiry (Smith, 1987, p. 91).

Smith's notion of "latent puzzles," arising out of a problematic, resonated for me as I considered the tragic and unusual circumstances surrounding Nina's death. The Coroners Service inquest brought to light the various professional texts associated with Nina; as I reviewed these texts I was curious about the process under which she became officially known in the health care providers' texts as a child dying from a "terminal illness." The health care providers' involvement with Nina, including their textual practices, impacted the life of a 'real' child living in the everyday world and shaped how she experienced her life in the two weeks prior to her death. Nina, her mother and the various health care providers' actions, became textually represented in the health care providers' official, administrative documents. I wanted to understand how this official and authorized view of Nina, as a child dying from a "terminal illness," arose.

By utilizing institutional ethnography as a research approach, I am able to bring a systematic reading to the health care providers' texts and textual practices in a way that will allow me to "see" and interpret them within a theoretical framework. In this way, I hope to contribute to a deeper understanding about the role texts and textual practices played in constituting knowledge about Nina and in shaping what happened to her in the last weeks of her life.

CHAPTER THREE: RESEARCH METHODOLOGY

Institutional Ethnography—A Theoretical Approach

Smith's preeminent work, as a sociologist and as a feminist, is reflected in her formulation of a sociology from the standpoint of women; it is a formulation which originates from her recognition of women's marginalized experiences and exclusion from the larger intellectual, political and cultural world. As a feminist research strategy, Smith's approach attempts to make "visible" what was previously made "invisible" by dominant ideological forces and seeks to give women, and their concerns, a voice in order to "provide a more accurate, fuller account of society by including them" (Nielsen in DeVault, 1990, p. 30). It is a methodology not limited to topics concerning women, however, as it also provides the inquiry tools for extending into the broader investigations of social life and how it is actually organized. As a form of inquiry, institutional ethnography renders "visible" those external processes, for example, affecting marginalized and invisible groups, such as children, who share the experience of women's subservience.

Institutional ethnography focuses on the everyday world of individual experiences in a society organized by "ruling relations," defined by Smith (1990a) as a "total complex of activities, differentiated into many spheres, by which our kind of society is ruled, managed, and administered" (p. 14). The term *institutional*, as it is used in institutional ethnography, directs the researcher's attention to the way the distinctive functions, such as those associated with health care, social services, and education, are situated within complex ruling relations (Smith, 1987, p. 160). "Institutional," unlike the concept of bureaucracy characterized by a prescribed form of social organization, refers to the way in which different work processes and conceptual orders combine and intersect. For purposes of my inquiry, therefore, "institutional" is a concept that defines how the health care providers' activities, occurring within divergent agencies and organizations, are linked as a "functional complex" (p. 160) by the interchange of their service responsibilities to Nina. According to Smith's theory, professional and organizational work routines, such as those the health care providers participated in, are coordinated through ideologies "developed to provide categories and concepts expressing the relation of local courses of actions to the institutional function …providing a currency or currencies enabling the interchange between different specialized parts of the complex and a common conceptual organization coordinating its diverse sites" (p. 160). It is what bound, for example, the emergency physician, hospice volunteer, and nurse's local practices to each other and the functions of the agencies they were associated with.

Institutional *ethnography* extends beyond traditional ethnographic approaches which include techniques such as interviewing and observing, in a fieldwork tradition, to incorporate a "commitment to an investigation and explication of how 'it' actually is, of how 'it' actually works, of actual practices and relations" (Smith, 1987, p. 160). Smith, who recognizes a research interest as a problematic to be identified, concludes that research must extend beyond mere description. The researcher must also explicate how the situation arises and continues as social relations. The concept of social relations, as it is used in this context, understands people's activities as components of, and contributors to, an ongoing series of courses of action "in which what people do is already organized as it takes up from what precedes and projects its organization into what follows" (Smith, 1987, p. 183). Smith contends that the notion of ethnography, situated in this broader theoretical and methodological context, commits us to an exploration, description, and analysis of a complex of social relations not conceived in the abstract but approached through the standpoint of a particular person or persons (p. 160). Within this approach, institutional ethnography presumes that these social relations, tied to institutional processes, are coordinated by ideological concepts and categories that define the relationship between the professionals' actual work and the institutional function.

As a methodological approach, institutional ethnography avoids transforming people into objects but rather preserves their presence as subjects as it investigates the "actual activities of actual individuals" (Smith, 1987, p. 151).

> It is an investigation in which the direction of looking is reversed. The institutional ethnographer takes up a point of view in a marginal location; she "looks" carefully and relatively unobtrusively, like any fieldworker, but she looks from the margins inward-toward centers of power and administration-searching to explicate the contingencies of ruling that shape local contexts. Through this conscious reorientation, she aims to produce knowledge for, rather than about, those in some particular location. Her analysis is an "insider's critique" (Smith 1990a, p. 204), rooted in but extending beyond a local setting (DeVault, 1999, p. 48).

Institutional ethnography, as it is used in my inquiry, will allow me to explore how Nina's experiences in the days preceding her death were socially organized. I have identified a "problematic" embedded in Nina's everyday world and I conceptualize it as constituted of social relations surrounding her life and death. Thus, my inquiry will explicate the health care providers' socially organized actions and interventions that arose from their contact with Nina and her mother. While the participants in these social relations may, or may not, have known one another, their localized, everyday experiences were, however, concerted. Their texts played an important role in combining and coordinating activities that otherwise might appear discrete and isolated:

> Texts are situated in and structure social relations (extended social courses of action) in which people are actively at work. Texts enter into and order courses of action and relations among individuals. The texts themselves have a material presence and are produced in an economic and social process which is part of the political economy (Smith, 1990b, p. 162).

Texts are, of course, activated by people. As elements of these social relations, the health care providers' texts—their administrative organizational accounts—can be traced back to people and events directly affecting Nina and her family.

Texts and Textual Practices

In the human service field, which includes such professions as health, social services, and education, professional workers generate documents, or texts, on a regular basis as part of their practice. Smith makes this observation in her writings. One of the central themes in institutional ethnography, for example, is the "phenomenon of textually mediated communication, action, and social relations" (Smith, 1990b, p. 209) and the way in which texts, as objectified forms of socially organized knowledge, permeate every aspect of our daily lives, including our professional practice. Smith notes that "the primary mode of action and decision in the superstructures of business, government, the professions, and the scientific, professional, literary, and artistic discourses is utterance–verbal and, more importantly, textual" (pp. 61-62). Professional human service workers, by virtue of the nature of their work, are invariably connected to a number of the "superstructures" Smith references—business, government, and the professions.

In Smith's opinion, therefore, the significant role of texts in these contexts has been undervalued, particularly in sociological research, and she credits the field of ethnomethodology with recognizing the text as a fundamental component of social relations (Smith, 1990b, p. 211). The text, as Smith explains it "directs attention to, and takes up analytically, how what people are doing and experiencing in a given local site is hooked into sequences of action implicating and coordinating multiple local sites where others are active" (Smith, 1999, p. 7). Interpretative practices that "activate" these texts are viewed as properties of social relations and do not arise through any one individual's initiative. In recognizing the text as a constituent of a particular social relation, we become drawn to how its production is socially organized in a prior phase in the social relation and distinguished from the work of a particular author. By increasing the visibility of texts and making apparent their relationship to the formal organization, the organizational process itself becomes visible (pp. 220-221). In this way, researchers explore texts, through textual analysis, as a way to deepen their understanding about local settings, including the experiences and activities of people located in them.

The significance of recognizing texts as constituents of social relations stems from Smith's (1990b) observation that texts develop a "capacity to crystallize and preserve a definite form of words" (p. 210) separated from the local social process as it evolves and is lived from moment to moment. This is an essential analytic feature of texts. Smith proposes that texts and their uses reconstruct social life as people live it. The analytical use (as distinguished from the administrative or "ruling" use) of texts requires a specialized inquiry that goes beyond (or behind) reading texts for meaning in the ordinary way one reads. "Meaning" in texts is detached from the "lived processes of its transitory construction, made and remade at each moment of peoples' talk" (p. 210) and those meanings are replaced by text, speaking in the absence of individuals. Inevitably, "meaning" becomes detached from the local contexts of interpretation; Smith points out that texts make it possible for the same meaning to occur simultaneously across various settings. Smith also claims that a textually mediated presentation of reality, a product of invisible social relations, replaces knowledge arising from direct experience in administrative contexts. This "reality" takes the form of an objectified, administrative knowledge acquired through a textual account. This account, constructed as "factual," results from unambiguous social organization.

> If we have not seen the text as an active constituent of organizational process, it is, I think, because we are ourselves so habituated to its use, to its appearance before us in that simple moment of engagement in which we seek to find out what it says and take what we have learned from it as our resource, rather than addressing that process as a topic. The text comes before us without any apparent attachments. It seems to stand on its own, to be inert, without impetus or power. But in the situations of our everyday life as contrasted with our scholarly activities, we find the text operative in many ways (Smith, 1990b, p. 122).

Institutional ethnography, therefore, proposes a research process aimed at explication. Researchers conduct inquiries that allow them to make texts visible as constituents of social relations and reveal those invisible determinations that impact the everyday lives of people. Texts can be read to reveal people's socially organized activities ordered through text-mediated discourse and ruling relations. In that way, the material text creates a link between local professional activities and more generalized, organizational relations. Nina lived, and died, in the everyday world but she is known to us—human service workers, inquest attendees, myself as researcher—through the operative forms of texts. Her everyday life experience, transformed into objectified forms of knowledge, is the basis upon which I have built my inquiry into how knowledge about Nina was organized and authorized (Campbell & Manicom, 1995, p. 7):

> The conceptual importance of experience lies in providing a real-life context against which, for instance, to reflect on administrative practices and their powerful effects on people's lives. In a project of this sort, the

> researcher explicates how administrative textual practices transform the experienced local and particular into standardized forms such that it can be ruled. Seeing textual practices as themselves real and experienced offers the researcher a course of practical action to explore. That is, once she sees that people follow special work processes to produce administrative texts-that opens up a different view of 'ideology'. Administrative practices can be explored as courses of organizational action that construct everyday life into something different from how it is experienced (Campbell & Manicom, pp 7-8).

My inquiry into the social organization of knowledge about Nina's life, and death, relies heavily upon the health care providers' texts as data. By drawing upon institutional ethnography as a theorized research approach, I am required to treat these data as enacted elements of social relations and not as objective features or conglomerations of 'facts.' In the next section I describe the method I use, drawn from institutional ethnography, to analyze the data—the texts—to discover the account of Nina that now 'stands in' for the child who lived and died.

Institutional Ethnography—Methods

Data

In conducting an institutional ethnography, researchers generally employ observational methods, interviews, and documentary analysis. The method's theoretical orientation directs the researcher to pursue the discovery and analysis of ideological practices organizing those work processes and connecting them to the organizational agenda. Ethnographic data is usually obtained through observation and interviews, however, for purposes of my inquiry, I have obtained data in the form of textual materials existing prior to its initiation. These textual materials consist of certain health care provider documents generated during the week following reported concerns about Nina's possible neglect and entered as exhibits at the Coroners Service inquest. All exhibits are located currently in the office of the provincial Coroners Service. As these documents, or texts, comprise part of a public record associated with the inquest proceeding, they are accessible to the general public. In my role as a researcher (and as a member of the public), I made a request for and obtained the following texts from the Coroners Service:

- a hospital emergency department admission form,
- a hospice society client information form and client referral form,
- home nursing care records, and
- a provincial Do Not Resuscitate form.

These documents represent the texts the health care providers, who saw Nina in the two-week period prior to her death, generated between the date of the child protection report made about Nina and when Nina died.

In order to inform various aspects of my inquiry, I have drawn upon all the Coroners Service exhibits and include those segments of information I obtained primarily in Chapter Five. As it will become apparent, I did not interview such people as Nina's mother, Nina's siblings, the child care worker, the teacher and/or the health care providers nor did I directly observe the health care providers' work settings. The alternative accounts provided in Chapter Five are derived from already accessible data (the exhibits) made available through the Coroners Service and generated prior to or shortly thereafter Nina's death. I have included these accounts merely to illustrate how other *service providers'* views about Nina, textually represented, appeared to contrast with the health care providers' official and authoritative textual view of Nina. I do not purport to make any claims of 'truth' nor does my inquiry make any assertions about

Nina's lived 'reality' or actual experiences. Rather, I include this information to offer the reader the opportunity to 'see' how alternative accounts of Nina were possible.

Text Analysis

According to Smith (1990b), and others, textual materials "have generally presented themselves to the sociologist as sources of information about something else, rather than as a phenomena in their own right" (p. 120). Institutional ethnography, its emphasis on knowledge as it is constituted in text, and "ideological" practices as constituents of text-based knowledge, focuses analytic attention on texts as the "entry point" into how knowledge is constructed. I, too, have endorsed the notion of texts and textual practices as worthy of investigation and, in doing so, I have used textual analysis as the method best suited to meeting my inquiry's objectives. Through textual analysis, I was able to examine the juncture between Nina's everyday world and the "professional and bureaucratic production of facts, where our discursive schemata generated by our work enters the process of constructing the textual realities of ruling" (Smith, 1990b, p 149). The health care providers' work processes, texts, and textual practices already existed in the public realm making it possible for me, as researcher, to explicate what is apparent to me, as a reader of those texts.

Institutional ethnography proposes a particular approach regarding what constitutes textual analysis and how this process should unfold. In textual analysis, the researcher attempts to explicate what is available to all textual readers as opposed to what is uniquely identified by the researcher.

> Interpretation or analysis does not rely on cogency, happiness, rhetorical effectiveness, or a contingent conjunction with how you or I see it. Analysis relies rather on processes and practices that are not private, that

> others, particularly those likely to read this, already know how to do. In spelling these out, I am only tracing on a map pathways that are already familiar, or, if unfamiliar, easily followed (Smith, 1990a, p. 149).

According to G. Smith (1995), the researcher resists looking for "meaning" in texts but rather investigates how the texts organize peoples' lives drawing upon an investigation of textual practices as way to map social relations. Characteristically, textual analysis examines how the "language of documents operates as a conceptual coordinator of social action and how texts are connected to a larger set of social relations" (p. 30). The intersection of extended social relations and the actual experience of reading is explored in a way that encourages the researcher to investigate activities in a particular location. The researcher is also invited to explore moments of observation and how they are organized by social courses of action extending beyond that particular location, time, and the people directly involved (Smith, 1990a, p 151).

In my inquiry, the health care providers worked for organizations in which they assumed responsibility for communicating textually about the service they provided Nina.

> The investigation of texts as constituents of social relations offers access to the ontological ground of institutional processes which organize, govern, and regulate the kind of society in which we live, for these are to a significant degree forms of social action mediated by texts. Bureaucracy, professional and scientific discourse, objective forms of management, are in various ways dependent upon textual communications, increasingly, of course in the form of computer print-outs or video displays, but textual none the less (Smith, 1990b, pp. 121-122).

As a method of inquiry, textual analysis focuses the research process on identifying and displaying how texts are produced and how they participate in ongoing sequences of action through a text-reader interaction. Textual analysis "attempts to make explicit the activities involved in producing documents, demonstrating procedures involved in writing and reading accounts, and showing how the account is legitimated within itself as an actual account" (Swift, 1995, p. 27). For institutional ethnographers conducting a textual analysis, it is essential to understand that texts intend specific interpretative practices while operating as a constituent of social relations. Texts of professional practice are constructed within both professional and organizational contexts of interpretation. In an organizational setting, Ng (1995) suggests that there is a particular interpretative schema conceived "which is embedded in and articulated to the ruling relations within the bureaucratic state apparatus. This interpretative schema can be recovered from the analysis: the 'analysis will display how the text makes sense'" (Ng, 1995). The texts I use in my analysis consist largely of forms provided by the health care agencies and used by the health care providers in their practice. My analysis displays how organizational work is accomplished in and through the texts.

Interpretative practices, as defined in this inquiry, refers to those methods in which "what we see and hear is interpreted in relation to an underlying pattern or schema; the underlying pattern or schema selects and orders the way we attend to things and hence what we see and hear" (Smith, 1999, p. 163). The text's ability to structure and intend interpretative practices, through an ideological schema, is made evident through the analysis process—it draws attention to "what we know how to do" (Smith, 1990a, p. 152). The researcher engages in discovering the underlying schema in the text and employed by knowledgeable readers who read it. Smith (1990b) suggests researcher analysis does not require the researcher to stand apart from her everyday world but rather it allows the researcher to draw from those experiences. Textual analysis, therefore, "must explain how the text as petrified meaning structures the reader's interpretation and hence how its meaning may be entered into succeeding phases of the relations" (p. 223). As a researcher

> I explore the reader doing knowing where knowing is specifically a practice of reading. In doing so, I rely on experiences of reading, of what I know to do as reader. The method explicates practices within which what might be recuperated as experience arises. Texts are analyzed to display what the subject knows how to do as reader and what the subject knows how to do in reading, and in so doing also displays the organizing capacity of the text, its capacity to operate as a constituent of social relations (Smith, 1990b, p. 5).
>
> The interest is in the social organization of those relations and in penetrating them, discovering them, opening them up from within, through the text. The text enters the laboratory, so to speak, carrying the threads and shreds of the relations it is organized by and organizes. The text before the analyst, then, is not used as a specimen or sample, but as a means of access, a direct line to the relations it organizes. It is in the same world as she is (Smith, 1990b, p. 4).

Through textual analysis, therefore, the researcher is able to explicate how the competent reader is able to activate the power of text. The notion of "competent" reader, in the context of an inquiry, requires the researcher to have or gain some familiarity with the interpretative practices required by the text in order to conduct a proper analysis. Smith suggests that in a situation where the researcher does not have this ability, she will have to learn it (Smith, 1990b, p. 223). In applying this to myself as researcher, I do not have the specific practice knowledge the health care providers had during their work. However, I do have considerable organizational experience working as a human service provider, familiarity with the professional discourses, and knowledge of the type of administrative forms used by each person involved. It was possible for me, I believe, to draw from those knowledges and bring them to my analysis. In doing so, I fully acknowledge that as I engaged in textual analysis by employing interpretative practices, I, too, had a place in the constituted social relations and, as explained in an earlier chapter, did not stand apart from my research.

As a 'competent' reader employing interpretative practices, therefore, I found it essential to ensure that I only used those practices the texts intended. In that way, my analysis is committed to discovering and displaying what the texts preordained the reader should 'see', such as various professional and organizational policies and practices. The second level of research is to find the organization of the texts themselves. According to Smith, this outcome is achieved when the texts demonstrate unity arising from the analysis. Operating within this framework, therefore, I conducted an inquiry to discover how the health care providers' texts mediated knowledge about Nina through designated interpretative practices and how those texts became a part of ongoing courses of action. I examined how the texts directed reader interpretation and what the resulting effects were. In that way, it was possible to accomplish the overriding purpose of institutional ethnography—"to discover the ways that generalized institutional relations shape the bases of everyday experiences" (DeVault, 1999, p 50)—and to achieve my inquiry's objectives. At the same time, I realize that many questions about Nina's experiences remain unanswered.

> In fact, the social relations structuring the "actual world" of interest to institutional ethnographers are constantly changing; as a result, analyses can never be settled or finished, but instead are thought of as "open at the edges"- always leading to new questions and projects. (DeVault, 1999, p 50).

Validity and Reflexivity

A review of the qualitative methodological research indicates that developing criteria for assessing the quality of research is an extensively debated and complex issue.

Researchers working within the positivist paradigms, for example, have concerned themselves with notions such as validity, reliability and objectivity as ways to evaluate their research. Postpositivists, constructivists, critical theorists, feminists, and postmodernists have reconceptualized the positivist criteria and have adopted varied approaches to determining what constitutes solid interpretation in qualitative research.

Altheide and Johnson (1998) suggest that a critical question to ask when evaluating research is "How should interpretive methodologies be judged by readers who share the perspective that *how* knowledge is acquired, organized, and interpreted is relevant to *what* the claims are?" (p. 284). They indicate, in response, that there must be a "logic for assessing and communicating the interactive process through which the investigator acquired the research experience and information" (p. 284). They argue that one significant conceptual way of addressing this issue is through *validity* which they believe is grounded in the notion that "the social world is an interpreted world, not a literal world" (p. 284).

Validity depends, in their view, upon interpretative practices of the researcher, the researcher's audience, and the goals of the research. "All knowledge and claims to knowledge are reflexive of the process, assumptions, location, history, and context of knowing and the knower" (Altheide & Johnson, 1998, p. 288). A "reflexive accounting" (p. 278), in which the researcher is a component of the "setting, context, and culture he or she is trying to understand and represent" (p. 285), requires the researcher to interpret data in a way that "directs attention to the situated, relational, and textual structures of the ethnographic experience" (p. 278). Institutional ethnography, while similar, introduces the notion of "social relations" which, as a theoretical concept, guides the research process. The researcher's task is to make explicit (i.e., to explicate) the social relations that are constitutive of social action and the settings in which she is interested.

According to Smith (1987), institutional ethnography is a commitment to "an investigation and explication of how 'it' actually is, of how 'it' actually works, of actual practices and relations" (p. 160). As a result, questions of validity "involve reference back to those processes themselves as issues of 'does it indeed work in that way?' 'is it indeed so?'" (p. 160). G. Smith (1995) describes the epistemological shift required in using this approach and states:

> This is not a shift from an objective to a subjective epistemology–which some feminists have chosen to make–but rather a move from an objective to a reflexive one, where the sociologist, going beyond the seductions of solipsism, inhabits an actual world, the social organization of which she is involved in investigating. (p. 22)

In making this observation, G. Smith (1995) highlights the notion of reflexivity which Rodney (1997) suggests does express itself throughout feminist methodology and is common to constructivist approaches (p. 135). Reflexivity, according to Rodney, is an aspect of inquiry that requires researchers to be familiar with themselves and "their interactions with others throughout the research process" (p. 135). As a sociologist, Smith (1990a) extends the notion of reflexivity:

> Partial reflexivity involves the explication of the theorizing, categorizing, and conceptual practices of sociology as features of settings; a second partial reflexivity recognizes the placing, person, and values of the researcher. Full reflexivity is achieved when we recognize our entry into the social relations of which we speak so that we can address our own practices as sociologists as well as grasp how we may enter these processes at the other end of a chain of organized social activities (p. 147).

My inquiry, therefore, is a reflexive inquiry in which I am investigating those social relations I actually participate in. By exploring my topic in this way, I bring into view my own actual practices of "thinking, reasoning, reading, making sense of accounts" (Smith, 1990a, p. 203) while also exploring the social relations relevant to my inquiry. As I draw upon my own knowledge and competencies, I, too, participate in the social organization of knowledge about Nina.

Generalizability

Institutional ethnography bypasses the issue of whether the study of a single case can be connected to a broader, more general statement about a societal issue or a subgroup of individuals or connected to a scholarly discourse. According to Smith (1987), "the relation of the local and particular to generalized social relations is not a conceptual or methodological issue, it is a property of social organization" (p. 157). In using a particular situation as a point of entry, it becomes the "locus of an experiencing subject or subjects, into a larger social and economic process…the problematic of the everyday world arises precisely at the juncture of particular experience, with generalizing and abstracted forms of social relations organizing a division of labor in society at large" (p. 157).

As the properties of social relations organize our everyday world, we often have difficulty seeing how the locally experienced is connected to the more generalized character of its social organizations:

> The generalized character of such local social organization is determined by the generalized social relations (of the market) to which its is articulated. . . Investigating the everyday world as problematic involves an inquiry into relations that are themselves generalized through exploration of the character of those relations from the standpoint of everyday experience (Smith, 1987, p. 159).

In this inquiry, the textual representation of Nina, which was located in the everyday world, serves as a point of entry into my inquiry about the more generalized relations of the health care providers. These health care providers—the emergency physician, the hospice volunteer, and the home care nurse—were linked through their work processes to their organizations and their relations made manifest through texts and textual practices. Nina's experience is a constituent of those complex relations that textually construct her as a child dying from a "terminal illness." The aim of my inquiry, therefore, is to explicate how those complex social relations construct knowledge in specific ways and how they "may be explored to uncover their ordinary invisible determinations in relations that generalize and are generalized" (Smith, 1987, p. 160).

Ethical Considerations

In a broad, general sense and in relation to this inquiry, Stake (1995) observes that "an ethic of caution is not contradictory to an ethic of interpretation" (p. 12). According to Stake, who raises this consideration in the context of case studies, I have an ethical obligation to "minimize misrepresentation and misunderstanding" (p. 109) in the way in which I present the data obtained for purposes of my inquiry. To achieve this objective, I have obtained and relied upon data located in the public realm and available to members of the public who wish to review it. The specific textual components, referenced in this inquiry and attached as Appendices, are photocopied directly from the documents and do not contain any alterations to their original form.

I have, however, addressed a second ethical consideration related to my inquiry that concerns whether the various people I have referred to – people who continue to live and work in the province - might be harmed in some way. Subsequent to Nina's death, for example, the RCMP, the Coroners Service, a provincial children's commission and other agencies conducted numerous reviews and investigations regarding the circumstances surrounding Nina's death, which received considerable media and public attention. The Coroners Service jury's classification of Nina's death as a "homicide" contributed to its sensitive and controversial nature. For those reasons, I have considered whether there is any potential harm that might arise to those persons referred to within the framework of this inquiry and the implications for them if I reveal their identities.

In an effort to prevent any possible harm to these individuals, I have put safeguards in place that are designed to protect the privacy and identity of those persons involved in the circumstances relating to Nina's death. I have used pseudonyms to conceal the identities of the people involved and the location of Nina's death. Secondly, I have obscured identifying information in the Appendices that might also reveal the names of various people, including Nina, and where the events took place. As the line is sometimes blurred between what is 'private' and what is 'public', protecting identities and concealing locations will hopefully alleviate any concerns that might arise about the concept of what is 'private'. My inquiry's focus is on texts and institutional textual processes, as opposed to the wrongdoing of individuals.

Finally, ethical considerations also arise in relation to Nina's mother and her siblings. In my analysis of texts generated by the health care providers, I discovered that Nina's mother is present only in "reported speech" while Nina's siblings exist in some textual accounts in name only. While it is possible to assume that information recorded about Nina in the health care providers' texts originated from conversations between Nina's mother and the health care providers, none of the texts I analysed indicate the health care providers elicited or recorded Nina's mother's or her siblings' own stories. The absence in the texts of Nina's mother's and the siblings' voices, therefore, has the effect of silencing them in my textual analysis despite their own unique experiences and perspectives. However, my inquiry does not focus on what they might have said about Nina, instead my analysis is centered upon explicating a text-mediated process coordinating the health care providers' work, which included what Nina's mother possibly reported to the health care providers prior to Nina's death. While Nina's mother's and her siblings' had their own accounts about Nina's story and their relation to it, my textual analysis examined the role the health care providers' texts played in the constructed view of Nina as a child with a "terminal illness". My inclusion of the child care worker and teacher's accounts of Nina in my thesis is not intended to diminish the significance of those other accounts. Rather, my purpose is to remain within the realm of service provision to Nina and to illustrate how people providing services to children sometimes 'see' those children in different ways.

CHAPTER FOUR: JOINING THE CONVERSATION

Introduction

> People-processing professions routinely compile documents and records of professional-client interactions, in the production of medical records, case notes in social work, and so on. These written records inform future action, and are themselves fed into the recording mechanisms of official statistics, performance indicators, efficiency league-tables and similar constructs…The point is to remind us of the pervasive significance of documentary records, written and otherwise, in contemporary social settings (Atkinson and Coffey in Silverman, 1997, p. 46).

As I formulated my inquiry I found it necessary to identify those scholarly discussions most pertinent to the issues raised in my inquiry. These discussions, I learned, fell within the realm of "discourse" about which many divergent and varied opinions exist. Dant (1991), for example, defines discourse as "the material content of utterances exchanged in social contexts that are imbued with meaning by the intention of utterers and treated as meaningful by other participants" (p. 7). For purposes of this inquiry, however, I have chosen to adopt Smith's (1990b) notion of discourse taken from from Foucault "in whose work it defines as an assemblage of 'statements' arising in an ongoing 'conversation', mediated by texts, among speakers and hearers separated from one another in time and space" (Foucault, 1972 in Smith, 1990b, p. 161). The conversation my inquiry brings me to, as a participant, is one that speaks about professional textual practice within an organizational context, and the role professionals' texts play in the construction of knowledge, particularly about children.

As a researcher, and as a human service practitioner, I have observed how professional workers providing services to children construct 'knowledge' about those children in their textual practices. For many of us, the question arises as to how accurate our knowledge is about what we claim to know and whether the knowledge we acquire truly serves the interests of children. The conversation I am interested in, therefore, falls within a body of theoretical approaches concerning professional practice as it relates to textually constructed knowledge within an organizational setting. Through an examination of the related literature, it is my intention to glean a deeper, more generalized understanding about the role texts play in the social construction and regulation of services to children. Throughout this chapter, I maintain an interest in the role of texts in professional practice, for reasons explained in previous chapters. By approaching my inquiry in this way, I am able to embed my analysis of the health care providers' texts in a theoretical reading that will allow me to make sense of what is before me.

Professional Practice and Ideology

I am studying the circumstances surrounding the death of a child, Nina, who came to the attention of social services and health care professionals approximately two weeks before she died. When that happened, Nina entered a world in which professional discourse was a prominent feature informing professional practice. In a broad sense, the poststructuralists, including Foucault, suggest it is impossible for any person to avoid participation in discourse whether it is professional or otherwise. De Montigny (1995b) notes, however, that professional groups—nurses, physicians, social workers, lawyers, psychiatrists, engineers—have developed a specialized language identifying their participation in a particular discourse and signaling their membership in an identifiable group (pp. 68-69). People associated with providing palliative care, for example, constitute a discernible group made apparent through a distinctive palliative care discourse with language and terminology specific to their group. This participation in a discourse, whatever its orientation, does not imply strict adherence to one's own professional language nor does it ignore the role texts and textual practices play.

De Montigny (1995b), who refers to the professional/organizational setting of social work as a single place, suggests that creating textual accounts within an organizational context is a part of professional practice, incorporating professional language and representing the organization of "daily activities into proper professional routines" (p. 216-217). The process of documenting professional work, in this context, unfolds as one in which "events in the ordinary world are reconceptualized and entered into documentary reality" (Smith, 1988 in De Montginy, 1995b, p. 217). This documentary (or textual) reality, represented through organizational administrative forms, expresses the organization's mandate and ties professionals' actions to their organization through the use of its concepts and categories. The textual language used commits the reader to an interpretation that is in keeping with the organization's mandated course of action (Smith, 1990b, p. 153). Eventually, the organizational account, "that is, the sequence of action described in properly mandated form, embeds and subsumes the observational mode. This operation depends heavily…on the use of distinctive terminology" (p. 153). This "distinctive terminology" fits within the realm of professional discourse.

According to De Montigny (1995b), professional discourse is ideologically constructed, and participants in a professional discourse, as distinct from people who speak an "ordinary" language, "construct the appearance that their speech acts and understandings are not indexical or tied to determinate lived and shared personal domains" (p 70). This construction is aided through forms of communication mediated by texts, constituents of ideological processes serving to coordinate forms of social consciousness located in different sites (Smith, 1990b, p. 214). De Montigny's observations, therefore, invite a certain skepticism about claims to professional "knowledge." As Smith suggests, when we identify local practices as located within the "social organization of textually mediated discourse," it is possible to identity those practices as existing at the level of ideology as opposed to "actual lived activity" (p 214).

The Oxford Dictionary of Current English (1992), in defining ideology in classic terms, refers to it as: "1. ideas at the basis of an economic or political theory (*Marxist ideology*) 2. characteristic thinking of a class etc. (*bourgeois ideology*)" (p. 436). In a departure from this traditional notion of ideology, Ng (1995) suggests the use of the term "ideological frame":

> Ideological frame does not simply refer to a bias or a set of beliefs. It identifies ideologies as processes that are produced and constructed through human activities. They are ways in which capitalist societies are ruled and governed (see Marx and Engels 1970; Gramsci 1971). Once an ideological frame is in place, it renders the very work process that produced it invisible and the idea that it references as 'common sense' (Gramsci 1971). That is, the idea(s) contained within the ideological frame become normalized; they become taken for granted as 'that's how it is' or 'that's how it should be'" (p. 36).

Like Ng, Smith (1987) also retreats from the characteristic view of ideology as strictly pertaining to political beliefs or as representative of a perspective grounded in a bias connected to a particular group or class. Rather, she proposes ideology as a conceptual practice in which the ideas and orientations of an intelligentsia organize, regulate, and sanction the social relations that sustain its authority:

> The concept of ideology brings into focus the conscious production of the forms of thought by a ruling class or that section of a ruling class known as the intelligentsia, which serves to organize and order the expression of the local, particular, and directly known into forms concordant with its interests, aims, and perspectives (pp 55 – 56).

Smith (1999) claims that ideology is an "organizer," along with concepts and theories, of discourse's relations and process (p. 173) and that ideology involves "methods of creating accounts of the world that treat it selectively in terms of a predetermined conceptual framework" (Smith, 1990a, p. 93). In an article arising from his study of the management of the AIDS epidemic in Ontario, George Smith (1995) specifically links ideology, as a form of social organization, to a dependency upon texts organized "from a standpoint, with an objective structure of relevancies located in documents, in a virtual reality, outside actual local settings" (p. 21). Dominant interests intent on ruling, he continues, impose "objective, textually mediated, conceptual practices on a local setting" (p. 21), such as those experienced by health care providers in their everyday practices. In other words, the discourses of the health care profession, for example, impose ideological features from outside the local setting that determine how textual information is collected and interpreted.

Socially organizing knowledge in this way produces the epistemological line of fault between texts read as authoritative within the organizational context, and everyday knowledge about people like Nina, her family, and 'significant others' in her life. When professionals, such as health care providers, submit to an "ideological gloss" in their production of textual accounts about an individual that person is taken out of her actual context and entered into a textual description that complements the "underlying pattern" supplied by discourse (Smith, 1990a, p. 182). When this happens, "the subject's voice is silenced, sealed over; its objectified invalidation validates the 'normal'" (p. 196). Readers who are competent in ideological procedures employ interpretative reading practices that also render the subject invisible when they endorse the objectified version represented in the text. The way health care providers' texts are produced and interpreted in their reading, therefore, influences what we, as readers, can know from the text about the subject's (such as a child's) "point of view, her feelings, and her responses to events" (p. 182).

In investigating the complex notion of ideology, Smith (1990a) proposes the concept of "ideological circles" in which ideology as a feature of organization is distinguished from systems of belief and the "intellectual practices of individual participants in a discourse" (p. 93). In her analysis of ideology as practice, Smith suggests that these circles construct "unassailable loops" in which organizing procedures for collecting, assimilating and producing information about people's lived experiences are structured through a predetermined conceptual scheme. For example, medical discourse, as a conceptual scheme, structures the organizing procedures on a hospital admission form and other standardized medical assessment forms. This conceptual scheme, originating in the prevailing ideology, determines what information is collected. That information, in turn, results in the construction of "knowledge" about a particular person who may be the subject of a health care intervention (p. 94). In many instances, the professional person engaged in these organizing procedures is situated within the context of an organizational setting. Both the professional and organizational relevancies structure the accounts professionals make.

Professional Practice—Organizational Relations

Sound professional practice is often equated with solid organizational work requiring the professional person, such as health care providers, to manage both their professional work and the work of the organizations that employ them. Professionals, with professional responsibilities and obligations, are also employees working for agencies and organizations requiring them to adhere to legislative mandates, policies, standards, and organizational directives. With the professional agenda linked textually to an organizational agenda, incompatibilities can arise between professional and organizational practice. This, in turn, raises questions about the role and influence of bureaucratic organizations on professional practice. De Montigny (1995b) suggests that a professional, such as social worker, "operates as a piece of organizational work processes and constructs the coherence, visibility, and warrant of activities as professional work performed on behalf of the organization" (p. 46).

Smith (1987) discusses the methodological significance of the organizational and professional work combination. She observes that institutional processes actually organize the responsibilities of professionals who work in bureaucratic settings such as hospitals and health care agencies - a consideration relevant to the "totality" of work processes as they exist:

> Addressing the institutional process as a work organization in this sense means taking as our field of investigation the totality of work processes that actually accomplish it: hence it means going beyond the functional boundaries as these are defined by its ideological practices to explore those aspects of the work organization that are essential to its operation. For these are an integral part of its operation, whether they are recognized or not and whether or not they might be considered positive (or functional) in relation to its objectives (pp. 165-166).

Smith's (1987) view encourages us to identify the processes that produce and order the extended involvement professionals have with each other and the lived experiences that people observe and describe. Texts, as a constituent of these processes, often invite scrutiny for that very reason.

According to De Montigny (1995b), the ideology of the social work profession, as an example, provides a set of conceptual tools for organizing practice and for managing a situated work process. In addition, "the art of producing a professional identity allows a person to insert himself or herself into discursively organized and warranted relations of power and authority" (p 48-49) within institutional settings in which professional work is functionally ordered by ideological practices operating within. Swift (1995), too, stresses the significance of ideology and its influence on practices and organizations. In her opinion, therefore, the concept of practice requires a "broad definition of work, including those activities of practical reasoning, speech and writing" through which the tasks of providing services to children, for example, are both produced and accomplished within an organizational setting (p 36). As Smith (1987) suggests, this concept of work incorporates "processes that both produce and are ordered by the social relations of the institutional process" (p. 166).

What About Texts?

Atkinson and Coffey (1997) suggest that organizational, professional, and various other social settings are frequently represented in research as though they have no textual component when they are "thoroughly dependent on paperwork" (p. 44). For that reason, they believe it is essential for researchers to "pay careful attention to the collection and analysis of documentary reality" within these settings (p. 46).

The process of documenting professional work is linked to professional accountability within the organizational setting. Within this context, Campbell (1995) has investigated the notion of textual accountability in nursing practice and its impact on professional nursing practice:

> The textually mediated practice of nursing has new importance in the information-structured hospital. The health care literature confirms that hospitals are relying ever more heavily on systemically produced information. Becoming information workers not only absorbs nursing time but it directs nurses' attention to particular elements of patient care and features of the patients themselves that provide the correct data for the required accounting (p. 231).

Textual practice is a skill that professionals learn. Campbell concludes that an accounting approach to nursing instruction, in which nursing students learn to follow procedures "for making their work known and knowable to others in documents" (p. 221), actually trains nurses to produce documentary forms that create the "appearance" of adequate professional practice. This approach displaces knowledge the students, and patients, too, may have about how they experience reality outside of these constraints (p. 232). Campbell expresses several concerns about the accounting approach to teaching nursing. She suggests, for example, that nurses learn to translate their experiential world into an organizational account. As a result, nursing as a textually-mediated activity undermines and replaces care-centered nursing. Secondly, an accounting approach to nursing obscures and organizationally obliterates nursing knowledge and nursing action beyond that which is mediated and documented (p. 232). In distinguishing between making sense of nursing situations for accounting purposes and making sense of nursing situations "in the everyday world of illness, pain, fear, medical emergencies, and so on," Campbell emphasizes the significance of recognizing and valuing both types of sense making. In other words, a strict adherence to textual accounting diminishes the potential for professionals to acknowledge a patient's, such as a child's, lived reality:

> Professional and bureaucratic procedures and terminologies are part of an abstracted system. Abstracted systems are set up to be independent of the particular, the individual, the idiosyncratic and the local….In actual operation…the abstracted forms must be fitted to the actual local situations in which they must function and which they control. In practice the abstracted system has to be tied to the local and particular…What actually happens, what people actually do and experience, the real situations they function in, how they get to agencies-none of these things is neatly shaped up. There is a process of practical interchange between an inexhaustibly messy and different and indefinite real world and the bureaucratic and professional system which controls and acts upon it. The professional is trained to produce out of this the order which he believes he discovers in it (Smith, 1975 in Smith, 1990b, pp. 153-154).

As Campbell (1995) argued, the professional is trained to participate in objectifying practices, which are textual in nature, by taking up the formal organizational records that have programmed them into their organizational mandates. She suggests that while texts incorporate professional agendas, there is an ideological effect in which professional interests are also subverted. Text-mediated processes make it necessary for professionals to set aside their systemic and individual professional agendas. Professionals are able to accomplish this by entering into and participating in constructing objectified textual accounts that constitute organizational and discursive relations beyond themselves (Smith, 1990b, p. 211). Swift (1995) states it is through those types of accounts and textual processes that "decisions about meanings and fact are conveyed to an audience not present at the actual events" (p. 27). The "audience" may be the organization's managerial decision-makers, other than professionals, who rely on textual information given to them by other individuals.

“Knowing Subjects” and Textual Knowledge

Professionals, such as health care providers, social workers, and educators working in organizational settings, are obliged to demonstrate their professional competency and accountability to the organization through their completion of administrative forms, or “textual accounts.” In the ensuing “textualization” of clients, professional practice is invariably subsumed and bound to those textual accounts. The knowledge of clients that is generated in such texts is shaped by organizational mandates that determine the categories commonly seen on official forms. In that way, professional knowledge is tied to the “ideological”:

> Work at hand is connected to organizational courses of action which are themselves outlined step by step in documentary form as policies, directives, and legislation. The textual mediation of everyday practice insures that it proceeds according to predetermined plan, inside determinate courses of action” (De Montigny, 1995a, p. 217).

When professionals, such as health care providers, participate in textual processes within an organizational context they record information about the client/patient who is the subject of their intervention. When offering services to a child, those professionals often rely upon the child’s representative as a knowledgeable informant who provides information the professionals subsequently record as what is “known.” What is “known” becomes “fact,” accomplished through complex, socially organized practices. According to Smith (1990a), who draws upon Foucault’s work, “knowing” is a subjective activity. It is an act with a social dimension. “Knowledge,” on the other hand, is a concept that renders invisible the presence of the knowing subject (p. 66). Knowledge, Smith claims, is “socially and materially organized, as produced by individuals in actual settings, and as organized by and organizing definite social relations” (p 62). Professionals, therefore, construct textual "knowledge" about a child, who may also be a "knowing subject" albeit without authority and a voice articulating what she knows about her daily experiences.

In her discussion about "knowing subjects," in the context of research, Prior (1997) draws attention to Charles Taylor's work in which he identifies the need for researchers to look beyond the knowing subject's "atomistic" world and "confront a dimension of human activity that cannot be contained in the consciousness of the isolated subject" (p. 64). Social life, according to Taylor, is connected to interdependent social relations with various dimensions. Like researchers, professionals providing services to a child may also find it necessary to look beyond the "atomistic" world of that child, and the child's representative, in recognition of these individuals as members of a larger social milieu and not isolated entities. While this concept of interdependent social relations is akin to Smith's (1990a) view, Smith distinguishes her view by acknowledging the continual significance of the knower as it is "embodied and situated in a local and particular world" (p. 62). While Taylor's approach suggests it is possible to "look beyond," Smith's analysis shows how professionals are connected to specific "ideological" ways of knowing and actually participate in it.

In her discussion about "knowing," Smith (1990a) draws attention to the difference between "knowing" as it arises from a person's direct experience and "knowing" as it arises from organizational factual accounts constituted as objective representations of events (p. 63). Professionals in organizational work settings, for example, shift "knowing" to "knowledge" through socially organized and coordinated practices – practices that structure knowledge production:

> The production of knowledge is often a complex organizational and technical process that gives the knowledge produced its distinctive shape. That social and technical organization is not apparent in the final product. Thus, a textually mediated reality incorporates the social organization of its production and the courses of action separating it from people's lived actualities. Furthermore, its character of knowledge involves the knower's own constitutive practices of reading and interpretation. Objectivity is accomplished through her practical knowledge of its social organization (Smith, 1990a, p 63).

Knowledge, constructed in this way, is generated in a predetermined manner through the social organization of ruling practices. A resulting effect is that professionals adhere to routine and authorized practices, which are endorsed in ideologically "known" terms. While the professionals are competent at doing the work involved, the texts structure their accounts according to their professional mandate, the organizational agenda and the type of services provided. The voice of the objectified client, or patient—filtered through the professional voice representing the client/patient's account—is also subsumed in the process. Knowledge about a child, therefore, is mediated by objectified textual accounts that subordinate and eclipse the child's voice (Smith, 1990a). Professionals such as health care providers providing services to children do not work in isolation from one another but rather are connected through these socially organized practices which structure original events to conform with their present involvement. The "knowledge" they record about a child, for example, suppresses or subdues the "knowing subject," such as the child, leaving her behind. The text moves forward as objective. The information recorded in the text as "knowledge" becomes organizationally known in a way that creates "virtual realities" directing interpretative reading practices.

> The realities to which action and decision are oriented are *virtual* realities vested in texts and accomplished in distinctive practices of reading and writing. We create these virtual realities through objectifying discourse;

> they are our own doing. Employing them, we separate what we know directly as individuals from what we come to know as trained readers of texts (Smith, 1990a, p. 62).

Textual Voice and Authority

In the generation of organizational textual accounts, data for that textual construction originates from a variety of sources, including the service recipients themselves, such as children. Health care providers, however, become the "authorized contributors" to the account by virtue of their direct professional involvement in providing service and their textual accountability. As they construct textual accounts, the health care providers stand as the authors of accounts representing, in textual authoritative form, what the patient has said, among other things. In these circumstances, Smith (1990a) states that the patient (such as a child), family and friends "appear only in 'reported' speech" (p. 99). In this way, a child's voice is silenced and what the child or the child's representative may say is located inside professionally dominated schemata, such as a medical discourse, and built into the categories existing in the administrative forms (p. 100). The totality of a child's experience, including such features as family and school life, is subjected to a selective accounting "assembled according to rules and conventions, and deploying categories and concepts expressing discursive schemata" (p. 100). De Montigny (1990b) observes in his analysis of organizational records produced by social workers that the clients' voices were absent among the file information representing documentary facts: "Inside the spaces of the file, the actual voices of the clients were silenced" (p. 212).

As the prior discussion suggests, keeping a child's voice alive in textual reporting is difficult. It may be impossible. In many instances, for example, a child's voice is represented by other people purporting to represent his or her interests. Professionals, such as health care providers, selectively record what information is already selectively offered on a child's behalf. According to Smith (1990b), these types of inscriptive practices in which the totality of a child's life experience is expressed through a discriminating, professionalized process produce a "textual reality" which only reveals what is admitted through that type of process (p. 100):

> Everything going on in the everyday settings to which a social worker (or nurse) has had access that does not fit the prescribed frameworks of reporting is left unsaid; there is, organizationally, no way of saying it. To step outside the professional role, to use a language that is not already fitted to the circular frameworks established by the professional division of labor, ensures that what is said will have at best an uncertain place, lacking authority. If it cannot be resolved into the appropriate terminology, it cannot gain currency in the system (p. 100).

When a professional person constructs an official organizational account of a professional intervention, for example, this account makes up a "proper file record" representing their professional knowledge and their competence in fulfilling the organizational mandate (De Montigny, 1995a, p. 212). The recordings in these accounts signify the professional's words as reconstructed from client's, or patient's, words and mediated through an institutional and professional voice (De Montigny, 1995b, p. 55). This approach gives professionals, such as health care providers and social workers, an authority or power that is denied the client/patient. Within the world of multi-disciplinary professionals, however, there is also an authoritative hierarchy structuring the organizations they participate in and impacting divergent professional worlds. Atkinson and Coffey (1997) suggest that organizational records actually "inscribe positions of hierarchy" (p. 58) in the way in which they report "discussions, decisions, and events to people or bodies that are superior to the originators" (p. 58). In that way, "documentary realities, based on complex inter-linkages between documents, *create* their own versions of hierarchy and legitimate authority" (p. 58).

Authority in textual accounts implicitly directs a reader on how to interpret a particular textual account. According to Smith (1990b), the "authorization rules" offer the person who constructed the account, the "witness," a privileged status not accorded to the reader. Under these circumstances, the reader can only speculate about an alternative account and limits her conjecture to what actually appears in the text before her (p. 49). Within an organizational setting, however, these accounts differentiate themselves from personal communications in their transferability, "facelessness," and ability to be combined in a variety of ways. The text becomes the conduit for the client/patient's story and takes on a permanence that does not exist for speech (De Montigny, 1995b, p. 213):

> The voice of the storyteller becomes the voice of the text. The text tells the story. The concreteness of a text-a book, or journal taken from a shelf by a hand and read individually-separates that which is said from the person who said or wrote it (De Montigny, 1995b, p. 64).

The foregoing discussion suggests that a professional who constructs authoritative textual accounts also participates in privileging, or giving authority to, some voices and not to others when, for example, that professional is not present at an actual event. When gathering information pertinent to children, professionals often privilege an adult voice over a child's voice. That child's voice, already silenced through representation, is further distanced and silenced by textual constructions purporting to reflect that particular child's reality by selecting information deemed "relevant" as predetermined by administrative, organizational textual forms.

Categories in Texts

Typically, organizations manage professional work through the use of textual accounts, such as administrative forms that utilize organizing procedures represented as categories in which the professional is expected to place "relevant" information:

> It is the normal feature of such accounts that they do not contain irrelevant material. Irrelevant material is material which neither (a) establishes the adequacy of the authorization procedures used nor (b) is appropriate to and can hence be appropriated interpretatively by the conceptual framework. The reader/hearer cannot go back to the personages of the original to recover material which might be relevant to an alternative construction (Smith, 1990b, p. 49).

According to Smith (1990b), placing relevant information in categories transfers the professional from the local place in which she observes a sequence of events to "organizational time" (pp. 212- 213). Swift (1995) discusses the use of categories in context of social work practice.

> Categories are created and sustained as a feature of the orderly processes of bureaucracies, brought into play, as Ferguson argues, in order to 'normalize' the poor, with an intended result of ordering social life in a way that addresses identified problems. Through the techniques of bureaucratization, which provide for 'problem identification' and for the creation of categories ordering their solutions, service to individuals can be provided without disrupting class relations (p. 54).

Swift's observations about social work practice can be applied to health care practice. Health care providers frequently work within bureaucratic structures requiring the use of written texts comprised of categories identifying "problems" and "ordering their solutions." While these written texts are tied to a practical usefulness, such as the need for professionals to account for their actions, there is underlying structure of power attached to their existence. From a theoretical perspective, Swift (1995) suggests that categories on administrative forms, an ordinary social concept, perform a function of social reproduction; it is a reproduction of the structure of power relations (p. 11). These power relations are maintained when an organization requires professionals to use standardized, administrative forms as they collect information about a particular client or patient and to complete the categories represented on these forms. These designated categories predetermine what information *will* be "relevant" and often do not allow for the recording of information for which there is no category:

> The categories structuring data collection are already organized by a predetermined schema; the schema interprets the data. Any questions bearing on the facticity of statements based on the intersection of data and interpretative schema (such as issues of accuracy, reliability, and the like) may be raised without breaking the ideological circularity of the procedure. For though it is perfectly possible to prove or disprove statements, issues of objectivity must be framed within the established structure. Issues, questions, and experiences that do not fit the framework and the intercalated relation of categories and schemata simply do not get entry to the process, do not become part of the textual realities governing the decision-making processes (Smith, 1990a, pp. 93-94).

These "textual realities," within the context of human service work, lead to the establishment of individuals as "cases" and their "current status," separated from their lived reality, becomes located in their textual histories. Foucault (1977), in his discussion about administrative documentary practices and medical examinations, speaks to the transference of an individual into a "case:" "a case which at one and the same time constitutes an object for a branch of knowledge and a hold for a branch of power" (p. 191). It is an objectifying practice in which the case records pertaining to an individual become an organizational achievement and exist in a definite form, removed from the lived, transitory experiences of the individual, as the property of the organization. Texts, and textual practices, play a significant role, therefore, in directing how children will experience their contact with professionals working within organizational settings.

"Facts," "Factual Accounts" and Texts

When professionals, such as health care providers, record information about a child in a textual account, there is definite movement from hearing about events in the child's life to recording it in an administrative form that represents it as objective "facts" of the situation. According to Smith (1990b), however:

> The actual events are not facts. It is the use of proper procedure for categorizing events which transforms them into facts. A fact is something that is already categorized, already worked up to conform to the model of what that fact should be like. To describe something as a fact or to treat something as a fact implies that the events themselves -what happened - entitle or authorize the teller of the tale to treat that categorization as ineluctable. 'Whether I wish it or not, it is a fact. Whether I will admit it or not, it is a fact' (Smith, 1990b, p. 27).

Smith (1990b) stresses the significance of the "process of inscription" where a person's lived experience is "converted into the conceptual and categorical order of organizational or discursive courses of action" (p. 216). An important consideration in this process is how factual accounts are produced for "if something is to be constructed as a fact, then it must be shown that proper procedures have been used to establish it as objectively known. It must be seen to appear in the same way to anyone" (Smith, 1990b, p.27). Facts, and the use of facts in textual form, are what coordinate activities among professionals and within organizations. Facts are external to the person constructing a textual account; they are construed as "the same" to everyone and retain that "sameness" throughout their circulation. De Montigny (1995a) draws attention to how entering information in a document, or text, relies upon "a complex organizational division of labour, elaborate professional knowledge, everyday organizational relationships, and a multitude of cultural and class assumptions…" (p. 210).

In Swift's (1995) opinion, when service providers, such as social workers, report on the "facts of the case," in actuality they obscure and distort the facets of other realities (p. 10). In her example, a child's reality is presented through an ideological lens informed by a social work discourse. Both Swift and Smith agree there is an unseen but operative schema in place that provides the framework for directing the selection of facts (Smith 1990b; Swift 1995). According to Swift, "these two operations reinforce one other [sic]: The facts that are selected are both directed by the framework and operate to substantiate, justify, and reproduce the framework" (p. 28). These factual accounts, once produced, make up the formalized, institutional accounts that allows them to be entered into organizational courses of action leading to decision-making about services required (Smith, 1990b, p. 217).

When the factual account—a reworked version of an individual's lived reality and "what actually happened/what is"—is an organizational account, it stands as an official version of what is not known in any other way.

> The social organization of reading factual accounts "inserts" categorical, conceptual, and syntactic procedures into the actuality. The interpretative schema established by the account governs the procedures used to select, assemble, and attend to the actuality. It appears not as an imposition upon the latter but rather a revelation of how it is (Smith, 1990a, p. 75).

The procedures inherent in factual accounts, therefore, determine how competent readers will interpret the information represented. The meaning derived from it will reflect what the factual account intends. In the course of recognizing this process of producing and interpreting factual accounts, however, it is also important to pay attention to where the "knowing" that informs those textual accounts originates and how it is distinguished from what actually happened.

Alternative Accounts

According to De Montigny (1995a), the "authority of professional accounts silences alternative accounts" (p. 218). The text-mediated organizational process, bound by commitments to professional and organizational discourses and mandates, employs terminology redefining experiential accounts such that they authenticate the organizational process.

> The powerful effect of this descriptive strategy is this: once the institutional language has been substituted for detailing, the information it locks in cannot thereafter be recovered. It is a language which is capable of subsuming and claiming an indefinite variety of actual sequences of action, transforming the indeterminate into the determinate, producing them as typical organizational events. Their distinctive local historical character disappears and information relevant to the selection of alternative interpretative schema is no longer available (Smith, 1990b, p. 154).

This effect directs the reader, therefore, to take up the textual content as it is presented. The competent reader, such as a professional worker, is already proficient in organizational and professional procedures and fluent in this kind of interpretative reading which is done within the fragmented structure of an organizational setting. Two authors, Smith (1990b) and Swift (1995), observed how the work of professional individuals is separated from the governing aspects of the organization (Smith, 1990b, p. 213; Swift, 1995, p. 54). According to Swift (1995), for example, "the child welfare setting displays all of the major features of bureaucratic organization which has become a highly fragmented process, with each worker performing only a small piece of the work involved in 'processing' any one case or client" (p. 54). As a result, a professional worker reads a textual account limited in her direct knowledge about the client/patient's story and is restricted in her ability to form an alternative account. The worker's inability to form an alternative account is already hindered by organizational administrative processes determining what information is admissible and what is not.

My inquiry explicates the health care providers' textual accounts produced as authoritative and official during the provision of services to Nina. In the process, I attend to how alternative accounts were subdued.

CHAPTER FIVE: LOCATING THE CHILD

> States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance, and facilitate the child's active participation in the community.
>
> Recognizing the special needs of a disabled child, assistance…shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development (Article 23, UN Convention on the Rights of the Child).

This chapter represents my attempt to personalize and humanize Nina's existence; it is an effort to heighten Nina's visibility as a child who had an emotional, psychological and social life coexisting with her physical existence. This chapter also tries to illustrate the extent of Nina's textually represented transformation within an eight-week period from a child living with her family and attending school on a full-time basis to a child who died from "severe malnutrition". To accomplish my objectives, I provide a brief overview of the sequence of events in Nina's life during the two month period before she died and, secondly, provide information reported by people who worked closely with Nina during that time—her child care worker and teacher. The documents entered as exhibits at the Coroners Service inquest provided the source of information I have drawn from. My primary intent is to offer the reader some insight into the broad context of Nina's life, as it existed in the months prior to her death and, through the child care worker and teacher's accounts, a glimpse of 'who Nina was' to them and possibly to others.

As a researcher, I do not purport to 'know' Nina's story nor do I suggest that the information I provide in this chapter characterizes how Nina would have described her life experiences. And, as a researcher, I acknowledge that the stories about Nina and the accounts of events in her life do not originate from her own voice but rather are gleaned from other persons' textually recorded observations provided by those people providing services to her. As author I have selected aspects of Nina's story which, as it will become apparent in subsequent chapters, vary from other facets of her story as they appear in the formal organizational accounts I later analyze. Through these constructed accounts, I hope to encourage the reader to consider what Nina might have liked and not liked, her strengths, the types of activities she might have participated in, and how her daily life unfolded in the weeks prior to her death. While these questions may not be answerable within the context of my inquiry, the textual information available about Nina may shed some light on how people who had intimate, daily contact with her described their experiences with her and how they might have addressed those considerations.

The accounts or 'stories' in this chapter attempt to locate Nina in her everyday world during the months prior to her death. By articulating these stories, however, I have introduced the complication of 'layering' voices in which my voice, as author, represents the voice of people who observed Nina within diverse locations and who experienced Nina's life with her during their time together. In constructing these stories, I have distanced the 'knowing subject,' Nina, by filtering other people's constructed accounts through my own voice. In many ways, this approach parallels the experiences of human service professionals working with children who are non-communicative. It mirrors, in many respects, the challenges human service professionals face when constructing and relying upon textual accounts under circumstances where a child does not speak directly. It raises questions, from my perspective, as to how we come to 'know' who a child is. As a researcher, I do not know how Nina would relate her own story. Nor do I make claims that one professional account is more accurate than another separate and perhaps divergent account. These accounts, like all textual accounts, involve a "selective representation rather than a reproduction of reality" (Hammersley, 1992, p. 69):

> We can never know with certainty whether (or the extent to which) an account is true; for the obvious reason that we have no independent, immediate and utterly reliable access to reality (p. 69).

I have no direct access to Nina's reality. My intent for providing these selective accounts, however, is to offer the reader a place to begin in Nina's life that, through its diverse accounting, encourages the reader to consider how Nina might have lived in her everyday world and to 'see' Nina's life in its broadest sense. I also hope to offer the reader an opportunity to distinguish Nina from how she was represented in the organizational texts I analyze in the following chapter.

Living with Rett Syndrome

In this section, I draw upon and include textual information made available to the public as a way to inform them about Rett Syndrome, a developmental disorder that is not commonly known. I also include information I obtained during my broad review of the exhibits entered at the Coroners Service inquest and have constructed an account of Nina's story as told through text.

In my review of the Coroners Service inquest exhibits, I learned that Nina began her life as a child who reportedly experienced typical child developmental stages until she reached approximately 18 months of age. At that time, Nina began to demonstrate certain characteristics, such as involuntary motor movements and loss of acquired skills, that are commonly associated with a developmental disorder called Rett Syndrome. After several medical investigations, physicians confirmed Nina's diagnosis and made recommendations about appropriate care for Nina as she grew older, participating in family and social life and attending school on a regular basis.

> [Rett Syndrome, first referenced in the scientific literature in 1983, was initially described as a progressive, degenerative disorder, but medical researchers subsequently revised their earlier conclusions and later depicted it as a developmental, or neurological, disorder. It occurs most often in females across a variety of racial and ethnic groups. At times, Rett Syndrome is misdiagnosed as autism, cerebral palsy or "non-specific developmental delay." According to the International Rett Syndrome Association, people with Rett Syndrome can expect to live to middle age and beyond (International Rett Syndrome Association web site)].

While living at home with her family, including several siblings, Nina's inadequate motor development skills made it difficult for Nina to attend to her basic needs, such as feeding herself and communicating with others. Through funding provided by the provincial government, Nina's mother received child care worker, respite and teacher aide services to assist with Nina's care and development. During the year prior to her death, Nina received speech/language pathology and occupational therapy services offered and provided by the educational system while she attended grade three. The child care worker who worked with Nina during the two-year period prior to Nina's death described her as walking with assistance during that period and as learning to use a spoon to feed herself. Like many girls and women with Rett Syndrome, Nina had a limited vocabulary and her involuntary hand movements inhibited her ability to adequately communicate with others. The speech/language pathologist and occupational therapist began assisting Nina, when she was in grade three, with learning to use an augmented communication device designed to enhance her communicative abilities (Coroners Service Inquest Exhibits).

> [Rett Syndrome is characterized by apraxia which refers to a person's inability to require her body to effect motor movements. As the most fundamental and severely handicapping aspect of Rett Syndrome, it can interfere with every body movement, including eye gaze and speech, making it difficult for the girl with Rett Syndrome to direct her body to do what she wants. Therapies such as physical therapy and occupational therapy are recommended as ways to inhibit motor disability and improve communication skills. Other approaches such as music therapy, horseback riding and hydrotherapy are also suggested (International Rett Syndrome Association web site)].

Nina's regular child care worker prior to her death, "Ann Marie," lived in an upstairs apartment located above Nina's family home. This child care worker began to provide care to Nina approximately two years before Nina died and worked with her on a daily basis for five days each week. During the nine month period before Nina's death, Ann Marie provided child care and teacher aide services for approximately 12 hours per day during the week. Her general responsibilities included getting Nina up in the morning and providing her breakfast; driving her to school and back each day; and working as her teacher's aide while Nina attended grade three on a full time basis. While at school, Ann Marie fed Nina her snacks and lunches. Later, after school, Ann Marie provided Nina her dinner, bathed her, played with her, and put Nina to bed each night. As demonstrated, Ann Marie played a key role as a primary caregiver and, in particular, in ensuring Nina met her food intake and nutritional requirements each day (Coroners Service Inquest Exhibits).

> [Growth in girls with Rett Syndrome is slow and they often benefit from receiving supplemental high caloric/high fat meals. When weight gain is delayed, it may represent difficulties with swallowing and chewing, receipt of an inadequate amount of food and nutrients, an imbalance in

> their energy expenditure and/or an inadequate utilization of their nutritional intake. As a result, the person responsible for providing meals to a girl with Rett Syndrome plays a crucial role in their lives as she or he must have the necessary skills to be able to evaluate and respond to her specific needs (International Rett Syndrome Association web site)].

In the last year of her life, Nina attended a school she had not attended as a student in prior school years. Her 'new' school, unlike her previous schools, was located a considerable distance from Nina's home and required Ann Marie to drive her for approximately one hour to reach it. Similar to her previous school, the new school was instrumental in offering an "independent educational plan" for Nina in addition to occupational and speech-language pathologist services. It also provided a supportive peer environment in which Nina participated with other children, with Ann Marie's assistance as her teacher's aide, in the regular school curriculum. Both the grade three teacher and the school principal taught various aspects of the school program to Nina and the other children throughout the school year (Coroners Service Inquest Exhibits).

> [It is difficult to make a precise assessment of intellectual abilities due to apraxia and the girls' lack of verbal communication skills. The literature stresses the significance of introducing a child with Rett Syndrome to age-appropriate books, toys and music at an early age and providing a stimulating environment. "Girls with Rett Syndrome can be seen in classrooms of all types, ranging from self-contained special education units to full inclusion in regular schools. The goal in education should be to provide her with the most stimulating program in the least restrictive environment, taking into account each girl's own special needs (International Rett Syndrome Association web site)].

Alternate Accounts: The Teacher and the Child Care Worker

The stories I have selected for this chapter derive from reports Ann Marie and Nina's teacher, "Elizabeth," generated and from a RCMP transcribed interview with Ann Marie shortly after Nina's death. As service providers to Nina, both people had a considerable amount of direct contact with her on a daily basis and, in particular, during the months prior to her death. I have utilized this information, obtained from the Coroners Service, to offer the reader insight into how Ann Marie and Elizabeth 'saw' Nina in the context of her everyday world and, in particular, in relation to the events occurring in the weeks prior to her death. Not all the Coroner Service exhibits pertaining to Nina are available to the public, such as the journals Ann Marie maintained about her daily relationship with Nina and the Ministry for Social Service child protection investigation documents. While I recognize my constructed account, therefore, draws from limited sources, I still believe the information I provide will allow readers an opportunity to broaden their sense of 'who Nina might have been' beyond what may be offered by the textual accounts I later analyze in my inquiry. Again, it represents my attempt to personalize and humanize a very 'real' child who had very 'real' experiences prior to her death.

The Teacher's Story

During the year prior to her death, Nina attended grade three on a regular basis beginning in September. As a result, Nina's teacher, Elizabeth, prepared two school reports subsequent to the fall and spring school terms in which she detailed her observations about Nina. The fall school report begins with the sentence: "[Nina] is a bright light in the classroom and her presence is an education for the whole class" (Coroners Service inquest exhibit #44). This report, reproduced in its entirety, also states as follows:

- Until recently, while [Nina] was feeling well, there was a steady increase in [Nina's] ability to stay in class and a reduction in the number of apnias she was experiencing which increases her potential for learning.
- [Nina] receives lots of listening practice with [Ann Marie] reading to her. Students also enjoy reading to her.
- [Ann Marie] scribes imaginative stories with [Nina]. Their method of coming up with ideas seemed to work well in this area.
- [Nina] takes part in class discussions. She listens well to the contributions of other students and gives non verbal indications when she wants to contribute. The students who spend a lot of time with [Nina] seem to be becoming quite proficient in understanding her.
- This term, we will work to extend [Nina's] ability to give clear unmistakable responses so even more people can understand her communication.
- Through the assistance of [Ann Marie], [Nina] has progressed well in our Mathematics lessons. Together they are covering the same work as the rest of [Nina's] peers. A focus for the upcoming weeks will be to encourage [Nina] to "reach" and point to the correct responses. This skill will be most useful for the "communication board" when it arrives.
- Keep up the good effort, [Nina].
  (Coroner Service Inquest Exhibit #44)

A second school spring report, dated approximately nine weeks prior to Nina's death, begins with the sentences: "[Nina] continues to be a welcome classmate from whom we are all learning to question many things that we take for granted. [Nina's] classmates are learning to be considerate of her different needs and enjoy helping her in anyway they can" (Coroners Service inquest exhibit #44). Other observations recorded and reproduced in their entirety include the following:

- Reading with [Nina] is one of the most valued activities in class and she has no shortage of people willing to read to her. [Nina] continues to receive ample listening practice with [Ann Marie] and students reading to her regularly. [Ann Marie] works with her to check that she understands the stories read.
- With the time change, [Nina] is less often present for writing time. When she is here, [Ann Marie] scribes for her.
- [Nina] is an enthusiastic participant in music class and has experimented with a number of instruments while the other students have learned recorders.

- [Nina] has been working on her reach in order to access the Alpha talker Communication Board. This process will be assessed at the upcoming meeting with SET [province name].
- Since mid January when [Nina's] health improved, she has increased her ability to stay present in class. Most often now, when she does get tired, she is able to rest in class for a short time and then join back in with the class.
- [Nina] continues to work hard in our Mathematics lessons. With [Ann Marie's] assistance, she has demonstrated an understanding of adding and subtracting three digit numbers. It is pleasing to see [Nina's] progress!
- Nina enjoys our Physical Education lessons. A smile from "ear to ear" is a common sight! Her recent effort on the vaulting box are indicative of how much she enjoys movement.
- Keep up the good work, [Nina]!
(Coroner's Service Inquest Exhibit 44)

This second report is dated March 15. Ten days later, Ann Marie became ill and was unable to continue to work with Nina as her child care worker/teacher's aide. Nina, and her sibling, remained at home in their mother's care until Ann Marie returned to work with Nina approximately six weeks later. At that time, Nina returned to school with Ann Marie for two days only – May 13 and May 14 – and subsequently remained at home until her death on May 28 (Coroners Service Inquest Exhibits).

The Child Care Worker's Story

In her interview with the RCMP made shortly after Nina died and later transcribed, Ann Marie confirmed that she began to provide care to Nina approximately two years prior to Nina's death and that during the previous school year, she had worked as a teacher's aide to Nina when the school district employed her in that capacity at Nina's mother's request. In fulfilling those two responsibilities, Ann Marie stated that Nina "was in my care from 7:00 o'clock a.m. to 7:00 p.m.". At approximately seven am each morning, Ann Marie, Nina and her sibling left the house early to drive to school and together they returned around 4:15 pm at which time Nina would nap until Ann Marie returned to work with her (Coroners Service inquest exhibit #49).

> Uhm, if she's in her room I take her out of her room, I look after her personal care, uhm, I freshen her up. I help her with her dinner. If there's time we play together with her siblings, uhm, we go outside for a [sic] walks, uhm, around 6:30 in the evening she starts getting ready for bed. At 10 to 7 I, uhm, sit down with her so she can watch about 10 minutes of TV and at 7:00 I tuck her into bed and once she's in bed I write in her journal. And in that journal I write what I've done with her for the two hours that I've worked with her, and if I work with her for three hours I write down 3 hours of what I've done with her (Coroners Service Inquest Exhibit #49).

Ann Marie also described Nina's communication style indicating that Nina would rock back and forth when she responded yes or she would turn her head in the opposite direction when she answered no to a question. When she wanted to eat, Nina raised her hand to her mouth and looked like she was holding a cup when she wanted to drink. According to Ann Marie, when Nina was tired, she would rub her face (Coroner Service Inquest Exhibit #49).

> Um, her vocabulary and me working with her, it went up to about, I don't know, ten to fifteen words. Over the summer holidays she was feeding my fish a lot so when I'd ask her you know, what do you want to do today she'd go, fish, she'd whisper; she'd whisper fish and as soon as she said fish we'd go upstairs and feed my fish. You know, sometimes she might, um, she [sic] hyperventilate, yes, she'd whisper it (Coroner Service Inquest Exhibit #49).

In her interview with the RCMP, Ann Marie stated that Nina had started to see an acupuncturist in January, the year she died, and had received treatments once a week. She stated that "through acupuncture [Nina] was moving her legs more, uhm, she was reaching more with her arms" and " her legs were straighten out really nicely, uhm, she was starting to put on a little bit of body fat through acupuncture" (Coroner Service Inquest Exhibit #49).

In providing an overall description of Nina during the months Nina attended school as a grade three student, Ann Marie stated:

> She was walking with assistance, she was eating, she was laughing, uhm, she was full of energy (Coroner Service Inquest Exhibit #49).

Ann Marie also described her experiences with Nina during the months prior to Nina's death in a report she had prepared, signed and dated before her interview with the RCMP constable. In that report, Ann Marie stated:

> Back in March of [**], when I was working with [Nina], I recall how full of life she was. She had a sparkle in her eyes, lots of colour in her face, she was walking with assistance, eating well and she was putting on some body fat. I got sick and ended up on sick leave for 6 weeks (Coroner Service Inquest Exhibit # 47).

After her six week period of sick leave, Ann Marie returned to work with Nina on May 13, the day they returned to school together.

Major Events Preceding Nina's Death

As the following information will demonstrate, several major events occurred in Nina's life beginning approximately six weeks before her death when Ann Marie became ill and Nina did not attend school until May 13. On May 14, the Ministry for Social Services received a "child protection report" and immediately began a child protection investigation into the possible neglect of Nina. As part of that investigation, a Ministry for Social Services' social worker required Nina's mother to take Nina to a physician for a medical investigation. Nina's visit to the local hospital, in fulfillment of that requirement, launched Nina's involvement with the three health care providers – the emergency physician, the hospice volunteer and the home care nurse – the week prior to her death (Coroners Service Inquest Exhibit #49).

The Child Care Worker's Illness

A critical event in Nina's life occurred approximately six weeks before Nina died when Ann Marie became ill and could no longer provide care for her. In the life of a child with Rett Syndrome, the loss of person with primary responsibilities for providing her meals requires serious attention and special care needs to be taken to ensure other people who feed the child have the necessary skills and understanding required. It is essential, for example, that people who provide meals to girls with Rett Syndrome offer food that is softened and made accessible; that the girls have the time they require to chew and swallow properly; and that the food offered has the necessary caloric, nutritional content. In Nina's situation, the loss of Ann Marie represented the loss of a primary caregiver who had significant responsibility for ensuring Nina received the foods she required to thrive.

Ann Marie became ill and required hospitalization on March 25, the day Nina returned to school after spring break. As a result, Nina did not attend school until May 13 when Ann Marie returned to work with her and together they attended school for two days. As previously indicated, in her interview with the RCMP made subsequent to Nina's death, Ann Marie described Nina up to the period of time when she became ill, in March, as "walking with assistance," eating, laughing and "full of energy." In response to a RCMP officer question about whether Nina communicated to the child care worker about Nina's life after Ann Marie became ill, Ann Marie stated:

> Well, I know that she was really bored and anxious for me to get back to work because like I said we had a pattern. We did so much together and it was like all of that stopped when I got sick and I don't know, she came, she became a couch potato and watched a lot of TV or uhm, went for buggy rides in her buggy. She wasn't as active as she was when we were together (Coroner Service Inquest Exhibit #49).

In her interview with the RCMP, Ann Marie indicated that Nina's mother had told Ann Marie, when she was in the hospital in the early stages of her illness, that Nina wasn't doing very well and that she missed Ann Marie:

> [Nina's mother] mentioned that when I was in the hospital and I was sick she brought to my attention that [Nina] wasn't, I asked how [Nina] was and one time she said she's not doing good, uhm, she sick today and she's not eating, she's fasting. And I said "what do you mean she's fasting?" "Oh, [Ann Marie], she won't eat for anybody but for you" (Coroners Service Inquest Exhibit #49).

Ann Marie left the hospital on April 8 and returned to her apartment located above Nina's home. While she had contact with Nina after her release, Ann Marie did not return to provide child care worker or teacher aide services until May 13 at which time she took Nina to school for the day. In her interview with the RCMP, Ann Marie stated that when she returned to work with Nina, Nina "had no energy whatsoever. She wasn't walking, she wasn't eating and she was just two different people." Ann Marie also described Nina as: "very low key, she hardly had any energy, she looked really tired" and indicated that Nina "looked a little dehydrated." She indicated Nina had slept the whole day at school and that she was "a little concerned because normally she doesn't sleep the whole day long." Ann Marie woke Nina during the day to give her some fluids (Coroners Service Inquest Exhibit #49).

In her interview, Ann Marie noted that Nina had fluctuating weight like other girls with Rett Syndrome:

> One day she could be thin and not eating and the next day she could be eating two plates full and putting it back on. It's always up and down with [Nina]. She could be full of energy, have no energy the next. It's been like that with her for two years. In seeing [Nina] on May the 13^{th}, yah she did look malnutritioned [sic]. She looked very dehydrated and yes I was worried about her and wondering exactly what was going on (Coroner Service Inquest Exhibit 49).

A Child Protection Report: Investigation Begins

Ann Marie reported that she took Nina to school on May 14 and that Nina was "still tired out but she was a little more perky" than on the previous day (Coroner Service Inquest Exhibit 49, Statement of Ann Marie). On that day, a concerned community member contacted the Ministry of Social Services (MSS) to express concern about Nina's apparently emaciated condition. Pursuant to the relatively new Child, Family & Community Services Act, which had come into force approximately five months earlier, the MSS social workers designated the contact as a "child protection report" and, after assessing the information in the report, initiated a child protection investigation into the possible neglect of Nina. The applicable legislation required the social workers to determine, through the investigation process, whether Nina was a child who required protection. In attempting to make this determination, MSS policy guided social workers in their practice which required, among other things, the social workers to make conduct interviews and gather information from people who had direct contact with Nina. Within this context, Ann Marie prepared a handwritten report detailing her experiences of "what happened" on May 13 and May 14 when Nina and Ann Marie returned to school. She also provided information about those two days during her interview with the RCMP (Coroners Service Inquest Exhibits).

Child Care Worker Report

Ann Marie prepared, signed and dated a handwritten report on May 14 for the MSS social workers who, as part of their child protection investigation, made a visit to Nina's home on that same day. In that report, Ann Marie described Nina as she remembered her before they returned to school together.

> Back in March of 1996, when I was working with [Nina], I recall how full of life she was. She had a sparkle in her eyes, lots of colour in her face, she was walking with assistance, eating well and she was putting on some body fat. I got sick and ended up on sick leave for 6 weeks" (Coroners Service Inquest Exhibit #47).

Also in the report, Ann Marie compared Nina's appearance on May 13 and May 14 to the way she remembered Nina.

> She looks like a total different girl. The sparkle in her eyes is gone, her face is skinney [sic] & her body is skin and bones. [Nina's] not walking and when I try to assist her, her legs cross over each other and she's constantly in fetal position. She hasn't gone pee all morning and into the afternoon and that concerned me. While in the washroom I noticed a number of bruises on [Nina's] legs. I mentioned them to [CH] my boss who then had a look for himself as well as [Nina's] teacher [BM]. Later in the afternoon [Nina] finally emptied her bladder. It wasn't much, but to me it was better than nothing. [Nina] spent a lot of time sleeping yesterday. In the whole 2 years of knowing [Nina] I don't ever recall seeing her like this. [Nina's] weight always fluctuates but this time it's not just her weight that's changed, its everything that I've already mentioned. [Nina] also wouldn't eat for me. I hate forcing food on someone, but yesterday I had to force feed [Nina]. I gave her lots of liquids and she ate her lunch. Today she looks much better than yesterday. She staying awake a little more, walking some, eating all and drinking lots of fluids (Coroners Service Inquest Exhibit 47).

Child Care Worker Interview with RCMP

In her interview with the RCMP, Ann Marie indicated that Ministry of Social Service social workers had arrived at Nina's house on May 14 "because somebody phoned in a concern on her, okay" (Coroner Service Inquest Exhibit 49). She stated the social workers told her they intended to take Nina to the hospital (Nina's mother was absent from the home) because she "wasn't well" and to remove the other children because the parent was absent; however, the social workers didn't follow through on their plans. Ann Marie noted that the ambulance, stationed up the road, drove away and the social workers left Nina's residence. Nina and her siblings remained at home. In her interview, Ann Marie stated that one of the social workers told her that Nina's mother had agreed to take Nina to a physician and to have her examined at the hospital the next day. According to Ann Marie, Nina's mother and a friend took Nina to the hospital two days later and while a social worker planned to attend the medical examination, "that didn't happen" (Coroners Service Inquest Exhibit #49).

The Child Protection Investigation Continues

Between May 14 and Nina's death, on May 28, MSS continued to investigate possible neglect of Nina. The documents detailing this investigation, while entered as exhibits at the Coroners Service inquest, are sealed and not available to the public. The events most relevant to this inquiry, however, concern the health care providers' interventions which began two days subsequent to the child protection report.

Health Care Provider Services

On May 14, the day the child protection investigation began, MSS's district supervisor required Nina's mother to take Nina to a physician. This medical visit was delayed, in part, by Nina's lack of recent involvement with a family physician in her community and the unavailability of local physicians who would examine Nina immediately. On May 16, Nina accompanied her mother to the local hospital where an emergency physician working in the hospital's emergency department examined her.

During Nina's visit, the emergency physician had a conversation with Nina's mother, examined Nina for approximately five to ten minutes, and released her from hospital with instructions for Nina's mother to "try Jevity," a high caloric supplement available at the local grocery store. He also indicated to Nina's mother that he wanted to check Nina's weight five days later (Coroners Service Inquest Exhibits).

Two days later, at Nina's mother's request, a hospice volunteer visited Nina's home in order to determine Nina and her families' eligibility for hospice services. After concluding Nina and her family required palliative care services, the hospice agency authorized services for them and prepared a care plan. Subsequent to her visit, the hospice volunteer also contacted a nurse and requested home nursing care services for Nina. Five days after the emergency physician's examination, the nurse attended Nina's home and conducted an assessment to determine the type of nursing care Nina required. The nurse identified Nina's "projected treatment goals" as palliative care and prepared to provide service to Nina three days per week. Despite their care plans, the emergency physician, the hospice volunteer, and the nurse did not see Nina after their initial contact with her and Nina did not receive any other health care services prior to her death (Coroners Service Inquest Exhibits).

During the health care providers' involvement with Nina, each professional participated in a process of enacting a Do Not Resuscitate (DNR) order. Both the hospice and home care nursing records demonstrate how the hospice volunteer and the home care nurse brought about the existence of a DNR order, made official when the emergency physician and Nina's mother signed the standardized, provincial form. The hospice records contain a recording, for example, that states Community Home Nursing Care can

"Help get letters in place i) Do Not Resuscitate order ii) Expected Outcome being death." The home care nursing records confirm the home care nurse provided a DNR form for Nina's mother to sign and subsequently placed it in the emergency physician's hospital box. On May 22, the emergency physician completed the loop of health care provider involvement by signing the form and returning it to the home care nurse's hospital box. This form identified Nina as a child dying from a "terminal illness" who had "come to the end of her natural life." Six days after the emergency physician signed the order Nina died (Coroners Service Inquest Exhibits).

CHAPTER SIX: NINA'S "TERMINAL ILLNESS"

Introduction

> States Parties recognize that every child has the inherent right to life. States Parties shall ensure to the maximum extent possible the survival and development of the child (Article 6, UN Convention on the Rights of the Child).

In the previous chapter I provided an accounting of some aspects of Nina's everyday life, a life changed dramatically when Nina's child care worker became ill and when a concerned citizen reported his concern about Nina's emaciated condition to the Ministry for Social Services. This account, compiled from textual information entered as exhibits at the Coroners Service inquest, shows that two days after a child protection report, Nina entered the official world of health care providers when the Ministry for Social Services' social worker required Nina's mother to take her to a doctor for a medical examination as part of their child protection investigation into possible neglect. An emergency physician, hospice volunteer, and home care nurse subsequently conducted individual assessments of Nina on separate days and recorded their observations and interviews with Nina's mother in organizational records, or texts. These texts—the hospital form, the hospice society records, and the home care nursing records—are the subject of my analysis in the next two chapters.

While the health care providers worked individually for separate organizations, they were united in their collective responsibility to provide service to the same child. In Chapter Six, I begin to explore the social organization of knowledge about Nina, including the processes under which she became known as dying from a "terminal illness". This chapter illustrates how the health care providers conducted their work in accordance with their professional and organizational agendas informed by the medical and palliative care discourses. In doing their work, the health care providers demonstrated their accountability to their various agendas by completing official administrative forms provided by the diverse organizations they worked for. These forms, or texts, constituted an official, authoritative and objectified textual version of Nina as a child dying from a "terminal illness", a version of Nina which culminated in the enactment of a Do Not Resuscitate order.

In Chapter Seven I argue that the health care providers' texts became "an integral part of individual and collective action" (Jackson, 1995, p. 168) in their provision of service to Nina. These textual accounts, as constituents of social relations, mediated the development of knowledge about Nina within the framework of the health care providers' professional and organizational agendas. Their agendas, informed by medical and palliative care discourses, provided the goals and objectives directing the health care providers in work largely focused on addressing a medical 'problem' and the dying process. As my analysis reveals, the Ministry of Social Services' concerns about possible neglect shifted, through the health care providers' interventions, to a focus on "terminal illness".

As this analysis will ultimately demonstrate, the notion of a "terminal illness" became entrenched in the Do Not Resuscitate order - an official, authoritative text. This text existed as a standardized account coordinating the actions of the health care providers who worked for diverse organizations and in relative isolation from each other. As one part of the 'conversation' about Nina, it stood as an authoritative testament to the work the health care providers' accomplished and to the construction of Nina as a child dying from a “terminal illness”. I argue that this official and authoritative view of Nina ‘stood in’ for and subordinated alternative views about her that might have directed professional attention and intervention differently. I use the health care providers’ texts, therefore, as an entry point to explore how this official and authoritative view of Nina as a child dying from a “terminal illness” came about.

Proceeding within this framework, I have adopted Smith’s (1999) approach, which is to ‘see’ the health care providers’ texts as components of a conversation.

> I mean to see them [texts] as being like speakers in a conversation; that is, though deprived of the possibility of hearing and responding to us, as nonetheless present and active in ‘speaking’ to us as our reading activates them. Our reading operates the text; in our reading, it becomes active. The artifice of the text detaches it from the local historicity of living and activity, or seems to do so. But its making was work done in actual settings by one or more people and as part of a course of action, whether of an individual, a group, an organization of some kind, or of an extended social relation concerting the activities of many (Smith, 1999, p. 135).

For purposes of my inquiry, I, too, see texts as “speakers in a conversation.” As speakers in a conversation, the texts I examined raised questions for me such as who speaks to whom and to what end? In what way do the texts ‘speak’ about Nina? As I observed, Nina’s health care providers worked within their individual “spheres of activity” (Smith, 1999, p. 135), conducting their specialized assessments and created texts as ‘part of’ and not ‘separate from’ their active engagement with Nina. These texts made up a conversation situated within a sequence of events, and while each text represents a different segment of the health field, they are linked by virtue of each person’s association with Nina and her mother. As Smith (1999) suggests, these texts “can be thought of as supplying one part of a conversation, but a part that can be standardized across multiple conversations in different local settings and at different times" (p. 218). As this analysis demonstrates, the part of the conversation in which Nina became constructed as dying from a "terminal illness" became standardized, as Smith suggests, across many conversations "in different local settings and at different times."

Individual and Collective Action

The three health care providers who assessed Nina's condition—the emergency physician, the hospice volunteer and the home care nurse—each worked for separate organizations and in an uncoordinated practice in relation to each other. At the same time, these three service providers had a collective responsibility for providing health care interventions to Nina, whom each person saw within a five-day period. As described in an earlier chapter, "institutional" (in institutional ethnography) refers to the way distinctive functions, such as those performed by each health care provider, combine and intersect through the interchange of service to a person such as Nina. While each person saw Nina on separate occasions and did not have direct, physical contact with each other, their work activities combined and intersected, in a textually-mediated way, to ultimately enact a Do Not Resuscitate order that officially constituted Nina as a child dying from a "terminal illness."

'Doing the Work': Text-mediated Health Services

When a community person reported concerns about Nina's emaciated condition, the Ministry for Social Service began a child protection investigation into the possible neglect of Nina. The first health care provider intervention, involving the emergency physician, occurred when Nina arrived at the local hospital pursuant to the Ministry for Social Services' requirement that a physician examine her as part of their investigation.

Nina's lack of a family physician necessitated her visit to the hospital's emergency department. Upon her arrival, it is likely Nina encountered an admission person who produced information recorded in some categories on the hospital form, such as Nina's name and address, before a nurse and the emergency physician saw her in the hospital's emergency department. It is a department, within the hospital, that typically offers services to patients on a short-term, interim basis.

Emergency departments, or "units", often search for ways to improve their efficiency in attending to the increasing numbers of patients who require medical services. Standardized hospital forms exist as a component of this attempt, which also encourages people to focus their work on dealing with "manageable problems."

> In the Emergency Units, the predominant practice pattern was one of "efficient processing." In the pattern of practice, patients were 1)"stripped down" (literally and figuratively) to 2) create a manageable problem (such as a chest pain, laceration, or fever), and 3) processed according to this manageable problem in order to 4) empty the stretcher. Various strategies were used to keep patients "on track." Assessments were routinized and proscribed and patients were encouraged to give only the information needed to identify the problem. Such strategies began with opening questions at triage such as "what brings you to Emergency today?" and continued with checklists and flow sheets tailored to identify physiological problems (Varcoe & Rodney, In press, p. 12).

Emergency Physician and the Hospital Form

The emergency physician had never seen Nina before her visit on May 16 and, under usual emergency service procedures, he would not expect to retain her as his patient over an extended period of time. Often when a patient has a family physician in the community where she receives emergency services, that physician or a medical specialist, assumes responsibility for the patient's care subsequent to the emergency physician's involvement. The emergency physician, who is not expected to have ongoing involvement in a patient's care, often conducts an initial medical assessment, makes recommendations and subsequently generates a textual accounting of her/his contact with a patient. In many instances, the hospital administration makes that textual accounting available to the patient's family physician. The emergency physician who examined Nina, however, made a 'plan' to see Nina five days later, a departure from the standard procedure common to emergency department practice. By doing so, the emergency physician established himself as the 'responsible' physician who would attend to Nina at that time. The totality of this work, conducted within the framework of his professional and organizational responsibilities, established the emergency physician as a medical authority in the social relations of health care provision.

In doing his work, the emergency physician completed a standardized hospital form (see Appendix A) consisting of a single page with categories specifying the type of information required. The hospital name and address are identified at the top. The hospital form is completed in a manner that suggests at least two, and possibly more, people participated in placing information in the various categories. For example, some of the information is typed on the hospital form while other information is handwritten (or not entered at all) with variations in handwriting in different sections. It is possible several authors participated in the production of the hospital form account as evidenced by these typewritten and handwritten sections. The significance of identifying the authors, in this instance, is that it permits us to 'see' who did and did not contribute to the production of knowledge about Nina.

Hospice Volunteer and Hospice Society Records

The next intervention occurred when a hospice volunteer visited Nina's home, apparently at Nina's mother's request, two days subsequent to the emergency physician examination on May 16. At that time, the hospice volunteer recorded Nina's mother's report that the emergency physician had said Nina's condition was "terminal" and used this information to direct her work as she conducted her subsequent assessment. The hospice volunteer's assessment, a hospice or palliative care intervention, differs from the type of intervention a patient might experience in an emergency department. A typical medical approach, for example, entails seeking an accurate diagnosis for a patient's medical 'problem' and offering appropriate medical treatment with an expected outcome to improve or cure the patient's condition:

> Prior to any consideration, saving life, curing, will be the response expected. In some situations, a medical judgement is made that the goals of ordinary medicine are no longer attainable, and that the patient has a limited amount of time remaining. These have been called "terminal illnesses": methods of cure are no longer available, and the hope of recovery is reduced to a non-rational belief, rather than being backed by weight of medical knowledge and experience with similar cases (B.C. Hospice/Palliative Care Association Resource Directory, 1994, p. 14).

When a patient is diagnosed with a "terminal illness," hospice societies often become involved in providing palliative care to that patient and her family. While a traditional medical model seeks to treat a patient's condition and, hopefully, find a cure for her medical 'problem' or illness, palliative care operates under a different set of goals. When a diagnosis of "terminal illness" is made, there is a shift required from "curing" to "caring" (p. 15). Palliative care is:

> Active total care offered to patients with progressive disease and their families when it is recognized that the illness is no longer curable, in order

> to concentrate on the quality of life and the alleviation of distressing symptoms in the framework of a coordinated service. The focus of Palliative Care is neither to hasten nor postpone death. It provides relief from pain and other distressing symptoms and integrates the psychological and spiritual aspects of care. Furthermore, it offers a support system to help relatives and friends cope during the patient's illness and bereavement (Edmonton Palliative Care Program, 2000).

While the provincial hospice societies offered a range of programs and services, which include a volunteer component, to assist with the transition to palliative care, not all provincial organizations provided the same number of services. The local hospice society responding to Nina's mother's request for services operated as a registered charity employing a part-time co-ordinator and several volunteers who provided "hospice support for the client in the home and respite for family members" (B.C. Hospice/Palliative Care Association Resource Directory, 1994, p. 95). The volunteers offered "support to the terminally ill, their families, and to those who [had] suffered a loss through death" (p. 95) and also facilitated a Grief Support Group in the community.

While the hospice volunteer's work—providing palliative care—shifted the emphasis from "curing" Nina to "caring" for her, it had depended upon receiving information from Nina's mother that Nina's condition was "terminal". The hospice volunteer's assessment, which she conducted in her 'official' capacity as a person associated with the local hospice society, generated references to what the emergency physician had said about Nina's condition. By 'taking up' the word "terminal," the hospice volunteer was able to fulfill her volunteer responsibilities within the framework of the hospice society's mandate. Informed by a palliative care discourse, this mandate centered upon providing care to those "patients with progressive disease" and with an "illness" that is "no longer curable." In order to provide the palliative care services

Nina's mother requested, therefore, the hospice volunteer needed to 'see' Nina—the client or patient—as having a "terminal illness" in order for Nina and her family to receive homemaker, respite and other support services.

Similar to the emergency physician, the hospice volunteer generated official, administrative texts subsequent to her assessment of Nina. At the Coroner Service inquest, the hospice society submitted two textual accounts constituting their file records relating to Nina and her family: the Client Information Sheet and the Client Referral Form. The Client Information Sheet is an informal handwritten textual account made up of four pages. The handwritten notes, unstructured in format and lacking categories, are written on lined paper without official, administrative references to the hospice society or authorship (see Appendix B). The Client Referral Form, on the other hand, is a formal, administrative textual account consisting of two pages. It has 30 typewritten categories on the first page and two typewritten categories on the second page. All the information recorded in the categories on the Client Referral Form is typewritten, some of which are filled in and some are not. The name of the hospice society appears at the top of page one; however, there is no reference to the author (see Appendix C).

Home Care Nurse and Home Care Nursing Records

In the sequence of events, the home care nurse became the third health care provider to respond to Nina's need for service after she received a telephone call from the hospice volunteer on May 20. In the home care nursing records, the first line in the Progress Notes section dated May 20 states: "T/c from hospice worker [SP] [phone number] regarding HNC referral for [Nina] – ten year girl who is dying from Rett Syndrome." The word "dying" informed the home care nurse that it would be appropriate to use the Community Home Care Nursing Services policy to guide her work. Chapter 7.3, in the policy manual, is entitled "Death in the Home" and subsection 7.3.1 is called "Anticipated Death in the Home" (Coroners Service Inquest exhibit #25). This provincial policy, developed by the Ministry of Health and Ministry Responsible for Seniors – Continuing Care Division, stated:

> If the care of the terminally ill person can be accommodated in the home environment and the individual meets all the necessary criteria of the program, Community Home Care Nursing Services will support the dying person's decision to die at home.
>
> In all instances of Anticipated Death in the Home, the guidelines for Anticipated Death in the Home will be followed (Coroners Service Inquest Exhibit #25).

The "Guidelines" section of the policy "guided" the home care nurse to "determine with the client, family/significant others and physician, client's preferred location at time of death, e.g. home, hospital, facility" prior to the patient's death and to document the client's preference (Coroner Service Inquest Exhibit # 25). A handwritten note adjacent to this sentence reads: "mother wanted [Nina] to die at home." Under these circumstances, the policy guidelines required the home care nurse to consider obtaining a Do Not Resuscitate (DNR) order from the "attending physician." A following section in the policy outlines the criteria for a DNR order when a death is anticipated:

> 1. The diagnosis may include cancer, A.L.S., C.H.F., C.O.P.D., and other end-stage diseases.
> 2. The attending physician establishes that the client's overall condition indicates that further curative treatments will not arrest the disease process and the treatment then becomes palliative.
> 3. The nurse participates in the discussion about a written Do Not Resuscitate order with the client, and/or family members, and the physician. At this time, the competency of the client must be established.
>
> (Coroner Service Inquest Exhibit # 25)

The criterion further identifies how the nurse should proceed in order to assess a patient's competency. Again, handwritten notes on the policy, Exhibit #25, state "mother unsure how much [Nina] understands. No verbal response. Mother wanting no aggressive medical intervention (i.e.) tube feeds." When another person is representing the client, or patient, the policy guidelines stipulate that the "representative of the person should be involved in the decision-making process with the nurse, physician, and other professionals where appropriate, in the event that the client is deemed incompetent" (Coroners Service Inquest exhibit #25). In this particular instance, the home care nurse discussed the DNR order with Nina's mother, as Nina's representative, after determining that Nina's treatment was "palliative" and arranged for Nina's mother to sign the DNR form. As the policy required the home care nurse to also discuss the DNR order with the physician, the home care nurse telephoned the emergency physician and arranged to have him sign the form as well.

Similar to the emergency physician and the hospice volunteer, the home care nurse produced an official, administrative recording of her contact with Nina. Again, at the Coroners Service inquest the home care nursing agency submitted its organizational records which consists of 14 pages with typewritten sections and the title "[provincial] Ministry of Health and Ministry Responsible for Seniors (Continuing Care Division) at the top of most of the pages. The sections in home care nursing records include the following: the "direct care patient data base," "assessment data base," "open flow sheet," "care plan," "progress notes," "drug profile," "physician's orders," and "discharge summary." Each section is comprised of typewritten categories that structure the type of information gathered and recorded in each part. All the information recorded in the home care nursing records is handwritten. While the author is 'invisible', presumably the home care nurse recorded the information as she conducted Nina's assessment as suggested by consistent handwriting recorded throughout. Segments of pertinent health care records, used in my subsequent analysis, are shown as Appendix D.

Professional and Organizational Accountability

The health care providers participated in an administrative formalized procedure by filling in categories on administrative forms in a manner consistent with a methodical process designed to "ensure that records are collected in standardized ways and not as idiosyncrasies of individuals or particular hospitals or clinics" (Smith, 1990a, p. 90). The standardized forms they used are often multi-purpose in nature. They are designed, in some instances, to identify a patient, organizationally account for professional work done with a patient (such as a medical assessment), and to inform other professionals. In their routine use of the forms, the health care providers selected particular information about Nina to insert into the categories located on the forms. Such categories, Smith (1990a) observes, structure information collection that is "already organized by a predetermined schema," a schema that subsequently operates to interpret the data (pp. 93-94).

The organizations each health care provider worked for managed their work through a formal, administrative accounting in which the categories in the forms structured what information was obtained, how it was interpreted, and how professional knowledge about Nina was socially organized. The categories in each administrative form, for example, provided the template for "proper procedures" each health care provider needed to follow in order to demonstrate their professional and organizational accountability. Each person followed the 'correct' procedures for filling in the categories, which had the effect of representing accumulated 'factual' knowledge about Nina. As Smith (1990b) suggests, "if something is to be constructed as fact, then it must be shown that proper procedures have been used to establish it as objectively known" (p. 27). Filling in categories constitutes a reading of "proper procedures followed." Each person demonstrated his or her professional accountability to their organizations by completing the forms in an appropriate manner. The forms, as constituents of social relations, became an objectified textual account of Nina's encounter with each person and in which 'knowledge' about her was represented.

In my subsequent analysis of the texts I will show how the home care nurse's textually mediated work linked to the emergency physician and hospice volunteer's earlier interventions. The emergency physician, informed by a medical discourse, examined Nina within the context of a medical setting and assessed her condition as related to her disability, Rett Syndrome. By focusing on his reported comment that Nina's condition was "terminal", both the hospice volunteer and the home care nurse were able to conduct their assessments in their 'official' capacities as a professionals responsible for carrying out their organizational mandates. By framing their work within a medical discourse and, specifically, a palliative care discourse, the three health care providers transposed their work from "curing" to "caring". The last health care provider to assess Nina, the home care nurse, then arrived at her assessment with the DNR form prepared to 'see' Nina as a child with a "terminal illness" who required palliative care. The process of enacting this form linked the activities of the emergency physician, the hospice volunteer and the home care nurse. The circle of text-mediated professional intervention was complete.

CHAPTER SEVEN: TEXTUAL ANALYSIS—NINA'S "TERMINAL ILLNESS"

> States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. State Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services (Article 24, UN Convention on the Rights of the Child).

In this chapter I argue that the health care providers' texts, as constituents of social relations, coordinated the development of knowledge about Nina that shifted from concern about possible neglect to an account of Nina as a child dying from a "terminal illness." The health care providers, in carrying out their professional and organizational agendas, focused on Nina's medical 'problem' and her perceived need for palliative care. As this analysis will show, this approach subverted alternative accounts of Nina and possibly redirected professional intervention.

As a professional who linked Nina's medical 'problem' with her disability, the emergency physician became an authoritative voice in the provision of professional medical services to her. According to the hospice society records, Nina's mother relayed his reported account of Nina as a child with a "terminal" condition to the hospice volunteer, who developed a textual account of Nina as a child with a "terminal illness". The home care nurse, who adopted the hospice volunteer's reported words about Nina as a "dying child", advanced this notion through her textually mediated actions. Her role in facilitating the signing of the DNR order, by Nina's mother and the emergency physician, completed the circle and resulted in an official and objectified view of Nina as a child with a "terminal illness".

In my analysis I note that each of the health care providers' texts provides the reader, such as myself, with a set of 'instructions' about how to read and interpret its content. The words at the top of the hospital form, for example, providing the hospital name and the words "Out-patient or Short Stay" make it evident to me, as reader, that the hospital form is framed by a medical discourse, located within an organizational setting. I do not, for example, read this particular text, or the other health care providers' texts, as fiction or as 'news' but rather as administrative documents associated with a particular organization and professional practice. As a reader competent in organizational literacy (Darville, 1995), I am encouraged to take up the objectifying medical and palliative care discourses and to interpret the textual content within this organizing framework.

The Hospital Form

Through my analysis of the hospital form (see Appendix A), I show how the emergency physician's work, framed by a medical discourse, identified Nina's condition as a medical 'problem' associated with her disability, Rett Syndrome, and separated from possible neglect. My analysis also demonstrates how the recordings in the hospital form represented the emergency physician as the responsible and authoritative physician. Later, in my subsequent analysis of the hospice society and home care nursing records, I will show how the emergency physician's text-mediated work is linked to the activities of the hospice volunteer and home care nurse while, at the same time, it is disconnected from the Ministry for Social Services' child protection investigation.

In the category "Physician History/Exam," the information recorded begins with a notation "Wt – 23.5#," "10 yr. old [girl][with] Rett synd". This recording established Nina as a child with a disability and as a child who was very emaciated. The subsequent notation – “has been losing wt. past 4-6 wk. due to inability to feed her” and “mother understands the disease well” together imply that Nina had a ‘problem’, that something was ‘wrong’ with her, and that recent attempts made to offer her food were unsuccessful. The word “disease” is associated with Nina’s disability, Rett Syndrome, and the accompanying phrase “losing weight” aligns her weight loss ‘problem’ with her disability. This information provides a context for reading the subsequent line “some concern by MHR that child is being neglected” insofar as I am already informed that Nina has a disability and her mother, who understands her “ disease well” has expressed difficulty in trying to feed her. The sentence about Nina’s possible neglect is followed by recorded, abbreviated observations about Nina’s physical condition on that day. These abbreviations represent the short-hand account of a physical medical examination, the type of intervention often performed in an emergency department setting. A medical discourse likely informed the emergency physician’s work which typically focuses on uncovering “illness” and “disease.”

On the other hand, Nina had arrived at the local hospital for her medical examination because the Ministry for Social Service needed to determine what caused her excessive weight loss and whether Nina was neglected. “Neglect,” a central issue in social work, is a component of child welfare work (Swift, 1995, p. 4) and social workers often take a lead role in assessing allegations of neglect when a child protection report is made. When the emergency physician examined Nina, he recorded that there was “some concern by MHR that child is being neglected.” In the Physician History/Exam section, therefore, the recorded information provides an account of Nina’s physical status on that particular day, reaffirms her disability status, and identifies “neglect,” along with Rett

Syndrome, as a possible reason for Nina's weight loss. However, the information recorded in the following category, with its focus on physical symptoms, tells me that the emergency physician has constructed Nina's 'problem' within the medical discourse, separate from the child welfare discourse. Nina's 'problem,' identified as medically related, directed the emergency physician to concentrate his work on evaluating her physical symptoms as they existed on that day and to set aside her social, environmental, emotional, and historical context.

In the "Assessment" category, the recording stipulates there is "no evidence of *Abuse*" (italics added) and the words "Rett Syndrome" appear. In this textual accounting, the emergency physician converted the social worker's query about possible "neglect" into "abuse" (which he subsequently ruled out) and I was drawn into an interpretation of Nina's condition that fit comfortably within the medical discourse when I read the words "Rett Syndrome." These words, in association with the words "23.5#, "disease," "emaciated," and "stiff legs," transformed Nina's everyday, actual situation located in her social world into a physical, medical 'problem' and, again, linked Rett Syndrome with Nina's condition. Several questions remain unanswered by the hospital form. If Rett Syndrome and Nina's weight loss were connected, what feature of Rett Syndrome caused such a dramatic loss of weight during the approximately six week period Nina remained at home? What attempts did professionals make to respond to the characteristic of Rett Syndrome that appeared responsible for Nina's condition? Did other factors, unrelated to Rett Syndrome, exist that might have been responsible for Nina's weight loss?

While the social workers expressed concern about "neglect," the emergency physician referred to "abuse". "Neglect" disappeared from the text as a relevant factor under consideration. Within a child protection context, this shift was significant as it provided the impetus, as my analysis will illustrate, for the hospice volunteer and home care nurse's palliative care interventions. The Ministry of Social Service's concern about possible neglect became subverted by a medical process focused on uncovering "disease" and "illness". In that way, Nina's hospital examination 'fit' the medical discourse as well as the hospital form's categories directing and recording the emergency physician's work. The medical discourse orientated the hospital form's categories and in that way formatted the emergency physician's examination. This direction, in which Rett Syndrome became the "disease" and "illness", initiated the construction of Nina as a medicalized object of professional attention.

The Hospice Society Records

In this portion of my inquiry, where I analyse the hospice society records (see Appendices B and C), I argue that the hospice volunteer's recording that Nina's condition was "terminal", as conveyed by Nina's mother, prompted her to invoke the palliative care discourse. Nina's disability, Rett Syndrome, provided the 'explanation' for why her condition was "terminal." These features of the hospice volunteer's intervention helped redirect an investigation into Nina's possible neglect and advanced a medicalized notion of Nina as a child dying from a "terminal illness." As this analysis demonstrates, the hospice volunteer's text-mediated activities provided the link between the emergency physician and the home care nurse - activities that ultimately led to the enactment of the Do Not Resuscitate order.

While it is apparent the hospice volunteer authored the first hospice society record, the Client Information Sheet, it is not clear who typed information into the categories on the second hospice society record, Client Referral Form. Presumably, the information in the Client Information Sheet constituting the results of the hospice volunteer's preliminary work process were later used as "data" to inform the various categories on the Client Referral Form. In my sequential reading of the Client Referral Form, for example, the first four categories consist of Nina's name, address, phone number and age. These categories are followed immediately by the categories "diagnosis," with the words "Rett Syndrome" written in it and "doctor" near the top of the form. In a similar sequential ordering, in the Client Information Sheet, Nina's name and age are handwritten at the top of page on (the same address recorded in the Client Information Form appears at the top of page two in the Client Information Sheet). While the word "diagnosis" does not appear, the words "Retz Syndrom [sic]" appear twice on the Client Information Sheet on page one. The majority of writing on page one in the Client Information Sheet is about four doctors and the history of the involvement with Nina and her mother.

Further evidence of the association between the Client Referral Form's categories and the information recorded in the Client Information Sheet is as follows:

- In the Client Referral Form, the category "Family or Caregiver" appears and the name of Nina's mother together with the word "mother" in the "relationship" category and a phone number. In the Client Information Sheet, the name of Nina's mother appears, the word "mother" beside it; however, there is no phone number in the text.

- In the Client Referral Form, the "care plan" is identified as: "emotional & practical support for mother and family, including respite. Taking young children for walks, reading books pertaining to death, helping to educate and comfort them process the death. Helping with housework. Helping with Nina." The "care plan" is unofficially identified in the Client Information Sheet as: "walking boys, helping around at home, helping w/ [Nina], anticipatory grief w/ kids and mom."
- In the Client Referral Form, the "referral source" is identified as the mother and in the "volunteer" category, the name "[B.V]" and a phone number appear.
- In the Client Information Sheet, the name "[B]" and phone number appears below the sentence "client requested for some supports from Hospice ask if available." In the Client Referral Form, in the category "Date Referral Initiated" appears May 18 and "date client interviewed" is May 18. The Client Information Sheet shows the words "Sat visit May 18th" and "Sat May 18" is written in the left margin on the first page.
- In the Client Referral Form, there is a category called "Bereavement Follow-Up" which is left blank. In the Client Information Sheet, the words "anticipatory grief w/kids & mom" appear.

These examples demonstrate a link between the Client Referral Form categories, informed by a palliative care discourse, and the hospice volunteer's handwritten notes, accomplishing the work necessary to inform the Client Referral Form.

An apparently significant recording that justified the move to the Client Referral Form is located on the Client Information Sheet's first page.

> Dr. [H]: Saw [N] @ emerg. on Tues. May 14th. He has said her condition is terminal. He has asked to see her again on Tues. 21st.

While this recording demonstrates a break in direct communication between the emergency physician and the hospice volunteer, it also formalized the word "terminal" in the hospice society records and provided the basis upon which the hospice volunteer carried out her responsibilities. In doing her work, the hospice volunteer used other words in the Client Information Sheet to support this construction of Nina as a child with a "terminal" condition; Nina is described as "not eating," "crippling up," "bruising easily," "Speaking w/her mother about her death" and, on the last page, the words "terminal illness" appear. Phrases exist such as: "condition progressing," "deteriorating condition," and "deteriorating disorder." On the second and third page, the words "Do Not Resuscitate (DNR)" appear. There is a notation "Put ambulance on call." These words illustrate how the hospice volunteer worked within the palliative care discourse, advancing her organizational agenda to provide hospice services.

A recording in the Client Information Sheet shows how the hospice volunteer also became an advocate for Nina's mother and, in doing so, developed the mother's views about what was happening to Nina.

> "Ethical Issues – or correctness of mothers decision should not be an issue. The child needs to be determined to be dying of natural causes and the expected outcome is that she will indeed die. * Make it clear to [the emergency physician] that the mother wants to keep her dying child at home. There is a false fear in the community that [Nina's] being abused (food withheld or ignored)."

These strong statements, underlined in the text by the hospice volunteer, communicate to me, as reader, that the hospice volunteer has concluded during her assessment that Nina "needs to be determined to be dying of natural causes" and that the "expected outcome is that she will indeed die." It is not apparent to me what those "natural causes" are or who has the expectation that Nina will "indeed" die. While it is not clear from the text whether the hospice volunteer spoke to the emergency physician or any other professionals about what she had labeled as "ethical issues," there are no "ethical issues" identified in the Client Referral Form. By omitting any reference to ethical issues, which might require a different type of hospice society involvement with Nina, the Client Referral Form establishes Nina as a child who has appropriately met the hospice society criteria for palliative care services.

When she recorded in the hospice society records that Nina's condition was "terminal," the hospice volunteer set aside the Ministry for Social Services' concern about possible neglect. It appears the hospice volunteer's references to the Ministry of Social Services in the Client Information Sheet originate with Nina's mother as there is no recording to indicate the hospice volunteer spoke directly to a Ministry for Social Service's social worker. There are varying references to the Ministry for Social Services such as:

> Social worker – [R] – has stated it is not their right to force life systems onto [Nina].
> Min of Social Services may need to reason w/ them.
> There is a false fear in community that [Nina's] being abused (food withheld or ignored).

It is not clear from these textual notes how the Ministry for Social Services is involved with Nina. However, the recording "there is a false fear in the community that [Nina's] being abused" follows the textual reference to the Ministry of Social Services, a ministry that as one of their responsibilities investigates concerns about child abuse and neglect. The hospice volunteer, working within a palliative care discourse, demonstrated her advocacy commitment to the construction of Nina as having a "terminal illness" when she recorded "Min of Social Services may need to reason w/ them." While the outcome of that anticipated action isn't noted in the Client Information Sheet, in the Client Referral Form it states: "Ministry of Social Services has been attentive to this case and family, with some misinformation and [Nina's] condition. They are now aware of the correct diagnosis." It is not apparent what happened, where this information originated or whether the hospice volunteer had direct contact with a social worker. However, this action has been advanced as the hospice volunteer suggested. Now, references to possible "abuse" and "neglect" are absent in the Client Referral Form and, in their place, Nina is officially established as a palliative care patient.

It is notable that other alternative accounts about Nina are replaced by an administrative, objectified knowledge, which became stabilized in the Client Referral Form. During the process of inscription and by following proper procedures, therefore, this 'knowledge' became 'objectively known' and 'facts' emerged as information construed as the same to everyone. These 'facts' supported the notion of Nina dying from a "terminal illness" and maintained her status as a child with a medical 'problem' rather than a child who had received insufficient nourishment. And, as demonstrated, the hospice volunteer's textually mediated work linked her to the emergency physician and, as my subsequent analysis will show, the home care nurse's activities, including the enactment of a DNR order.

The Home Care Nursing Records

This segment of my analysis (see Appendix D) shows how the hospice volunteer relayed information that Nina was "dying" to the home care nurse who, on the basis of that information, planned palliative care for Nina. In doing so, the home care nurse arrived at Nina's home for her initial assessment with a DNR form and facilitated the mother's signing before the home care nurse left Nina's home. The home care nurse subsequently arranged for the emergency physician to also sign the form which officially enacted the Do Not Resuscitate order and entrenched Nina's objectified status as a child with a "terminal illness."

On May 21, the home care nurse visited Nina's home after the hospice volunteer telephoned her to advise the home care nurse about Nina's need for service. In the home care nursing records, there is a recording in the "Progress Notes" section (see Appendix D(a)) dated May 20 in which the recording shows a "T/c from hospice worker [SP] [phone number] regarding HNC referral for [Nina]

> ten year old girl who is dying from Rett syndrome apparently was
> diagnosed [with] disease at 18 month
> states mother needing support re: care of child - child apparently not eating
> only taking sips of [water] - + sleeping for hours at a time - Hospice
> worker states mother needing to have [Nina] weighted tomorrow and was
> hoping that RN could visit + do weight -otherwise was having to take
> child to hospital to be weighed – child apparently unable to stand and
> weighs approx 22 lbs
> unable to reach mother as she has been out – message left that Rn would
> contact in AM to arrange time of visit

It appears these notes represent information the home care nurse received from the hospice volunteer prior to her visit to Nina's home - information that would have guided the home care nurse in her work on the day she conducted Nina's assessment. The word "disease", on the second line, fits within the provincial policy criteria (as described in Chapter Six) that refers to "other end-stage diseases." Other information such as "dying from Rett syndrome," "not eating," "only taking sips of water," "sleeping for hours at a time," "unable to stand," and "weighs approx 22 lbs" support the construction of a child who is "dying" and who also appears extremely malnourished. Similar to the hospital form and the hospice society records, there is no information to indicate what aspect of Rett Syndrome is purportedly responsible for Nina's condition. The same questions I raised earlier in this context remain unanswered.

In the home care nursing record section "Admission Data" (see Appendix D(b)), for example, words and phrases such as, "recent weight loss of 10 lbs over 2 months, gone from 32 lb to 21 lb, drinking fluids and taking very small amount of solids, lying in fetal position, no verbal response, and grinding teeth appear." In the section "other relevant data," the first several categories direct the home care nurse to focus on Nina's physical symptoms connected to her "illness"; these categories include "medication," "wound/skin," "pain," "signs & symptoms," "medical supervison/follow up," "elimination," and "mobility." A compilation of the information from each category tells me: Nina is not taking medication, bruises easily, has skin intact, weighs 21 lbs., is incontinent, needs to be carried, is taking sips of fluids and small amount of solids, and is sleeping for long periods of time. While the recording states "mother feels [Nina] has no pain," there is no recording to indicate whether the home care nurse consulted Nina directly or attempted to evaluate whether she did or did not experience pain. At the bottom of the page, under "projected treatment goals," the box "palliative care" has a mark beside it.

Following the "Assessment Data" section, there is a form dated May 21 (see Appendix D(c)) which appears related to the home care nursing policy on providing palliative care. In that form, the categories appear: Aware of Diagnosis, Expectations –

What do they envision happening? – resuscitation, - death at home, - care expectations, - of physicians, - of home nursing, Options Discussed, Planning for Death, Who to Phone if Death Occurs at Home 1) Doctor will make house call or pt to hospital to be pronounced 2) Funeral Home notified 3) Others to call – eg. Minister, friend or volunteer to stay with family. In the section "Expectations," the recording states that "mother wanting [Nina] to die at Home – wants no medical intervention (ie) tube feeds. Under "Planning for Death," the recording confirms Nina's mother and the emergency physician have signed the DNR form. Nina is officially confirmed, in text, as a child whose death is inevitable.

As indicated earlier, when the hospice volunteer contacted the home care nurse on May 20, the home care nurse recorded in the Progress Notes section: "[Nina] – ten year old girl who is dying from Rett Syndrome." There is no reference to the Ministry for Social Services and their concern about possible neglect. The next day, the home care nurse went to Nina's home to conduct an assessment and recorded her work in the Assessment Data section. In that section, the recording states:

> Expressing her fears that social services may apprehend child – states that last Tues social worker arrived at residence and was going to apprehend [Nina], but after they spoke to Dr. who was familiar [with] Rett Syndrome + [Nina] they decided not to.

Later, the home care nurse's recordings (see Appendix D(d)) for May 28 (the day Nina died) show the home care nurse had received a telephone call from the MSS social worker.

> T.C. from [social worker] at Social Services – wanting to know if [Nina] is eating and concerned that competent person feeding her – made aware that [Nina] no longer eating/drinking – social services had been in contact

> [with][Dr. H] and aware DNR in place and [Nina] is dying – aware HNC will visit and support mother with dying process.

The words "will visit" suggest the home care nurse had not provided services to Nina since her assessment on May 21 and that the home care nurse still planned to provide support services to Nina's mother. The lack of an earlier recording implies this recording represented the first contact between the home care nurse and the social worker. Similar to the hospital form and the hospice records, the home care nursing records acknowledge a Ministry of Social Services involvement but redirected child protection concerns to a focus on palliative care. In this way, the home care nurses' intervention contributed to advancing a medical diagnosis of "terminal illness".

Text-Mediated Activities

As shown in a previous section, the health care providers' texts coordinated specific knowledge about Nina and mediated their subsequent interventions. These activities emerged subsequent to the health care providers' assessments in which Nina became 'known' as having a "terminal illness." The following analysis maps those activities and plans arising from textually mediated knowledge about Nina and, in particular, shows how they became directed at responding to Nina as a child with a "terminal illness" and not as a child who was malnourished.

Developing Plans - Hospital Form

On the hospital form there is a category entitled "Plan" in which the emergency physician recorded "Advised re: [increased] caloric intake – Try Jevity" and "Check Wt. Tues. + consider admiss or consultation [with] Dr. [L]." This recording informs me, as reader, that the emergency physician decided not to admit Nina to hospital and released her with instructions to Nina's mother to increase Nina's caloric intake with a food supplement available at the local grocery store. His plan to "consider admiss or consultation [with] Dr. L" would apparently occur on "Tues" when he would re-evaluate Nina's status. The emergency physician scheduled his anticipated contact with Nina for five days subsequent to his initial examination. This particular recording in the hospital form suggests the emergency physician's authority as a 'responsible' physician involved in Nina's care who intended to follow-up with medical care five days later. As this analysis will later show, this approach becomes an important feature of the health care providers' developing plans.

It is not apparent from the hospital form, however, what happened to the Ministry for Social Services' concern that Nina was neglected. Several questions remain unanswered: Did the emergency physician have contact with the Ministry for Social Services social worker? If so, what was the outcome? Who saw the hospital form? Where did it go? Did Nina return to the hospital? Did the emergency physician request a consultation with a medical specialist? What happened next? Although the emergency physician used the word "terminal," according to Nina's mother, his plan to "consider admiss or consultation" suggest he possibly intended to treat Nina's malnourished condition at a later date.

Activating Plans - Hospice Society Records

The emergency physician's plans became derailed when the hospice volunteer visited Nina's home two days after his medical examination and completed Nina and her family's assessment. The hospice volunteer's text-mediated activities, framed by the palliative care discourse, refocused the emergency physician's planned action of possible hospitalization and treatment. In turn, the hospice volunteer’s ‘new’ plan of action became directed at providing palliative care services to Nina and her family. While the hospice volunteer noted, for example, that the emergency physician “asked to see her [Nina] again on Tues 21st”, the hospice volunteer subsequently recorded: “make it clear to [the emergency physician] that the mother want to keep her dying child at home.” This statement appears to contradict the emergency physician’s plan to possibly admit Nina to hospital the following Tuesday. The hospice volunteer also recorded that she had “contacted CHNC [note: an acronym for Community Home Nursing Care] and they are able to attend on Tuesday.” It is a recording that implies the home care nurse’s visit would substitute for Nina’s return to hospital.

In the hospice records Client Information Sheet there are several references to “plans” that emerged from constructed knowledge about Nina as dying from a “terminal illness.” For example, the hospice volunteer listed several activities she anticipated the home care nurse could attend to – all tasks related to supporting the dying process.

> CHNC could: 12. [V] 3/4 hr. weekly.
> 1) Advocate w/ dr for [Nina’s mother]
> A) Help get letters in place
> Do not resuscitate order
> Expected outcome being death
> *letter from Dr. to MHR
> B) Put ambulance on call.
> C) Inform mother of agencies of support (Homemaker)
> D) Can talk & listen to mothers medical concerns
> E) Assist in med’s & open wounds if they should occur
> watch she’s not dehydrated”

And, a reference from further down the page:

> Help w/questions about the dying process ie: mouth care

As my analysis will later show, the home care nursing records illustrate how the home care nurse 'took up' these activities and, in that way, further advanced interventions that focused on providing Nina with palliative care rather than treatment for her malnourished condition.

In the hospice records Client Information Sheet, the hospice volunteer also recorded a list of anticipated activities for whoever (such as another hospice volunteer) would eventually provide palliative services to Nina and her family:

> Assist with family – and clients during period of anticipatory grief and [Nina's death]
> Help w/ questions about the dying process i.e. mouth care
> Help children understand

In the Client Referral Form, there is a category entitled care plan in which several tasks are identified as comprising the plan:

> Emotional & practical support for mother and family, including respite. Taking young children for walks, reading books pretaining [sic] to death, helping to educate and comfort them process the death. Helping with housework. Helping with [Nina].

All of these recordings show how the particular construction of Nina as dying from a "terminal illness" mediated the type of response the hospice volunteer made to her condition. These responses, as indicated above, resulted in several planned activities. It is not apparent from the texts, however, whether these plans actually materialized.

Advancing Plans - Home Care Nursing Records

After receiving the hospice volunteer's telephone call, the home care nurse arrived at Nina's home with a DNR form. In the first phase of her intervention, the home care nurse completed the "Assessment Data" section of the home care nursing records which, as stated previously, focused the nurse's work on Nina's presenting physical problems on that day and affirmed Nina's apparent need for palliative care. Following the "Assessment Data" section is a form dated May 21 that appears linked to the palliative care policy as suggested by the form's various categories such as "planning for death" and "who to phone if death occurs at home" (see Appendix D(c)). The recordings on this form show several plans in place and activated: the Coroner was notified, Nina's mother would take Nina to the hospital after her death and Nina's mother would phone the emergency department at the local hospital prior to arriving. The last recording states: "Emergency then will contact pathologist who will prepare for autopsy + will take brain sample for Rett research."

The "Care Plan" section in the home care nursing records consists of a one-page form with several categories: "Date," "Assessment Category Number," "Description of Problem," "Expected Outcome," "Nursing Intervention" and "Intervention Change" (see Appendix D(e)). In the first section, at the top left side of the page, Nina's 'problem' is described as follows:

> recent wt loss [with] [decreased] appetite. weight requires monitoring – as so little is known about Rett Syndrome unsure if wt. loss is associated [with] progression of disease.
> Mother wishing for no medical intervention wanting to keep child "warm, comfortable & loved" needing support regarding deterioration of child.

In the "expected outcome" category, the recordings state: "[Nina's] st will be monitored" and "Family (mother + siblings) will be given support re: [Nina]."

The "nursing interventions", recorded in the appropriate category, consisted of the nurse leaving her agency's weigh scales at Nina's home so Nina's mother could weigh Nina , keep a record, and report to the doctor and nurse. In addition, the home care nurse would "monitor appetite + intake." The second recorded "nursing intervention" states:

"allow mother to voice her concerns" "allow time each visit for support" and "provide emotional support".

The home care nurse's planned and effected actions appear to have acted as a substitute for Nina's return to the hospital; a return scheduled for the same day the home care nurse attended Nina's home. This substituted action occurred despite the absence of information recorded in the home care nursing records that spoke to the statement "unsure if wt. loss is associated [with] progression of disease." While the statement suggests Nina's weight loss remained undiagnosed (and therefore untreated), there is no information recorded that links the statement with the emergency physician's plan to consider hospitalizing Nina and consult with another physician. Nor is there any statement that informs that reader as to whether *any* physician would be investigating the possible cause of Nina's weight loss and providing appropriate medical treatment. The home care nurse's statement, as it appears, was abandoned as 'relevant' information when the home care nurse pursued her professional and organizational agenda to provide palliative care to the patient, Nina, who was constructed as a child dying from a "terminal illness". That textual construction, entrenched as an official and authoritative view, led the home care nurse to put various plans in place, such as phoning the coroner and ambulance, to support Nina's 'inevitable dying process' rather than ensuring her condition was properly diagnosed and treated. The home care nurse's actions became linked to the enactment of a DNR order.

Enacting the Do Not Resuscitate Order

The actions of the three health care providers—the emergency physician, the hospice volunteer and the home care nurse—became textually linked with the enactment of the Do Not Resuscitate order (see Appendix E). This process began when, according to the home care nursing records, the hospice volunteer referred to Nina as a "ten year old girl who is dying from Rett Syndrome." In the home care nursing records "Progress Notes" section, the first recording is dated May 20 and reflects the contents of a telephone call the home care nurse received from the hospice volunteer (see Appendix D(a)). The home care nurse went to Nina's home the next day, on May 21, to conduct her assessment. In the home care nursing records, under the date May 21, the nurse recorded:

> client 10 years old unsure what she understands. Mother, sisters, brothers aware Rett Synd. Mother wanted [Nina] to die at home – wants no medical intervention (ie) tube feeds. Hospice worker involved. DNR form started. Mother signed – given to Dr. H. for signatures.

Under the category "Coroner notified," the words "yes" appear with two handwritten names and phone numbers.

There is no information in the home care nursing records to show that the hospice volunteer asked the home care nurse to initiate a DNR order. However, the records indicate that the home care nurse arrived at Nina's home for her assessment with the DNR form which required Nina's mother's and a physician's signature. In the Assessment Data section, for example, under the "projected treatment goals" heading, the box with the words "palliative care" is marked. On the next page, in a category entitled "Planning for death," the date May 21 appears with the recording "DNR form started mother signed – given to Dr. [H] for signatures. A recording associated with this one, dated May 22, states: "signed by Dr. + will return to HNCP."

The home care nursing record for May 22 indicates the home care nurse had a telephone conversation with the emergency physician. – "states he signed DNR = will return to HNC box at hospital – wanting RN to weigh [Nina] each visit (Tues – Thurs – Sat) to see what her wt. is doing and to provide support to mother." Also on this date, the recording shows that the ambulance and coroner were notified by telephone of above. The records do not indicate if and when the home care nurse picked up the DNR order from the hospital after the emergency physician signed it. However, the home care nursing records include a copy of the order, which shows the Nina's mother's signature, the emergency physician's signature and the name of an alternate physician (the local pediatrician). When the emergency physician signed the DNR form, in his official capacity, the emergency physician's actions authorized and enacted the order which subsequently became a component of the home care nursing agency's administrative records.

In those records, there is a written note dated May 28 stating:

> T.c from [social worker] at Social Services – wanting to know if [Nina] is eating and concerned that competent person feeding her – made aware that [Nina] no longer eating/drinking – social services had been in contact [with][emergency physician] and aware DNR in place and [Nina] is dying – aware HNC will visit and support mother with dying process.

Nina's "Terminal Illness"

A medical decision to enact a DNR order is often associated with the need to "ensure that dying patients and their families receive appropriate treatment and care at the end of life" (Rodney et al, 2000, p. 3). A DNR order requires health care professionals not to attempt cardiopulmonary resuscitation if a patient experiences respiratory and/or cardiac arrest. At the same time, it does not imply that a patient should not receive appropriate medical treatment or care at any time. In addition, the physician responsible for the patient's care, and other health care providers, must review the DNR order periodically, particularly if there is any change in the patient's condition.

The DNR form, entered as an exhibit at the Coroners Service inquest, consists of a standardized, typewritten format with boxes containing descriptive statements and several spaces for names and signatures. The name of the province and the Ministry of Health and Ministry Responsible for Seniors is written at the top of the page. At the top of the form, in typewritten style, it states:

1. Patients who know they have a terminal illness or who are considered at the natural end of their lives can request beforehand that no active resuscitation be started on their behalf if they are dying. This should be done after discussions with their doctor. "No active resuscitation" is defined as no cardiopulmonary resuscitation in the event of a respiratory and/or cardiac arrest.

2. This form is provided to you and/or your next of kin by your doctor to allow you to clearly state that you do not want active resuscitation to be given to you in circumstances where you can no longer make the decision by yourself. It instructs people such as ambulance attendants and emergency room personnel not to start active resuscitation on your behalf whether you are at home, in the community or in a long term care facility. The personal information collected on this form assists the health care professionals noted above to carry out your wishes. If you have any questions about the collection to this information contact: [information omitted]

3. It is recommended that your doctor or alternate be called first to attend to your needs and not the Ambulance Services. You or your next of kin should have the form available to show to emergency help if they are called to come to your aid.

4. If you change your wishes about this matter, then please inform your doctor and community nurse and tear up the form.

(Coroners Service Inquest Exhibit # 10)

As the DNR form stipulates, it is for patients who "know they have a terminal illness or who are considered at the natural end of their lives" and who want to request no active resuscitation if they are dying. Clearly, it is not apparent from any of the health care providers' texts that Nina 'knew' she had a "terminal illness" or that she considered herself "at the natural end" of her live. Nina relied entirely upon other people associated with her to make that determination and representation on her behalf. The existence of the form, as it was, shows that it was not an appropriate form to use with children and the wording in the categories suggest it did not contemplate situations involving children. Regardless, this text stood as an official and authoritative view of Nina as a child with a "terminal illness". Its very existence, made known to the Ministry of Social Services social workers, signified Nina had come to the "end of her natural life".

In summary, the historical complexities of Nina's everyday life, before the emergency physician's examination on May 16, is reduced to one sentence in the hospital form: "has been losing wt. past 4-6 wk. due to inability to feed her." The medical discourse, employed in the construction of Nina as dying from a "terminal illness" is clearly evident and unchallenged by information that might, if introduced, have generated a text that "filled in the gaps." The palliative care discourse and organizational requirements "structured" and stabilized this view. In relation to Nina, "everything that contextualizes her has been rendered invisible or has been packaged into reports that use the observer's experience to replicate an organizational form, and that practice structuring procedures" (Smith, 1990a, p. 92).

Notably, the combined activities of the three health care providers occurred between May 16 and May 21, a relatively short period of time for three professionals, who had no prior involvement with Nina, to enact a DNR order. Their socially organized accounting of knowledge about Nina, it appears, was taken for granted and the local context of her life, before and after Nina's hospital visit, is completely obliterated. Nina's experience had "no apparent history other than that incorporated into the text (or in features of its frame) and [did] not acquire a history as a product of the various occasions of its use" (Smith, 1975, p. 116).

CHAPTER EIGHT: CONCLUSION AND REFLECTIONS

From the moment I learned about Nina's death and the surrounding events, I wondered 'what happened' in the few prior weeks when numerous service providers became aware of her circumstances. Adequate legislation, policy and practice standards - mechanisms to guide and instruct professionals in their service provision- existed at the time Nina was alive, presumably to ensure her safety and well-being. I became perplexed, therefore, despite numerous public reviews, about why Nina failed to receive the protective and medical interventions she appeared to require. I began to consider how the professionals, particularly the health care providers who saw Nina the week prior to her death, came to 'know' who she was and how their professional 'knowledge' about her might have impacted their actions. In my reading of the health care providers' texts, as a place where I began searching for 'knowledge', I felt a sense of 'disquiet' about how the texts constructed Nina as a child dying from a "terminal illness." This 'disquiet' arose from my awareness that a retrospective review of the circumstances pertaining to Nina's live had revealed she had died from "severe malnutrition".

The health care providers' texts, I realized, offered me a place to begin to explore 'what happened' to Nina in way that did not replicate how other public inquiries had proceeded. In conducting my exploration, or inquiry, I relied upon institutional ethnography as a theoretical and methodological framework to analytically explore what professionals often take for granted – texts as components of their everyday practice. By analyzing the texts in this way, I argued that the health care providers' texts, as constituents of social relations in which the health care providers' carried out their work, mediated and coordinated their activities. Through my analysis of the health care providers' texts, I was able to 'see' how the health care providers came to 'know' Nina as a child dying from a "terminal illness", how they came to 'know' Nina as a child whose disability was synonymous with "terminal illness" and how they came to 'know' Nina as a child who required palliative care. I was also able to observe, through my analysis, how the health care providers' textually constructed knowledge about Nina mediated their actions and led to a particular type of intervention that appropriately fit within the medical and palliative care framework.

The emergency physician's plan for Nina to return to hospital, for example, did not appear to materialize. The health care providers' texts revealed how the emergency physician's reported words that Nina's condition was "terminal," textually represented in the hospice society records, provided the impetus for the hospice volunteer's work and diverted the emergency physician's plan for Nina to return to the hospital. The hospice volunteer's work, situated within a professional and organizational framework informed by a palliative care discourse, required her to 'see' Nina as having a "terminal illness" and to offer palliative care services. As the analysis shows, the home care nurse then 'took up' the hospice volunteer's work, from the information she received in a telephone conversation, and substitute her "caring" intervention for Nina's return to hospital. The home care nurse, who arranged for Nina's mother to sign a DNR form in a manner consistent with organizational policy and practice, subsequently had telephone contact with the emergency physician who signed and enacted the order. The DNR order, as an official and authoritative text, 'stood in' for any other reality Nina might have experienced. As a textual account, it represented the health care providers' coordinated and concerted efforts to construct Nina as a child dying from a "terminal illness" and as the "right" approach for Nina in her circumstances. Remarkably, the health care providers' activities - from 'diagnosis' to palliative care - occurred over a five day period between May 16 and May 21.

While the health care providers did not participate in a formalized, coordinated multi-disciplinary team approach to providing service to Nina, my analysis demonstrates how their individual activities coordinated a textual construction of Nina as dying from a "terminal illness" and the enactment of the Do Not Resuscitate order. It is notable that the health care providers' activities came together for the specific purpose of providing palliative care services but that they lacked a coordinated effort to determine what factor specifically led Nina's weight loss in a relatively short period of time. The analysis suggests that the view of Nina as a child with a "terminal illness", stabilized in the texts, obliterated other 'knowing' about her and rendered her entire historical context invisible. Nina, as she appeared in the health care providers' texts, had "no apparent history other than that incorporated into the text (or in features of its frame) and does not acquire a history as a product of the various occasions of its use" (Smith, 1975, p. 116). The absence of an "apparent history" made it more difficult, I believe, for the health care providers to 'see' how Nina's condition compared with her prior experiences as a child who had lived with Rett Syndrome for approximately ten years.

As my analysis also shows, the health care providers' lack of a coordinated approach to assessing and responding to the cause of Nina's weight loss, highlights the disconnect between the Ministry for Social Services child protection investigation and the health care providers' interventions. From the textual accounts analyzed, the disparate health care providers' textual accounts suggest confusion among the health care providers as to the social worker's role in relation to Nina. The health records I examined give no indication whether the Ministry for Social Services' child protection investigation was connected to, or coordinated with, the health care providers' assessments. In light of the concern about neglect that initiated Nina's entry into the health care world, it is puzzling that the two processes – the child protection investigation and the health care providers' interventions – appeared to coexist without intersecting. It is also disconcerting to observe the dominance of the health care agenda, defined in Nina's case as palliative care, in a situation whereby alternative views, or accounts, appeared to be absent from the health care providers' textual representations of 'knowledge' about Nina. Perhaps, this outcome reflects the hierarchical nature of professions in which a dominant discourse, such as the medical discourse, subverts and undermines less dominant discourses, such as the children's rights and child welfare discourses.

As the analysis demonstrates, professional and organizational work demands textual accountability that, in turn, links everyday practice to the relevant professional and organizational agenda. The health care providers' textual accountability did not link their work to the Ministry of Social Services agenda. And yet the health care providers, and others, depend upon constructed 'knowledge' appearing in official texts to inform and direct their decision-making. In that way, texts are an essential and significant component of professional activities. The health care providers, whose completion of their respective organizational forms appear properly done, did not respond to Nina with necessary medical treatment for her malnourished condition. This observation suggests that while the health care providers followed "proper procedures", it did not result in what might be viewed as an appropriate response to organizationally relevant policies and procedures. There is no apparent divergence from expected textual practices. However, the interventions that might have saved Nina's life did not occur.

This analysis demonstrates, therefore, the inherently unreliable nature of textual constructions and their inability to fully represent the nature of a child's reality and her everyday experiences. As Smith (1990b) suggests, texts have a tendency to become static in their structure, separated from local social processes as they unfold. The health care providers, by strictly adhering to their professional and organizational practices situated within their respective discourses, risked 'not seeing' and 'not knowing' Nina in her broadest, contextual sense. Rather, the health care provider's texts, as objectified constructs of Nina, 'stood in for' Nina's actual experience and represented a view of her divorced from how she may have lived her life. At the same time, these texts came to represent official and authoritative 'knowledge' about Nina and, in that capacity, effected significant decision-making that ultimately determined how Nina experienced the last week of her life.

Reflections

The learning from my inquiry continues and, in the words of DeVault (1999), has left me with an analysis that doesn't feel "settled or finished," but rather is one that I would prefer to leave "open at the edges." I discovered, for example, that the specific insights I gained led me to reflect on broader issues largely concerning children. By sharing some of my reflections about these issues, I hope I will encourage new questions and ongoing inquiry into all matters concerning children.

From my observations about the health care providers' interventions in relation to Nina's apparent need for service, I have learned about how essential it is for professionals, and others, to differentiate between a child's disability and her presenting condition. In Nina's situation they appeared to became 'one and the same'. Her 'diagnosis', or her 'problem' associated with her malnourished condition, was identified in the texts as Rett Syndrome, a disorder Nina had lived with since she was 18 months old. Rett Syndrome advanced, through text-mediated activities, as the 'explanation' for Nina's weight loss. Did any medical investigations take place into what specific aspects of Rett Syndrome might have been responsible for Nina's weight loss? Did any medical investigations occur that 'ruled out' other possible explanations? What was the appropriate medical treatment for a child with a disability in her condition? While these questions are not answered in the health care providers' texts, it appears that Rett Syndrome, Nina's disability, evolved through textually related activities to become a "terminal illness"; it provided the rationale for the designation:

> In a number of incidents people with disabilities have shown distinct signs of an acute condition, yet it has remained undiagnosed or misdiagnosed for many months. With hindsight it seems that there has been a reluctance to strive for diagnostic accuracy. This apparently occurs because it is felt that treatment or intervention will be of little significance or value to the person's perceived quality of life or because the symptoms of an acute condition are believed to be a feature of the disability (A Report on Accessing Equitable Health Care in British Columbia for People with Disabilities, 1997, pp. 22-23).

This report suggests that failing to make a distinction between a child's disability and her acute condition (or chronic illness) can operate as a barrier to that child receiving adequate medical care. For that reason, health care services to children with disabilities must be considered an entitlement, as it is for all people, and not treated as a privilege (Globe and Mail Newspaper, 1999, p. A7).

In conducting my inquiry, it also became apparent to me that professionals working with children may have difficulty 'seeing' those children as unique individuals, separate from their parents, and may face challenges fulfilling their responsibilities to both children and their parents. While some professionals adhere to the ideological notion of the family as a sacred, "private domain", societal interests also support the nuclear family's role as the primary, private institution responsible for attending to children's interests. According to McGillivray (1992), parent-child relations largely fall into the realm of the private and it is "only in hard cases of severe failure and disclosed injury that the private becomes public" (p. 215). Family privacy is largely strengthened "by 'non-interventionist' decisions upholding the right of parents to dictate educational, disciplinary, religious and residential choice. This legitimizes the power of parents to interpret the child's reality" (p. 216). Minow (1996), with whom I agree, has suggested this ideological approach has tended to isolate children within the world of the private family. In turn, it has reduced the awareness and visibility of children as a distinct and separate group with their own special interests (p. 46).

The tendency to isolate children brings me to what I believe is the importance of distinguishing between *a child's welfare* and *"child welfare."* In the child welfare discourse, the term 'child welfare' has a fairly narrow implication and has taken on a notion of child welfare as one that incorporates concepts of protection and intervention. Authors such as Swift (1995) define child welfare as a system throughout Canada that has common characteristics premised on a belief tied to ideological notions of family:

> Parents bear the primary responsibility for the welfare of their children and a concomitant right to raise their children in accordance with their own wishes. It is a residual system, one that deals with the most serious problems of care and generally intervenes with the most vulnerable of families. It is a system that provides more investigation than preventative or treatment service, and it is an underfunded system, one that requires service providers to respond to the greatest crises while overlooking or postponing attention to other serious, high-risk situations (p. 38).

Another author, Callahan (1993), also equates child welfare with the notion of a child welfare "system" and suggests it is a system for which the state has assumed responsibility (pp. 189-190). While Wharf (1993) suggests that "community ownership of child welfare is important in order to provide an opportunity for social learning-for citizens at large to learn about and become interested in child welfare" (p. 9), I believe that community ownership of *a child's welfare* is where we, as a society, need to begin. "Welfare rights," as it has been defined in children's rights discourse, includes "adequate nutrition, housing and medical treatment, education and care, love and protection" (Fox-Harding, 1991, p 167). By taking responsibility for ensuring *children's welfare*, perhaps all professionals providing services to children, and others, will become more apt to stretch beyond the strict boundaries of their professional and organizational agendas.

It is sometimes difficult, when working within the narrow confines of a professional discourse, for professionals 'see' children as unique individuals who live in the everyday world. I have attempted, in my thesis, to offer a glimpse of Nina that would allow the reader to 'see' her life in a broad sense and to understand how she might have lived as a child with likes, dislikes, strengths and challenges. I wanted to ensure that Nina was visible and present to the reader as a 'real' child who had an everyday existence beyond what she experienced with the health care system. My intent for incorporating alternative accounts about Nina, therefore, was to offer the reader an opportunity to recognize how professionals providing services to children, myself included, often construct what we believe are 'knowledgeable' accounts about the children we serve. As my inquiry demonstrates, this 'knowledge' tends to reflect our professional and organizational agendas, to distort a child's reality and to obliterate historical, contextual 'knowledge'.

Coincidentally, as I write my final chapter, I read in my local newspaper about a 14 year old girl with Rett Syndrome, Chelsea, who died after her mother (allegedly) gave her a "poison cocktail." I do not want to draw attention to what the mother did (or didn't do) in this particular instance, rather I want to illustrate how the article has textually constructed 'knowledge' about Chelsea and to highlight how she is largely described in terms of what she 'can't do' because she has a disability. One newspaper article reported a neighbour's description of Chelsea.

> "She couldn't communicate," said the elderly man said of Chelsea. "She was badly handicapped. She wasn't able to look after herself. She had to be fed so it was a real chore to look after her" (Times Colonist Newspaper, 2001, 2001).

There is an analogy between what is missing from the newspaper article and what was missing from the health care providers' textual accounts of Nina, that is, information about what the girls *could do*, what they liked, what strengths they had, their school connections and other positive descriptives. Sadly, the textual accounts of Nina and Chelsea remind us of our need to begin by 'seeing' children with disabilities as children with strengths and challenges akin to all children.

I began my inquiry text with a statement about the vulnerability and powerlessness of children. As I have learned from my inquiry, it is sometimes difficult for professionals to recognize children in their own right, "with interests, needs, and wishes that may differ from or even conflict with those of their parents" (Ladd, 1996, p. 60) and, I would add, other people in their lives. Adult perception of children and the child's perception of the adult are always to some extent influenced by personal needs and interests:

> As individuals and as groups adults have conscious and unconscious attitudes towards children which directly and indirectly influence their work for children. . . the different attitude components in a society or between sub-societies may be conflicting, but the composite will determine the views of private as well as public adult responsibility towards children (Flekkoy, 1992, pp. 135-136).

It is important to understand these attitudes and their consequences in order to improve our work with and for children in order to achieve a universal, societal goal of raising healthy children to become independent and fully functioning adults:

> We need to resolve the problem of variable social construction and find universality, we need to explore the folklore surrounding the treatment of children: the inarticulate beliefs, culturally defined responses, social conventions and pretensions, formalistic manifestations of state concern (McGillivray, 1992, p. 231).

We need, as a society, to recognize the moral integrity of children and treat them as persons entitled to equal concern and respect" (Freeman, 1992, p. 37) with their own unique needs and interests.

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APPENDIX A

[redacted]

I HEREBY AUTHORIZE THE HOSPITA
PROVIDE ALL DIAGNOSTIC SERVICE
MEDICAL TREATMENT AS NECESSA
THE PATIENT NAMED BELOW.

[redacted]

Out-Patient or Short Stay (H1A-16)

PATIENT NAME	PERSONAL HEALTH NUMBER	ENCOUNTER NO.	PIN
[redacted] [redacted] [redacted]		[redacted]	[redacted]

PATIENT INFORMATION

DOB: [redacted] Age: 10 Y Sex: [redacted] Citizenship [redacted] BC Reg Since:
[redacted] [redacted] Tel: [redacted]

ENCOUNTER INFORMATION

EXAM

EMERGENCY NOTIFICATION

MOTHER [redacted]
Res: [redacted]

ADMISSION INFORMATION

Arrived By:
Admitted: 16 MAY [redacted] 15:24
PAH Dr: [redacted]
ADM DR: [redacted]

FINANCIAL INFORMATION

[redacted] [redacted]
HOSPITAL PROGRAMS

EMPLOYMENT INFORMATION

T 36.° P R BP WT 23.5#
Meds:
Tetanus Status
Allergy:

Nursing Assessment Pt. s/e and assessed by Dr [redacted]

[redacted]

Physician History/Exam Wt – 23.5#

10 yr. old ♀ c̄ Rett synd.
has been losing wt. past
4-6 wks. due to inability
to feed her – mother understands
the disease well – some
concern by MHR that child
is being neglected
O/E V.S. afebrile P-88 reg
ENT-clear Chest-clear
P/A-NAD CNS-Tremor-no ~~Meg~~
Gen: emaciated -stiff legs -good ROM

Plan:
Advised re: ↑ calo
intake -try
Jevity
Check Wt. Tues
+ consider admi
or consultatn
c̄ Dr. [redacted]

Investigations

Med Orders:
Tim

Assessment: No evidence of Abuse
Rett Syndrome.

[redacted]
Physician Signature

INSTRUCTION SHEET - YES ______ NO ______ N/A ______

DISPOSITION:
CONDITION ON DISCHARGE ______

HOUR	DAY	MONTH	YEAR
630	16	5	[redacted]

DISCHARGED ✓ ADMITTED ______
LEFT AGAINST ADVICE ______

Fee Code DC

ORIGINAL - MEDICAL RE

APPENDIX B

22

[illegible]

Sat visit

Sat visit May 18th

Client Information Sheet

Client : [redacted] 10yrs old.
[redacted] & mother
Retz Syndrom
22 lbs.

① [redacted] - Childrens Hospital
Retired Dr. But active at childrens
Knowledgable in Retz Syndrom.

Sat May 18th Mother last spoke w/ [redacted] Tues May 14th +
2 weeks prior regarding [redacted] deteriorating
condition.

Dr. (4) (1) ★ assured the mother her care would
be better than hospital care.

② Dr [redacted] : reg. family doctor, but
hasn't seen [redacted] for quite awhile
as he is not familiar w/ her condition.

③ Dr. [redacted] - [redacted] Dr, but he's left Nelson

④ Dr [redacted] : Saw [redacted] @ emerg. on
Tues May 14th. He has ~~seen~~ said
her condition is terminal. He has
asked to see her again on Tues 21st.
Social Worker - [redacted] - has stated it
is not their right to force life systems
onto [redacted]

I have contacted CHNC and they
are able to attend on Tuesday.

Retz Syndrom Deteriorating Disorder

[illegible] [redacted]

DR [redacted]
[redacted]
Dr. [redacted]

[redacted] is:
not eating
crippling up
Bruising easily
Speaking w/ her mother about her death.

Are you avalible —
nt Requested for some support from Hospice
ask if avalible

[redacted] [redacted]

> walking bag — 4 hrs @ week +
> helping around home
> " w/ [redacted]
> Anticipatory grief w/ kids & mom.
>

Confidentiality Huge issue — Essential

([redacted])

Service
CHNC [illegible] on Sat. Urgent - [redacted]
THINGS in place
- DO NOT RESUSITATE (DNR) =
- Expected outcome =
min of Social Services
may need to liason w/ them.

- daughter not eating
- another chair ???
- nutrition
[illegible] Significant Nutritional

[redacted]

CHNC call: 3/4 hr. weekly
1- Advocate w/dr. for [redacted]
A) Help get letters in place
i) Do not resusitate order
* ii) Expected outcome being death.
B) Put ambulance on call.

C) inform mother of agencies of support (Hm m.
D) Can talk + listen to mothers medical concerns
E) assist in meds + open wounds if they should occure.
F) watch she's not dehydrated

Hospice Volenteer – [redacted] ✓
Assist with family – and clients during period of anticipatory grief and [redacted] death.
{ Help w/ questions about the dying process
*{ (i) Mouth Care
– Help children understand +

Ethical Issues – or correctness of mothers decision should not be an issue. The child needs to be determined to ~~bing~~ be dying of natural causes and the expected outcome is she will indeed die.
* Make it clear to Dr. [redacted] that the mother want to keep her dying child at home. There is a false fear in community that [redacted] being abused (food withheld or ignored)

Dr [redacted] – Dr [redacted] [redacted]
Terminal Illness.

CORONER'S COURT

CASE [redacted]

MARKED
#22

ENTERED

EXHIBIT NO.

SUBMITTED BY:
☐
☐

CLERK ACKNOWLEDGMENT
DATE

APPENDIX C

[redacted] HOSPICE SOCIETY
CLIENT REFERRAL FORM

NAME: [redacted]

ADDRESS: c/o [redacted]

PHONE # [redacted] **AGE:** 10 years

DIAGNOSIS: Rett Syndrome (a rare deteriorating desease) [redacted] was diagnosised at 18 months of age.

DOCTOR: Dr. [redacted] / Dr. [redacted]
Dr. [redacted] Retired Dr. at [redacted]

AWARE OF REFERRAL:

FAMILY OR CAREGIVER

NAME [redacted] **RELATIONSHIP** Mother **PHONE#** [redacted]

PATIENT AWARE OF DIAGNOSIS? Y **FAMILY?** Y

PATIENT AWARE OF REFERRAL? **FAMILY?** Y

REFERRAL SOURCE: Mother

CARE PLAN: Emotional & practical support for mother and family, including respite. Taking young children for walks, reading books pretaining to death, helping to educate and comfort them process the death. Helping with housework.
Helping with [redacted]

VOLUNTEER: [redacted] **PHONE #** [redacted]

VOLUNTEER: **PHONE #**

DATE REFERRAL INITIATED: Saturday May 18, [redacted]

DATE CLIENT INTERVIEWED: May 18, [redacted]

DATE VOLUNTEER ESTABLISHED: May 20, [redacted]

DATE OF REVIEW WITH CLIENT:

DATE OF DEATH OR TERMINATION OF SERVICE: Died. May 28 [redacted]

TOTAL HOURS:

BEREAVEMENT FOLLOW-UP?

NAME: **TYPE:**

SOCIAL HISTORY: There are [redacted] children in this family. Oldest [redacted]

A restaining order is in place against the father, furthering the need for confidentiallity.

COMMENT FIELD:

Ministry of Social Services has been attentive to this case and family, with some misinformation about [redacted] condition. They are now aware of the correct diagnosis.

Community Home Nursing Care is attending to [redacted] DNR and Esxpected Outcome Letters are being put in place.

It is the wish of the family and [redacted] her to die at home.

APPENDIX D(a)

Ministry Responsible for Seniors
COMMUNITY HOME NURSING

PROGRESS NO

143

NAME [redacted] [redacted]

DIRECT CARE No. [redacted]

DATE Y M/D	TIME	ASSMNT CATEGORY NUMBER	PROBLEM NAME AND NOTES	SIGNATURE
05/20	1500		T/C from hospice worker [redacted] ([redacted]) regarding HNC referral for [redacted] - ten year old girl who is dying from Rett syndrome apparently was diagnosed c̄ disease at 18 mon. States mother needing support re care of child: - child apparently not eating only taking sips of H2O - + sleeping for hours at a time - Hospice worker states mother needing to have [redacted] weighted tomorrow and was hoping that RN could visit + do weight - otherwise was having to take child to hospital to be weighed - child apparently unable to stand and weighs approx 22 lbs ——	[redacted]
	AC		unable to reach mother as she has been out - message left that RN would contact in am to arrange time for visit ——	[redacted]
5/21	1200		Lengthy visit (1200-1330) see assessment data base ——	[redacted]
~~05~~/05/22	1145		T/C to Dr [redacted] - States he signed DNR + will return to HNC Rx ā at hospital - Wanting RN to weigh [redacted] each visit (Tues-Thur, Sat) to see what her wt. is doing and to provide support to mother C[illegible]	
	1500		Ambulance - coroner [redacted] notified by	

APPENDIX D(b)

[redacted]

Ministry of Hea and
Ministry Responsible for Seniors
HOME NURSING CARE

DATA BASE CONTINUE
ASSESSMENT DAT

145

E [redacted] [redacted]

DIRECT CARE No. [redacted]

ISSION RELATED DATA

past medical history - diagnosed at 18 months of age c̄ Rett Syn
resent - now 10 years old - child has had recent wt
loss of 10lbs over past 2months - has gone from 32l
ō 21 lbs - [redacted] drinking liquids + very small
nt of solids - mother unsure of why wt loss - wondering
progression of the disease is causing ↓ appetite c̄ wt l
[redacted] lying in fetal position on couch - no verbal response
nding teeth - mother unsure how much [redacted] understa
ther wanting no medical intervention (aggressive)
tube feeds - States her main concern "is to keep [redacted]
m, comfortable + loved" Expressing her fears
c̄ social services may apprehend child - States the
- Tues social worker arrived at residence and was
g to apprehend [redacted], but after they spoke @ Dr
o was familiar c̄ Rett syndrome + [redacted] they decided
t to - mother upset + crying during visit - feeling
whelmed c̄ everything. [redacted]

ESSMENT EGORIES	BASELINE ASSESSMENT ✓ NO INTERVENTION N.I. NSG. INT. & DATE BLANK NOT ASSESSED	OTHER RELEVANT DATA	SIGNATURE
1. ✓ EDICATION	[redacted]05/21	nil	[redacted]
2. ✓ OUND/SKIN	[redacted]5/21	Mother states [redacted] now bruises easily - states [redacted] intact reviewed importance of skin-care + S+S of skin breakdown	
3. ✓ PAIN	[redacted]05/21	Mother feels [redacted] has no pain	[redacted]
4. N.I. GNS & MPTOMS	[redacted]05/21	wt 21 lbs	

SSESSMENT DATA

E [redacted]

SSESSMENT ATEGORIES	BASELINE ASSESSMENT ✓ NO INTERVENTION N.I. NSG. INT. & DATE BLANK NOT ASSESSED	OTHER RELEVANT DATA	SIGNATUR
5. MEDICAL SUPERVISION/ FOLLOW UP	✓ [redacted]/05/21	H/s recently seen Dr [redacted] - didn't have fam Dr in [redacted] since Dr [redacted] left.	[redacted]
6. ELIMINATION	✓ [redacted]/05/21	Incontinent of urine + stool - wears diapers	[redacted]
7. MOBILITY	✓ [redacted]/05/21	needs to be carried -	[redacted]
8. UTRITION & ATING HABITS	Nl [redacted]/05/21	Sensitive to milk + milk products. taking sips of fluids - Small amt of solids	[redacted]
9. SLEEP & REST	✓ [redacted]/05/21	sleeping for long periods of time please assess next visit	[redacted]
10. A.D.L. SSISTANCE			
11. MOTIONAL SOCIAL IFESTYLE	Nl [redacted]/05/21	Lives c̄ mother, brothers + sisters. Family needin support re deterioration of [redacted]	
12. IRONMENT	✓ [redacted]/05/21	cluttered house	[redacted]
13. NANCIAL	✓ [redacted]/05/21	social assistance	[redacted]

O PROGRAM STAY)	PROJECTED TREATMENT GOALS (✓ one only)		PATIENT OUTCOMES (✓ one only)	
S THAN 2 WEEKS ☐ E. 6 MONTHS OR LONGER	☐ A. FULL REHABILITATION	☐ E. NO INTERVENTION REQURIED	☐ A. FULL REHABILITATION	☐ E. DETERIORATED
WEEKS	☐ B. PARTIAL REHABILITATION		☐ B. PARTIAL REHABILITATION	☒ F. PATIENT EXPIRED
WEEKS	☐ C. MAINTENANCE		☐ C. MAINTENANCE	☐ G. OTHER
ONTHS	☒ D. PALLIATIVE CARE		☐ D. PALLIATIVE CARE	

APPENDIX D(c)

Aware of Diagnosis	Patient client 10 years old unsure what s understands 148	
	Family ... mother, sisters, + brothers Aware Retts	
Expectations - What do they envision happening? -resuscitation -death at home -care expectations -of physicians -of home nursing	Patient	
	Family mother wanting [redacted] to die at Home - wan no medical intervention (ie) tube feeds.	
ptions discussed	Hospice Room	
	Hospice Hospice worker involved	
	Homemakers	
	Home Care	
	Private arrangements? covered by extended benefits	
anning for death NR form started other signed - given to [redacted] for signature signed by Dr + will return o -	discussed	plans mad.
	Discussed with doctor	
	Coroner notified [redacted] yes,	
	Ambulance notified	
	Funeral Planning	
	Name of Funeral Home	
TO PHONE IF DEATH RS AT HOME	[redacted]/05/27 discussed	
octor will make house all or pt to hospital o be pronounced	Dr not making house visit at time of death - mother will bring [redacted] into hospital after dea Will phone [redacted] emergency prior to leaving to let	
uneral Home notified	them know of her Arrival in approx 1Hr -	
thers to call - eg. Minister, friend or volunteer to stay with family	emergency then will contact pathologist who will prepare for autopsy + will take Brain sample for Rett Research -	
ents		

APPENDIX D(d)

Ministry Responsible for Seniors
COMMUNITY HOME NURSING CARE

150

NAME [redacted]

DIRECT CARE No. [redacted]

DATE Y M D	TIME	ASSMNT CATEGORY NUMBER	PROBLEM NAME AND NOTES	SIGNATURE
.05-27	Cont'd		Urine sample needs to be obtained 2-3 hrs following de	
.05.28	1600		T.C from [redacted] [redacted] at Social	
			Services – wanting to know if [redacted] is	
			eating and concerned that competent person	
			feeding her – made aware that [redacted] no	
			longer eating/drinking – social services had	
			been in contact c̄ Dr [redacted] and aware	
			DNR in place and [redacted] is dying –	
			aware HNC will visit and support mother	
			with dying process ———	[redacted]
[redacted]/05/29	0900		T.C to mother – she informed HNC	
			that [redacted] had died yesterday	
			Support given to [redacted] over phone —	
			discharged from HNCP —	[redacted]
/06/28			Returned call to Coroner [redacted]	
			regarding [redacted] – will speak to	
			my supervisor [redacted] on Tuesday	
			July 2 regarding this. ——	[redacted]
/07/02	1145		Telephone call to coroner [redacted]	
			Information given re role of Home	
			care nurse (ie) what we did – initiation	
			of DNR and dates of contact by home	
			visits or telephone ———	[redacted]

APPENDIX D(e)

NAME [redacted]

DIRECT CARE NUMBER [redacted]

DATE Y M D	ASSMNT CATEGORY NUMBER / DESCRIPTION OF PROBLEM	EXPECTED OUTCOME	NURSING INTERVENTION	INTERVENTION CHANGE	DATE AND INITIAL
/05/91	recent wt loss c̄ ↓ appetite. weight requires monitering - As so little is known about Rett Syndrome unsure if wt loss is associated c̄ progression of disease.	[redacted] wt will be monitored	using HNEP scales that are at the residence mother to weigh herself then weigh herself c̄ Katie to obtain [redacted]. wt. Keep record of wt + report to Dr prn monitor appetite + intake	Weight Tues-Thur. JAT.	
05/91	Mother wishing for no medical intervention wanting to keep child 'warm, comfortable + loved' needing support regarding deterioration of child	Family (mother + siblings) will be given support re [redacted]	allow mother to voice her concerns allow time each visit for support provide emotional support.		

APPENDIX E

Figure 5

Province of [redacted]

Ministry of Health and
Ministry Responsible for Seniors

BRITISH
COLUMBIA
MEDICAL
ASSOCIATION

DO NOT RESUSCITATE

s who know they have a terminal illness or who are considered at the natural end of their lives can request beforehand that no active tation be started on their behalf if they are dying. This should be done after discussions with their doctor. "No active resuscitation" is as no cardiopulmonary resuscitation in the event of a respiratory and/or cardiac arrest.

rm is provided to you and/or your next of kin by your doctor to allow you to clearly state that you do not want active resuscitation to be o you in circumstances where you can no longer make the decision for yourself. It instructs people such as ambulance attendants an ency room personnel not to start active resuscitation on your behalf whether you are at home, in the community or in a long term care

The personal information collected on this form assists the health professionals noted above to carry out your wishes. If you have estions about the collection of this information contact the ***Executive Director, Acute Care Division, 1515 Blanshard St., Victoria, 8W 3C8, Phone: 952-1237.***

commended that your doctor or alternate be called first to attend to your needs and not the Ambulance Services. You or your next of uld have the form available to show to emergency help if they are called to come to your aid.

hange your wishes about this matter, then please inform your doctor and community nurse and tear up the form.

ENT RMATION

SURNAME: [redacted]

BIRTHDATE (YY/MM/DD): [redacted]

GIVEN NAMES: [redacted] [redacted]

ADDRESS: [redacted] [redacted] [redacted] [redacted]

TELEPHONE NUMBER: [redacted]

ED BY THE ENT

I, ____________________ *(patient's name in full)* understand and accept that I have been diagnosed as having a terminal illness or am considered to be at the natural end of my life and that my care is to include support and comfort only and that no active resuscitation is to be undertaken. I have requested that in the event of a respiratory and/or cardiac arrest, no cardiopulmonary resuscitation is to be undertaken. This order shall be in effect unless rescinded and should be reviewed in one year.

PATIENT'S SIGNATURE	DATE

ED BY THE HORIZED RESENTATIVE HE PATIENT

ERE THE ENT IS BLE TO SIGN AUSE OF OMPETENCY)

I, [redacted] *(the authorized representative of the patient)*

[redacted] *(patient's name in full)* understand and accept that care is to include support and comfort only and that no active resuscitation is to be undertaken. I have requested that in the event of a respiratory and/or cardiac arrest, no cardiopulmonary resuscitation is to be undertaken. This order shall be in effect unless rescinded and should be reviewed in one year.

SIGNATURE OF AUTHORIZED REPRESENTATIVE OF PATIENT [redacted]	DATE May 31 [redacted]	SIGNATURE OF WITNESS [redacted]
RELATIONSHIP OF THE AUTHORIZED REPRESENTATIVE TO THE PATIENT Mother		WITNESS (IN PRINT) [redacted]

OT USCITATE ER

The above identified patient has been diagnosed as having a terminal illness, or is considered to be near the natural end of their life. I have discussed the prognosis of this illness, the life expectancy, the persons wishes and the treatment options with the patient/patient's next of kin. Based on this, I order that in the event of a respiratory and/or cardiac arrest no cardiopulmonary resuscitation is to be undertaken. This order shall be in effect unless rescinded and should be reviewed in one year.

ATTENDING PHYSICIAN'S NAME (IN PRINT) [redacted]		ALTERNATE PHYSICIAN'S NAME (IN PRINT) [redacted]
ATTENDING PHYSICIAN'S ADDRESS [redacted]	PHONE NUMBER [redacted]	ALTERNATE PHYSICIAN'S PHONE NUMBER [redacted] [redacted]
ATTENDING PHYSICIAN'S SIGNATURE [redacted]		DATE [redacted] / 5 / [illegible]

PHYSICIAN PINK COPY – COMMUNITY HOME CARE NURSING SERVICES (IF PATIENT IN CAR

VITA

Surname: Bell Given Names: Nancy Marie

Place of Birth: Saskatoon, Saskatchewan, Canada

Educational Institutions Attended:

York University	1971-1974
University of Saskatchewan	1974-1975
University of Saskatchewan	1979-1980

Degrees Awarded:

Bachelor of Arts Degree	York University	1975

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Title of Thesis:

A Child's "Terminal Illness": An Analysis of Text-Mediated Knowing

Author [redacted]

Nancy Bell
April 30, 2001