

VOICES OF PARENTS:  
THE LIVED EXPERIENCE OF CARING FOR A CHILD WITH A LIFE-  
THREATENING AND LIFE-LIMITING DIAGNOSIS  
WITHIN EXISTING SOCIAL POLICIES

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## ABSTRACT

The purpose of this naturalistic inquiry was to describe, interpret, and link through voices of parents the lived experience of caring for a child with a life-limiting and life-threatening diagnosis within the context of existing social policies. Critical ethnology and Habermas' critical theory framework together provided a broad framework from which to delve beneath the surface of everyday appearances and to produce theoretically informed accounts of social phenomena grounded in parents' perceptions of caring for children who have palliative care needs. This framework provided the means to deconstruct power structures and relationships to reveal and redress oppression by unlocking silent discourses, emancipating voices, and empowering families. The stories of six parents were captured and presented a critical discourse concerning outcomes of the operationalized welfare state within a liberal paradigm that celebrates the autonomous individual as the appropriate unit of political analysis.

Four themes emerged that illuminated and provided a fuller understanding of the lived experiences of parenting a child with a life-limiting and life-threatening diagnosis. The initial theme, "Mother as Caregiver", described the profound effect that assuming the caregiving role had on the lives of these mothers. The theme, "Respite and Coping", explored and identified the overwhelming need for parents to obtain relief through respite, so they could parent better. The third theme, "Surviving Past Expectancy", explained how their child, outliving their initial diagnosis, placed yet another new stress and burden on the family. The final theme, "Getting Everyone on the Same Page",

described frustrations parents experienced on a regular basis trying to find services and then act as coordinator for their child and family.

This study provided a unique and valuable optic to an untapped data source, which until now has remained silent. Results demonstrate the significance and meaning of the identified themes and their interrelatedness, and the study concludes with a discussion of the findings and policy implications. The main findings were the untapped resilience and strength of each participant, the uniqueness of each of their stories, and the reality that the harms associated with having a child with a life-limiting and life-threatening diagnosis can certainly be lessened through social policies that direct the provision and access to pediatric palliative care services to all who require them. A researched-based understanding of the lived experience and the contextual nature of parents' perceptions provides policy-makers, politicians, and health care professionals an opportunity to offer specialized services and programs to children with life-limiting and life-threatening diagnosis and their families.

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## Dedication

This dissertation is dedicated to parents everywhere, who are living and have lived with a child diagnosed with a life-threatening and life-limiting diagnosis. It is my profound hope that results from this work will provide useful information to develop a more sensitive, more humanistic, understanding of the needs of parents who live within this reality.

I wrote this dissertation as an outsider – I hope as a knowledgeable outsider, but an outsider nonetheless. Many lessons have been learned from listening to the voices of these parents. The most poignant lesson for me is best described in the words of Maya Angelou, poet, author, mother, sister, role model

*I can be changed by what happens to me. I refuse to be reduced by it.*

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## CHAPTER ONE

It is not how much we give, but how much love we put into giving.

Mother Teresa

### *Overview*

Everyday the unthinkable still happens, children die from trauma, lethal congenital conditions, extreme prematurity, heritable disorders, or acquired illness, and thousands more are trying to live with life-threatening and life-limiting illnesses. With every medical breakthrough reported, every child saved creates a burden of expectation that the next child can also be saved. Aggressive treatment in our death-denying society has become synonymous with buying time and holds out the possibility of a cure. When a child's life is at stake, many in our society believe there is no such thing as going too far, a philosophical position misunderstood in relation to what is palliative care. A situation that places society, policy makers, and health care professionals on a collision course with the real life needs of children and their parents (Carspecken, 1996; Foley, 2002; Guba & Lincoln, 1982; Lincoln, 1995; Noblit, Flores & Murillo, 2004). Thus the intent of this critical ethnographic study is to describe and interpret through voices of parents the lived experience of caring for a child with a life-limiting and life-threatening diagnosis within existing social policies.

Childhood is an enigma. It is the home of all the great questions about life and death, reality and dreams. How then do we preserve and honor this special time for families facing the harsh prospect of their child dying? Pediatric palliative care, a relatively new specialty within health sciences, is devoted to providing the necessary

services and supports to families from diagnosis (whether or not a child receives curative treatment) through illness and following death. Pediatric palliative care focuses on achieving the best quality of life for the child and support for the family that includes the management of distressing symptoms and the provision of respite and care through death and bereavement (Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT), 2003; World Health Organization, 1990).

National, provincial, and territorial governments, as well as private individuals and groups, have important and complementary roles in the development of social policy approaches directed at improving the current state of pediatric palliative care services.

Pediatric palliative care is a philosophy of care congruent with the discipline and professional practice of nursing where nursing provides care for people in the midst of health, pain, loss, fear, disfigurement, death, grieving, challenge, growth, and birth. A location described as the “privileged place of nursing” (Benner & Wrubel, 1989) establishes that the primary goal is to be responsive and relevant to the health needs of people and society. Rooted in this goal are codes of ethics from both national and international nursing associations, reaffirming nursing’s ethical responsibilities for the contexts and organization of health care and for influencing broader social forces for societal health (Canadian Nurses Association, 2002; International Council of Nurses, 2000). Nursing as a profession must continue to engage in political activities and to advocate for social policies that will continue to provide health systems that deliver universal quality care to all peoples, regardless of age, ethnicity, race, and geographical location (Austin, 2001). Nursing in the 21<sup>st</sup> century must embrace a renewed passion and commitment to activism as an instrument for social change by incorporating theories of

policy, organizational change, and critical theory within practice contexts while retaining its unique perspectives on stress and coping in health and illness.

Canada has been described as a country that “cares”. The Canadian Council on Social Development has published, “A Profile of Health in Canada”, which addresses a number of factors affecting individual health and well-being, as well as key health outcomes. “Canadians are among the healthiest people in the world, but some Canadians are not as healthy as others. Socio-economic status, Aboriginal identity, gender, and geographic location are significant factors associated with health disparities that can cause early deaths, disease, disability, and distress--at a significant cost to the individuals themselves and for Canadian society as a whole” (Canadian Institute for Health Information, 2007, p. 2). Children with life-threatening and life-limiting illnesses and their families are part of this marginalized and vulnerable population of Canadians who experience significant disparity in service delivery--a situation that can no longer be tolerated in a civil society. Through covenants of law, the World Health Organization (WHO) has established “the right of health” as an inclusive right extending not only to timely and appropriate health care but also to the underlying determinants of health (WHO, 2002).

Committed to improving the current state of affairs with these children and their families, I undertook this study, using a critical social theory perspective proposed by the contemporary philosopher Jurgen Habermas (1979). His framework provided a theoretical basis to utilize a significant lens for acquisition of knowledge leading to the formulation of options that effect policy change in pediatric palliative care. Habermas’s view of planning emphasizes widespread public participation, sharing information with

the public, reaching consensus through public dialogue rather than through an exercise of power, avoiding privileging experts and bureaucrats, and replacing the model of the technical expert with one of the reflective planner (1975; 1979; 1986; 1996). A practice of strongly endorsing the emancipation of voices is too often forgotten in the policy process, and, in this case, the voices are those of parents with children who have palliative care needs. Understanding how policies or lack thereof, impact the lives of citizens who experience them and for whom they are ostensibly designed, is critical to pediatric palliative care and forms the overarching research focus of my PhD research study (Aronson, 1993; Athens, 1994; Bessant et al., 2003; Frank, 2000; Newman, 2003; Woodgate, 2005).

### *Public Policy Development*

Public policy development is the most pervasive public decision-making process in a democratic society. Described as a dynamic and highly complex process, policy development is about making choices in relation to the course of action or inaction. Stone (1997) suggests that this process should be most fundamentally a deliberation of the core community values of equity, efficiency, security and liberty. However, the current reality is that market discourse dominates discussions of public policy, and all too often decisions are predicated on efficiency as a core value in health, health care, and other key areas of public concern. Health economists continue to identify the limitations of economic models for the analysis of policy directed at health and health care (Coburn, 2000; Dobuzinskis, Howlett & Laycock, 1996; Hankivsky, 2004; Manga, 1998; Pal, 1997).

Within the Canadian context, this process has had a distinctive normative dimension that is directed toward maintaining or creating social safety nets that promote the welfare of all citizens through education, housing, social security, and health, which includes palliative care services (Pal 1997; Rice & Prince, 2000). Canada has not been immune to the impact of globalization and market-based economics, which has and continues to challenge the existence of the welfare state. Market discourse is now becoming a dominant feature of public policy and replacing a process that had been driven by ideas as much as or even more than by conventional political process (Lavalette & Pratt, 2001; Ruggie, 1996). The result, Pal & Weaver (2003) suggests, is that full and inclusive debates surrounding policy issues are becoming more limited. Moreover, there appears also to be a degree of arbitrariness about what is to be taken seriously as a problem, and controversy often surrounds how a given issue will be understood (Fried & Gaydos, 2002), a point that both Minister Pat Atkinson, (personal communication, October 19, 2006) and Deputy Minister Bonnie Durnford (personal communication March 27, 2007) concede.

The Government of Canada states that proper palliative care be universally available and provided in a manner that respects the wishes of the individual and his or her loved ones. To achieve this end, Kirby & LeBreton (2002) and Romanow (2002) recommended that the federal and provincial/territorial governments work together to ensure that Canadians are well-cared for and have choice in care at the end of their lives. These recommendations are congruent with the established principles inherent within the Canada Health Act. While these recommendations imply the importance of providing access to palliative care services, the discourse and use of terminology such as ‘the dying

person' and 'end of their lives' strongly suggests that the focus of palliative care does not consider the unique needs of children and youth.

### *Pediatric Versus Adult Palliative Care*

Confusion between pediatric and adult palliative care models (Claxton–Oldfield, 2004) has created additional and unnecessary barriers to treatment for children and youth. There are significant differences between palliative care services for children and those for adults, most noteworthy being the timescale of service involvement with patient and family. For children, the implementation of pediatric palliative care begins when the child is diagnosed with a life–limiting or life–threatening diagnosis (World Health Organization, 1998; Goldman, 1994). Adult definitions are framed within a context where curative options are no longer an alternative making a clear delineation between active treatment and palliative care. Thus for an adult, palliative care signals the transition into the end stages of life, which according to Employment Insurance (EI) Canada, equates to 26 weeks of compassionate benefits to provide care or support for loved ones at significant risk of death. For a child, their diagnosis influences both the type and length of palliative care that they and their family require. Pediatric palliative care is not always discrete, and it's not uncommon to have children receiving both curative and palliative interventions implemented in conjunction, each becoming dominant at different times, with the intent to prolong a good quality of life.

Some pediatric palliative care services now also include the caveat that there children are likely to die before their parents (i.e., 40 years), and, consequently, they are expecting to have a long-term relationship with children and their families. While

palliative care services for adults focus on the last few weeks or months of life for an individual dying of cancer or other illnesses, young children and youth with an ongoing life-threatening condition are a challenge to these services and the health care system. With improvements in medical care, the capacity to manage the special, complex health care needs of these children has steadily increased, however the evidence-base on which to plan care is patchy, and parents and communities are often left to devise their own care plans based on limited experience and evidence.

### *Underpinnings of Canadian Pediatric Policy*

As Canadians entered the new millennium, the well-being of the world's children emerged as an internationally established philosophical commitment. Known collectively as the *First Call for Children*, the declaration arising from the World Summit for Children and the United Nations (UN) Convention on the Rights of the Child, made health child and development and the treatment of children as citizens with rights a global priority (UN, 1990). On December 11, 1991, Canada ratified the UN Convention on the Rights of the Child thereby acknowledging the inherent needs and rights of children. The Saskatchewan Legislature also confirmed its own support with the provincial government stating, "Support for the convention is essential because it reaffirms our responsibility for the care and well-being of all children in our society. The convention also serves as a reminder that as long as there are still children in this province who are not receiving the care and protection to which they are entitled, there is more which must be done" (Bernstein, 2007).

The UN convention created the impetus for increased interest in child policy research in Canada. For example, the federal and provincial/territorial governments made the *National Children's Agenda* (1999) a cornerstone of the social policy renewal process. This document was founded on the belief that children's well-being is a priority for all Canadians. While Canada and Saskatchewan have made some progress in protecting the rights and promoting the well-being of children, these entitlements have not been sufficiently implemented and, to a great extent, have been relegated to mere "paper rights". Many children continue to encounter barriers to health service, social support, and education on the basis of gender, income, disability status, culture, geography, and diagnosis (Canadian Institute of Child Health, 2000). For example, children who suffer from life-limiting or life-threatening illness too often fall through the cracks in the bureaucracy within systems that were not designed to put the needs of children first.

Saskatchewan has a long history of progressive community development. It was the first jurisdiction in North America to adopt the Human Rights Charter, embrace a publicly-funded Medicare system, and pass labor laws resulting in a 40-hour work week with 8 hours per day. Additionally, Saskatchewan has continued to lead in advocating and implementing seminal social policies directed at improving the lives and well-being of children and youth. Examples of this leadership are evidenced in policies including the *Employment Supplement* (1997), *Saskatchewan's Action Plan for Children* (1994), *School PLUS* (2000), and, in the 2006 budget, in increased numbers of daycare openings (personal communication with Minister Atkinson, Advanced Education and Employment, October 20, 2006; and with Deputy Minister Durnford, Advanced Education and

Employment, March 27, 2007). Social policies were initiated, individually and collectively, with the aim to develop programs and services to support and enhance the care and protection of children, a notable example was the establishment of the Children's Advocate Office. It was a good beginning, but, as a province, Saskatchewan must now implement the steps to ensure that the fundamental rights of children and youth under the convention are given sufficient priority, and that they are integrated in legislation, government policy, and practice, to make them into "lived rights".

The UN Convention on the rights of the child (1989) identifies that humanity owes to the child the best it has to give. All children have rights: the right to protection, to education, to food and medical care. Every child, no matter where he/she live, has the right to grow up feeling safe and cared for. The Saskatchewan Children's Advocate Office established a set of eight Children and Youth First principles for Saskatchewan children and youth; that are contained in the 2006 Annual Report Children's Advocate Report (p.5):

- 1) That all children and youth in Saskatchewan are entitled to those rights defined by the United Nations Convention on the Rights of the Child.
- 2) That all children and youth in Saskatchewan are entitled to participate and be heard before any decision affecting them is made.
- 3) That all children and youth in Saskatchewan are entitled to have their 'best interests' given paramount consideration in any action or decision involving them.
- 4) That all children and youth in Saskatchewan are entitled to an equal standard of care, protection and services.

- 5) That all children and youth in Saskatchewan are entitled to the highest standard of health and education possible in order to reach their fullest potential.
- 6) That all children and youth in Saskatchewan are entitled to safety and protection from all forms of physical, emotional and sexual harm, while in the care of parents, governments, legal guardians or any person.
- 7) That all children and youth in Saskatchewan are entitled to be treated as the primary client, and at the centre, of all child serving systems.
- 8) That all children and youth in Saskatchewan are entitled to have consideration given to the importance of their unique life history and spiritual traditions and practices, in accordance with their stated views and preferences.

Recent developments at the federal level, the Senate and the Supreme Courts of Canada, have supported Saskatchewan's Children and Youth First principles, which incorporate a Child First focus on the issue of rights. Consideration is also being considered to establish an independent, national children's commissioner, to monitor the federal government's implementation of children's rights—an initiative which provides a unique opportunity at the national level to bridge inter-jurisdictional issues.

Senator Landon Person on her website (accessed April, 10, 2007) states that, "standards set by the UN Convention should not be seen as entitlements that set the child against the adult world. On the contrary, they represent the highest norms of civilized behavior." So it is against this backdrop of entitlements that the current patchwork of pediatric palliative care services exists, where children and their families encounter numerous barriers including demographics, geography, and a lack of awareness by politicians. Thus, it is the aim of this research study to contribute valuable information by

identifying similarities in beliefs and values, and also inconsistencies, expressed by parents to assist in identifying strategies for implementing policy and subsequent programs to improve the lives of these families.

### *Conceptual Approach*

With advances in medical technology, we are saving more infants and children than in any previous decade. While there are many unique ethical considerations that can and should be debated, the fact remains that these medically complex children have been given a “new lease on life”. Their parents and the community are now facing a growing number of challenges for which neither they nor the health care system is prepared. These children and their families require comprehensive palliative care services, but for the majority, this model of care remains unavailable.

To situate my perspective, I will present two examples that are complementary and that reflect my personal growth over nearly 27 years as a practicing registered nurse. In the first instance, the situation exposed to me how health policies and programs can violate human rights in design or implementation; in the second instance, a young child taught me a truth about life and death.

Social injustices have long been a passionate issue for me. They were never more so than during my tenure working as an RN in Washington, D.C. where I was constantly exposed to issues around the commodification of health care, which was especially true for the uninsured or indigent patients. Working at Children’s Hospital National Medical Center in Washington, D.C., it became clear that life and death decisions meant also that families could be instantly forced into financial ruin, a situation completely foreign to me

at the time. Early in my career at Children's Hospital National Medical Center, I encountered a scenario that has forever influenced my commitment to a socialized model of health care. A young girl aged 14 years came into the holding area in a wheel chair with her mom and dad. She had a diagnosis of sarcoma of the tibia (malignant bone tumor) and was booked for an above the knee amputation. She was visibly upset and her parents were doing the very best they could not to break down. After I admitted her to the holding area, I sat down with the family. The silence as I recall was deafening and intensely uncomfortable. Finally, mom said, "we need to ask you some questions about our daughter's surgery." The questions reflected a significant amount of misunderstanding about the surgery and recovery, so I paged the surgeon. When he arrived, I felt both his demeanor and tone of voice conveyed little or no sympathy. Finally, in the course of the brief discussion, the question of costs came up and the fact that father had just lost his job and no longer had health coverage. Suddenly, someone appeared from hospital accounts, initiating a discourse about how payment could be set up, what would be covered, what would not be covered a conversation that was public to everyone in the holding area including the young girl. I remember feeling so outraged and so powerless that anyone at this time would be humiliated and forced to contemplate financial decisions about their daughter's care moments before surgery.

Post surgery, I visited this young girl several times in my role as a member of the pain management team. She recovered quickly following the surgery and was discharged to her local hospital. Several months ensued, and I received a consult for pain management for this young girl. Her cancer had metastasized to her lung and prognosis was bleak. The family lived in rural area of Maryland. Dad had just recently found

employment, and mom stayed home to look after the 3 other younger children. Once it was clear she had not long to live, it was her wish to go home to be with her siblings, friends, and most of all her dog. Steps were initiated by the discharge coordinator to transfer her home under home care. Then suddenly the transfer was called off because her father's new insurance had a 3-month waiting period and because she had a pre-existing condition the new insurance would not cover any expenses incurred from home care.

The family was absolutely devastated and took her home anyway, but in no time she was experiencing uncontrollable pain and was re-admitted to Children's. The local hospital near their home would not admit her due to insurance issues. I have often wondered how the family ever dealt and recovered from the death of their daughter.

Later as a new faculty member at the University of Saskatchewan, my office was located just outside the pediatric ward. One afternoon, I could hear the voice of a young child crying, clearly in distress. The nature and tone of the cry sent cold shivers up and down my spine. I followed the crying to find a little girl aged 3 ½ named Allison. Her little body was very emaciated and accentuated by her bald little head. You could easily see the metastatic bone tumors on her skull and arms, indicating the terminal nature of her diagnosis. Her pain management was a challenge, and she was often experiencing intense breakthrough pain. With the help of the Adult Pain Service, over the ensuing days her pain became better managed. Her mom was a single parent of 2 other children under the ages of 10 years. She had to quit her part-time job and apply for welfare benefits because it was difficult to juggle child commitments that were becoming increasingly more challenging with Allison's deteriorating condition. She was also clearly having difficulty

accepting the terminal nature of her daughter's illness and was emphatic that her daughter not be told that she was dying.

I spent a lot of time with Allison when her mom wasn't visiting. She did not like being alone, and now that her pain was under control she, like all children, wanted to try to play, watch TV, and read books. Halloween was approaching, and the ward was decked out in decorations. Allison was quite excited about carving a pumpkin and making it into a "weirdo" to scare the nurses. It was during one of my visits that she told me her story of going on a trip. So I asked her to tell me more about her trip, and she then described a journey to see Santa that would include no more "owies happening in her legs" and a ride on a special red bike that she really wanted. Her story caught me by surprise. At first I was perplexed that anyone would be talking with her about Christmas given her prognosis, but as she continued with her wonderful story, I realized that she was telling me that her death was imminent; She was looking forward to the next journey free of pain and full of joy in a way that only a child could imagine. She died days after this conversation. After her death, I spoke with her mom about Allison's story. The pain of Allison's loss was enormous for this mom, but in the ensuing years when I would on occasion run into her, she told me that knowing that Allison was at peace and happy now provided her with at least some comfort. While aware of a growing body of literature describing the introspective nature of children regarding their impending death, I had never personally experienced such an event until Allison. She taught me an inerasable lesson about the nature of life and that death maybe is the hope of a better place.

Over many years of working internationally, nationally, and locally, I have never ceased to be amazed at the strength and resiliency of these special children and their

families living in what would be described as extraordinary circumstances. Few of us are privileged to hear these stories first-hand. I have, through witnessing the experiences of these two children, come to understand that their vulnerability must be reduced by taking the necessary steps to respect, protect, and fulfill their human rights. Health, I have come to believe, is a basic human right and serves as the influential foundation for this study. Habermas (1975; 1979; 1986), described as the last great social critic (Fay, 1987), provided the necessary contextual and theoretical base from which—together with critical ethnology as a research methodology—I could begin to deconstruct contexts and unshackle voices of parents, who have for too long remained marginalized and silenced due to unimaginable circumstances. This approach is innovative in that it values normative deliberation about goals and values not as an inferior to science discourse, rather only as different. Normative deliberations, a Habermasian approach, when examined in terms of their own inherent standards are regarded as a rational exercise that infuses power to those whose voices and stories have been silenced. While there may be some who consider my choice of a research paradigm to be less exacting than the scientific mode of reason per se, the reality is that the culture of evidence-based medicine depends on a body of research that draws from both the qualitative and quantitative domains. Throughout this process, I could now validate myself as a research instrument and provide an opportunity for the silenced voices of parents to become emancipated. Their stories could be given value and meaning; and, most importantly, through this critical discourse they were given an opportunity to hear themselves and all that they have lived with and through, which was a process described by all the participants as cathartic and empowering.

### *Purpose*

Because each individual brings his/her own unique interpretation to life events, the purpose of this critical ethnographic study was to describe and interpret through the voices of parents the lived experience of caring for a child with a life-limiting and life-threatening diagnosis with the existing or non-existent social policies. In addition, data was also collected from key stakeholders and policy-makers to help construct meaning and locate the current state of palliative care.

### *Research Questions*

This study was guided by the following general questions, which were directed at the parents of children with life-threatening and life-limiting illnesses. The questions were designed to elicit their stories:

1. How do parents deal with their child's diagnosis of life-limiting or life-threatening?
2. How does a diagnosis of this magnitude impact families?
3. What supports and services do parents find and use on this life journey?
4. What do these families need from the health care system?
5. How can we make this journey better for you now and for those who will be faced with similar life challenges?

## *Significance*

We cannot live for ourselves alone. Our lives are connected by a thousand invisible threads, and along these sympathetic fibers, our actions run as causes and return to us as results.  
Herman Melville (1851) *Moby-Dick*

Children are dependant individuals who rely on adults they know and on thousands more who make decisions every day that affect their health and well-being. While our national rhetoric proclaims that children are our most important resource, we as a society are too often responsible for squandering these precious lives as though they do not matter. Children, whether or not you are a parent, are intimately connected to all of us; they represent the very essence of who we are and who we will become. Therefore what happens to children, globally, nationally and locally, affects our present and our future. Providing this forum to listen and document stories from each parent, brings attention to their special and diverse needs; this must then be translated into policies directed at improving their lives.

CHAPTER TWO  
PRESENT STATE OF THE LITERATURE

*Background for the Study*

The goal of this literature review is to provide further clarity and understanding as to the state of policy as it relates to children with palliative care needs. Pediatric palliative care is a new and emerging specialty with a less than 30-year history (Pfund, 2006; Steele, 2002), whereas the pedagogy of policy as a discipline has a well established history evidenced by a plethora of published work within this field (Brooks & Miljan, 2003; Manga, 1998; Pal, 1997). Attempting to critique this body of literature would be a formidable task and outside the scope of this specific inquiry. Therefore, this review will be limited and reflective of literature that relates specifically to children's health in general and more specifically to children with palliative care needs and will be organized under three major headings *Epidemiology of Children with Life-Limiting or Life-Threatening Conditions, Economic and Sentimental Value of Children, and Dimensions of Social Policy within the Canadian Context*. The heading of Social Policy will be further elaborated through a discourse focusing on the context of the current liberal ethic of justice and on how this impacts the rights of Canadian children. This review concludes with a summary of policy analysis.

### *Epidemiology of Children with Life-Limiting or Life-Threatening Conditions*

It remains an unavoidable fact that children die and that their deaths are painful for them, their families, their communities and their caregivers (ACT, 1994; Doyle et al., 1993; Goldman, 1998; Kane & Primo, 1989). The epidemiology of childhood death has changed radically over the last century (Fowler-Kerry et al., 2006; Himmelstein et al., 2004; Steele, 2002) with the majority of children in the developed world dying as a result of trauma while those in less developed countries are dying from acute preventable diseases such as infectious diarrhea and respiratory infections. Cancer is responsible for claiming the lives of a small number of children in the developed world with a 67% cure rate overall, a scenario not replicable in the developing world where a diagnosis of cancer means almost certain death (American Academy of Pediatrics, 2002; Institute of Medicine, 2002). A larger number of children will die in the developed world with chronic, life-limiting disorders and conditions, such as central nervous system malformations or hypoxic ischemic damage conditions, frequently present and diagnosed at birth (Davis & Higginson, 2002). While life-prolongation may be an appropriate goal, there must also be acceptance of the eventual lethality of these disorders to ensure that the physical, spiritual, emotional and psychosocial ramifications of the condition for the child, family and community are addressed (American Medical Association, 2002; Patterson, 1991; Patterson et al. 1994; Rallison & Moules, 2004).

Children with life-limiting and life-threatening illnesses represent a very diverse population; with no accurate statistics available, the magnitude of need within this populace remains at best a rough guess (Davis, 2003). Conservative estimates range from 10 per 10,000 children who from birth to 19 years live with grave medical conditions

requiring palliative care services in the United States (Hynson et al., 2003), to an expected 0.1% of children in the United Kingdom living with this situation (Institute of Medicine, 2002). In Canada, it has been projected that only 3.1% of children who require palliative services actually receive any services (personal communication with Senator Sharon Carstairs, December 14, 2005). Statistics, while extremely restrictive, reveal a startling picture that depicts a significant disparity, which has come to be called the “patch work quilt effect” of palliative care services. The lived experience today for these children and their families, where the majority are not receiving comprehensive palliative care, is a situation that in a civil society can not longer be considered acceptable (Martinson, Armstrong, & Geis, 1978; Poland et al., 1998; Romanow, 2002; Ruggie, 1996; Young & Malley, 2004).

Every child living with a life-threatening or life-limiting conditions and his or her family have the universal right to expect to have their pain and suffering ameliorated by palliative care (Goldman & Reynolds, 1994; Heyland, 2006; Meler, 2001). This is a basic entitlement whether or not the child lives in a wealthy or third world country. Palliative care is about living life as well as possible, despite the presence of a life-threatening or life-limiting diagnosis (Donnelly, 2005; Jennings, 2005; WHO, 1998). It is also about bolstering families’ abilities to cope, maximizing the quality of time remaining because dying happens on the last day. Dame Cicely Saunders so eloquently stated, “Palliative care is about living until you die” (Saunders, 1960, p. 10). WHO (1998) clearly articulates that aspects of palliative care should be initiated immediately at the time a diagnosis of a life-threatening or life-limiting illness is made. Whether or not the child actually dies is irrelevant, but specific attention to the physical, emotional, social, and

spiritual issues of all children and their families is critical (McGrath, 2005; American Academy of Pediatrics, 2002; Donnelly et al., 2005; Jennings, 2005). Here are some examples childhood diagnoses that would potentially Benefit from Palliative Care (American Academy of Pediatrics, 2002; Falik, H, 2004; Liebert, 2004):

- Aids
- Cancer
- Chromosomal disorders
- Congenital defects or anomalies
- Metabolic disorders
- Complex medical needs, which together are life-threatening (e.g. trauma, prematurity)
- Muscular dystrophy
- Neurodegenerative disorders
- Static encephalopathy (e.g. permanent vegetative state, ischemic or hypoxemic injuries)

There is no ‘right way’ to provide pediatric palliative care, rather each program or model of care must be contextually suited to meet the resources and cultural expectations within its own locale (Fowler-Kerry, 2002; Ufema, 2006). Each delivery model must strive to adhere to universal principles, and health care professionals should have the requisite education, skills and experience in the care of children and their families (Davis et al., 2003; Fowell et al., 2002; Papadatou, 1997; Romesberg, 2000). In Canada, the current state of palliative care services for children and their families reveal major regional inequalities in both the comprehensiveness and accessibility of services

(Canadian Institute of Child Health, 2002; Williams et al., 2001; Romanow, 2002). A number of explanations have been advanced in an attempt to explain the current situation, including limited health care funding—particularly for any service that is not defined as medically necessary under the Canada Health Act—and cost–benefit issues relating to the shifting of funds from the cure–orientated focus within hospitals to a community care one (Canadian Nurses Association, 2000; Labonte, 1993; Wallack, et al., 1993). Whether the barriers are real or imagined, the current situation is clearly not acceptable.

### *Economic and Sentimental Value of Children*

Historical and philosophical changes have a direct affect on the views and attitudes of society, and these are then reflected in normative dimensions of policy or the lack thereof. The first question is what significance does today’s society really place on children? It is now commonplace to hear politicians and advocates for children’s rights stating aphorisms enunciating the value that the state, society, and community place on the health and well–being of children and youth (Mahon, 2005). Examples of this rhetoric include ‘children are everyone’s future’ and ‘children come first because they are our most scared trust’. These kinds of expressions suggest that children are autonomous, independent individuals discovering their own reality and that while in this stage of development they are economically ‘worthless’, they are, however, emotionally ‘priceless’—a transformation into what today some would describe as the contemporary notion of the contextualized child. This *sacralization* of children, a term coined by Zelizer (1985), has resulted in an increased intolerance of death in childhood, whether by illness or accident. Stainton & Stainton (2001) contend that ideals of children’s sanctity

and purity, of the ‘safe, happy, healthy and protected child’, are products of the Judaeo-Christian beliefs that have merged with demographic trends accompanying the rise of capitalism (Lund, 2002), and that these ideals are also culturally and historically bound to the social preoccupations and priorities of the capitalist countries of Europe and North America. O’Neil (2004) further expands on this position by arguing that children’s futures are becoming increasingly more dependent upon the political culture of capitalism, and the resulting actions or inactions of governments have a more significant impact on the health and well-being of children than on any other group in society (Bock et al., 1983; Evans & Stoddart, 1990; Furstenberg et al., 2004).

Changing societal views and values of children become increasingly evident with a review of late-nineteenth century documents that outline the creation of a new medical speciality, *pediatrics*, designed to treat and diagnosis childhood diseases leading to improved health outcomes (Ennew, 1994; Freeman, 2004). By the mid-1890s the majority of large cities in Britain and the United States had at least one children’s hospital as well, and the psychological health of children was also emerging as a focus of scientific interest and inquiry. Most significant from all of these initiatives was the awareness that children’s health challenges were not only distinct from those of adults but changed within childhood and by age (Heinze, 2000). By the twentieth century, infant and child mortality rates were becoming a critical gauge from which to judge the economic success of a nation. Death in childhood was no longer solely a private and personal tragedy, but also a sign of the collective failure of the state (Hymowitz, 1999; Keating & Hertzman, 1999). Today, the experience of childhood is not viewed as an imaginary event, but rather it has come to be regarded as a natural set of experiences that

should be protected and respected and be free from adult worries and responsibilities; it is regarded as a time of learning and play, a period of happiness, health and relative freedom (Aries, 1962). This belief spurred on a movement to universalize children's rights and universalize a culturally specific perspective of childhood (Heinze 2000). Through this process, the basis of children's rights evolved at the international level and then informed national and local political processes and helped shaped law and policy governing the care of children (Mahon, 2002; Mahon, 2005).

The first international treaty identifying children was promulgated by the League of Nations in the form of the first "Declaration of the Rights of the Child" in 1924. Subsequent developments led to the "Universal Declaration of Human Rights" in 1948 and the United Nations General Assembly's "Adoption of the Rights of the Child" in 1989, where again the distinctive character of children was illuminated. This boosted the idea of children as citizens in their own right and as independent bearers of rights--considered to be neither the possession of their parents, nor of the state, nor as mere people-in-the-making. This impressive manifesto clearly articulated the worldwide moral standards for the treatment of children (Freeman, 1997) by suggesting that children must be construed as persons and not valued only for their future potential, but also for their present agency (Veerman, 1992).

The genesis of Canada's commitment to protect the rights of children stems from the adoption of these human rights instruments; they provide a moral vision of a civil society that works to ensure all citizens have a fair chance to enjoy health, education, employment (Walker, 1998; Young & Malley, 2004; Zelizer, 1985). Canada has made some progress in protecting the rights and promoting the well-being of the first

generation of children born with universal rights under the convention. One of the first major initiatives in this area by the federal, provincial, and territorial governments was the creation of the *National Children's Agenda* (1999), which is described as a cornerstone of the social policy renewal process. This document was founded on the belief that children's well-being was a priority for all Canadians, and it translated into numerous important child policy studies initiated by research institutes, including the Canadian Policy Research Networks, the Canadian Council on Social Development, and others.

This surge of interest within some institutions, including universities, has not always translated into funded research programs and projects directed at improving and sustaining the health and well-being of children and their families (Canadian Institute of Child Health, 2000). Although within these environments there certainly can be found a plethora of pursuits, highly-valued, richly-funded, and directed at the 'big R questions' such as the effects of globalization, the impact of health care reform, productivity deterrents in the knowledge based economy, and mapping of the human genome: issues of child health research have not been a priority and are too often left to the small world of everyday life. In other words, children's issues have come to be viewed as "soft", the territory of softhearted people (usually women) at the margins of the larger social problems (Canadian Coalition for the Rights of the Child, 2001; Canadian Institute of Child Health, 2002). These issues are not soft. They are hard. Examining and evaluating child policies is but one means from which to gauge how Canadian governments and other institutions of society are responding to the myriad of changes in families, labour markets and social contexts, all of which impact at the micro level families with children,

including those with palliative care needs (Covell & Howe, 2001; Ennew, 1994). In addition, child policies can also be considered a lens from which to view the convergence of a number of social changes; they are an optic that serves to provide useful insights and understandings about the changing needs of providing and financing care for children and families (Hankisvsky, 2004).

### *Dimensions of Social Policy within the Canadian Context*

There are two dimensions of social policy that will illuminate insights into Canada's responses to the health challenges of children. One approach is the formulation of policy initiatives targeted at enhancing quality, social solidarity, and democracy as demonstrated in countries such as Sweden and Japan (Fried & Gaydos, 2002), where there exists little disparity between rich and poor. The second approach adopted by the British and American governments substitutes the market for policies having the potential effect of creating greater economic and social disparity (Fischer, 1995; Poland et al., 1998; Ruggie, 1996). Canada's location could best be described as somewhere between these two juxtaposed ideologies. Historically, Canada has developed social policies influenced by a welfare state tradition that support security, redistribution, and social integration with the promise of protection against the uncontrollable and unexpected contingencies of life reflected and reinforced by the notions of caring (Rice & Prince, 2000; Vayda & Deber, 1992). However, since the mid-1980s demand created by globalization and national pressures has resulted in what Ruggie (1996) would describe as an erosion of the welfare state. What has emerged within the Canadian context is a

new policy regime best described as a welfare state operationalized within a liberal paradigm (Brooks & Miljan, 2003; Rice & Prince, 2000).

Within the parameters of this new paradigm, there is considerable variance concerning the extent to which the state should respond to the needs of its citizens. For example, the post–World War II governments were committed to social programs directed at maintaining a standard of living through redistribution in order to ensure equality of opportunity for all citizens (Labonte, 1993; Lund, 2002). Currently, the new policy regime is increasingly critical of social dependency on the state and challenges traditional approaches to social welfare as reflected through assumptions and values that are not particularly oriented towards caring (Mahon, 2005; Rachlis, 2004).

Liberal paradigms and the liberal ethic, as ideology, support limiting the power of government (Lavalette & Pratt, 2001; Rice & Prince, 2000; Ruggie, 1996) and assume for the most part that autonomous individuals are able to attend to their own basic needs. Thus simply dependency on the state is considered to be the exception and not the norm. By placing a high value on independence and self–sufficiency, this philosophy fails to grasp the reality of human interdependence and the need for caring mechanisms in both the private and public spheres of our lives (McWilliam, 2004). A further assumption is that human needs are essentially universal, leading to impartial regard for all persons. As humans we are not all the same, nor are we equally situated or equally empowered; moreover, people have different capacities and abilities to attend to their needs (Pigou, 1952). Social policies within this liberal paradigm have a limited capacity to capture and respond to issues of diversity and difference (Magna, 1998) by obscuring and reinforcing various forms of disadvantage and discrimination, and, for this reason, Ruggie (1996)

would contend that the welfare state has become inadequate, patriarchal, classist, and racist. This position lends some understanding and explanation about why, despite promises of a universal social safety net, Canadian social policy has not always been sufficiently directed to those who require assistance (Rice & Prince, 2000). Policies in the liberal paradigm have largely been concerned with promoting and encouraging the autonomous individual as the appropriate unit of political analysis, impartial universalism as the desirable form of moral reasoning, and rights as a measurement of fairness required for the realization of social justice (Hankivsky, 2004; Lund, 2002; Manga, 1998). Given these parameters, coupled with ongoing concerns of cost–containment, it becomes highly unlikely that this philosophy of thought can respond effectively to Canada’s care deficiencies in social policies, which include pediatric palliative services (Hertzman, 2002; Mustard, 2005).

Cost–containment is a critical element in social policy decisions and economic evaluations of policies and programs, and nowhere can this be more widely observed than in the field of health policy (Mann et al, 1999; Rachlis, 2004; Sawatzky & Fowler-Kerry, 2003; Wallack et al, 1993). Economic evaluations operationalized within the current liberal theoretical paradigm assume that individuals are rational economic actors and selfish profit maximizers (Rice & Prince, 2000) who create a civil society because the benefits of doing so outweigh the costs and that, once established, these individuals will continue to peruse choices that maximize their welfare largely in terms of material possessions and gains. Interactions are focused on the premise of an ideal market in which prices form the only necessary form of communication (Brooks & Miljan, 2003, Ruggie, 1996) making the relationship between buyer and seller the model of all human

interactions. This point of view does not allow for the injection of moral values such as altruism and cooperation because human behavior and political and social interactions are linked to the rational pursuit of self-interest and optimal economic results, described by Habermas (1984) as the discourse of commodification. Efficacy has become the most decisive value controlled by the corporate world (Magna, 1998). Within the health care context, compelling evidence exists from economic costing studies demonstrating that the focal point of economic measurements and efficiency has meant simply that economic measurements have encroached on areas of citizens' lives that, previously, have been valued according to non-market methods (Lomas & Veenstra, 1997; Rice & Prince, 2000).

This discourse of commodification, with its roots in positivism, has led some economists to argue that serious problems will result from attempts to quantify certain human goods, properties of persons, and their human interactions (Lomas & Veenstra, 1997; Lund, 2002; Rist, 1989). Cash symbols for the value of human life, they believe, should be resisted especially where life is not considered a marketable good and no obvious alternative market signals exists to serve as indicator for this evaluation. A position that translates further to the notion that it is easiest to measure those things that are the most easily measured and does not take into any account that the most valuable things in human life have a value (Canadian Nurses Association, 2000; Evans & Stoddart, 1990; Freid & Gaydos, 2002; Lavalette & Pratt, 2001; Mann et al., 1999; Rist, 1989; Romanow, 2002). Continuing this discourse raises yet another question about the contextual reality concerning relationships with others and sustaining community as an integral component of the human condition. Much of our lives are spent receiving or

providing some form of care: illnesses, disease, death and dying result in multiple forms of dependency and are regular occurrences throughout the life cycle (Paringer, 1983; Sawatzky & Fowler-Kerry, 2003; Williams et al., 2001; Zelizer, 1985). The liberal perspective that regards the provision of care for others as a private responsibility, where society is composed of autonomous equals, creates a real blurring of the inevitability of interdependencies and the provision of care as essential to human life.

The act of giving care can involve a range of activities, including but not limited to the physical and emotional activities associated with looking after, responding to, and supporting others. Caregiving has been classified as formal and informal. Informal care is typically unpaid care provided by family, and formal care is provided by paid workers (Nelson & Nelson, 1996; Mahon, 2002). Within the current context, the most important source of all forms of care is informal care, and informal care also responds to care deficiencies that develop as the result of sudden and unexpected circumstances and/or government policies. The most common form of informal care is home care, which covers both short-term and long-term care needs and requires a combination of skills of hand, brain, and a compassionate heart. The matter of home care has become and continues to be at the center of recent discourses, especially since the implementation of the liberal policies of deinstitutionalization (Canadian Broadcasting Center, 2006; Conservative Party Platform, 2006; Government of Canada, 2003; Mahon, 2002). The home care policy initiative was, and continues to be, premised on a number of faulty assumptions, most notably that there is an untapped pool of private labor available to provide home care (Paringer, 1983; Rachlis, 2004; Romanow, 2002; Sawatzky & Fowler-Kerry, 2003). An option that is substantially less expensive than the alternative,

which would require massive infusions of capital to back fill resourcing the policy decision (Lund, 2002). Implementing this policy had the effect of instantly creating a burden of care on families and specifically women, who were seen as having a choice to provide the care themselves or buying services on the market (Evans & Stoddard, 1990; Canadian Healthcare Association, 1996; Lomas & Veenstra, 1997; Canadian Nurses Association, 2000). While little has been done in the policy arena to adjust or alleviate the current disparity in care, there have been discussions highlighting the current state of affairs as unjust. Most recently, the Romanow Commission (2002) proposed expanding the principle of comprehensiveness, as it appears in the Canada Health Act, to include home care services. Further, the Federal Government in 2003 introduced a 16 billion dollar reform fund for provinces and territories targeting primary health care, home care and catastrophic drug coverage. Short-term acute home care, including acute community mental health and end-of-life care, were identified as an area of priority. Under Employment Insurance (EI), the government introduced a six-week compassionate care leave benefit to enable people to care for a gravely ill or dying parent, spouse, or child. While these policy initiatives attempt a remedy, they do not attend to the full scope of health needs especially for children who require palliative care services (Canadian Institute for Health Information, 2006; Canadian Institute for Child Health, 2002; Coffey & MacCain, 2002). For example, according to a 2002 Decima poll, the majority of caregivers provide care for longer than six months, and over 20 percent report providing care for more than ten years. In addition, compassionate care leave under the EI program does not attend to women caregivers who do not work or who, because of their specific work situations (e.g., part-time, contract work), do not qualify for EI.

Child health researchers have long advocated that an investment in children is as much a part of ‘social investment’ as large Research Council grants that promote the development of the high technology sector (Coffey & McCain, 2002; Covell & Howe, 2001; Freeman, 2004; Heinz, 2000; Hertzman, 2002; Hertzman et al., 2002). Investing in the health and wellbeing of those less-advantaged, such as children, represents a significant investment in the future productive capacity of society (Coffey & McCain, 2002; Keeting & Hertzman, 1999). Valuing children as an important area of economic investment serves as the basis for the RBC Community Development Program in Child and Youth Health at the University of Saskatchewan College of Nursing. The notion that children are a vulnerable population is not new and has effected and reshaped social policy in Canada--for example, the report co-authored by Dr. Fraser Mustard and Margaret Marland, Minister Responsible for Children, Ontario Government, “Reversing the Real Brain Drain: the Early Years Study” (1999). Dr. Mustard’s work has been instrumental in persuading the Canadian government to devote over \$2 billion dollars towards improving the educational and intellectual performance of Canada’s children, which is a recommendation based on the premise that the whole nation will benefit economically and socially (Coffey & McCain, 2002) and is consistent with the philosophy underlying the “National Children’s Agenda”.

The enthusiasm that child health researchers and advocates bring to the policy arena has not always been met with an equally supportive response by either Federal or Provincial governments. During the 1980s governments globally were experiencing the effects of a significant down-swing within economic markets, and the subsequent recession resulted in significant challenges and claw backs to the traditional welfare state

social policies and programs. Within this difficult economic period, the Federal Liberal Government launched the “National Child Benefit Supplement” (NCBS) in 1997 as an attempt to prevent and reduce the effect of child policy. This initiative was a partnership among federal, provincial, territorial governments and First Nations. The NCBS was a part of the existing “Canada Child Tax Benefit” (CCTB), similar to what used to be known as the *Baby Bonuses*. The CCTB replaced existing child benefits including the “Working Income Supplement”. This agreement required that the amount of NCBS be deducted from the families on social assistance and became known as the *NCBS Claw back*. In spite of recommendations inherent in the agreement, Manitoba and New Brunswick elected not to recover the NCBS, but all other provinces and territories, including Saskatchewan, recouped some or all of the benefit. The federal government and certain provincial governments took the position that the NCBS must be clawed back to ensure working families were always better off than families on social assistance. They argued clawing back the NCBS from families on social assistance was necessary to maintain the status quo as well, parents on social assistance "needed" some sort of incentive to find their way off of assistance into paid work.

Saskatchewan never subscribed to this position and was unique in its approach to the application of the NCBS claw back due its historical and philosophical orientation. The provincial government was reeling from the economic impact of the recession and also conscious of its moral commitment to the tenants of the welfare state and issues of social justice, which continued to focus on maintenance of social programs to prevent and support those disadvantaged. Saskatchewan’s position within this economic context was that monies saved from one program, like NCBS, should be reinvested in new programs

targeting low-income families, and they launched what became known as the Employment Supplement (personal communication with Minister Atkinson, October 20, 2006; personal communication with Deputy Minister Durnford, March 27, 2007). In 1999, the Saskatchewan Government moved the agenda of children's health a step further by mobilizing and implementing "Saskatchewan's Action Plan for Children". A health promotion plan promoting "Healthier Places to Live, Work and Play...A Provincial Population Health Promotion Strategy for Saskatchewan". The philosophy behind this unique and novel program integrated seven government departments and secretariats—including health, social services, education, justice, culture, youth and recreation—to collaboratively assist communities in enhancing the well-being of children, youth and families. The major thrust of the program was to address the needs of the very young and their families in the areas of mental well-being, accessible nutritious food, decreased substance use/abuse and active communities. The province was divided into Regional Sectorial Communities that would respond and tailor interventions to meet specific regional needs. An approach very much congruent with current and ongoing research initiatives directed at early child development (Hertzman, 2002; Hertzman et al., 2002; McCanin & Mustard, 1999).

Similarly in this same time frame, Nutana Collegiate in Saskatoon was named a provincial demonstration project, which was directed toward creating schools as *hubs* for multiple levels of service delivery programs. The Health Minister, Pat Atkinson at the time, with the Social Service Minister, Calvert, and the newly elected Assistant Minister of Health, Judy Junor who had as part of her portfolio programs dedicated to children, together felt that the "time was right" and that the "right people" were situated in place to

launch this new program model (personal communication with Minister Atkinson, October 20, 2006). The vision of utilizing schools as a hub from which to provide integrated, comprehensive programs directed at children, youth and families, was yet another example demonstrating the leadership role of the Saskatchewan Government in the area of child health (personal communication with Deputy Minister Durnford, March 27, 2007). These provincial program initiatives were uniquely situated and embedded in the principles of health promotion, implementing principles espoused by Epp (1986) and Lalonde (1974). Like other well-intentioned programs, Saskatchewan's Action Plan for Children seems to have slipped off the political landscape. An observation supported by Minister Atkinson (personal communication with Minister Atkinson, October 20, 2006), and one that really defies logic. Minister Atkinson sums it up this way, "There was no clear point of origin for this program, just a constellation of what was considered the right people in place, just as there appears to be no distinct ending and turning points in this program are quite elusive, other than to propose that the right people were no more."

While there appear to be no direct links, one assumes that the "SchoolPLUS" (1999) program similarly emerged as a result of a social policy environment with its origins in Saskatchewan's Action Plan for Children. SchoolPLUS was another creative and innovation approach describing a new conceptualization of schools as centers of learning, support and community for the children and families they serve. This model evolved and built on successful practices of schools and community partners to further strengthen the capacity to meet the needs of all children and young people through the creation of a new social institution directly supported through human services.

Presented as an exemplar initiative and representing a fundamental reform within the human service public policy forum, this program has also fallen from the public arena. Reports suggest the demise of this program resulted from a shift in government priorities due to the government misunderstanding that SchoolPLUS was a philosophy rather than a program to be implemented. From conversations with Minister Atkinson and Deputy Minister Durnford (personal communication with Minister Atkinson, October 20, 2006 & Deputy Minister Durnford, March 27, 2007), there were numerous reasons for this program to lose funding, most importantly the lack of an advocate to spearhead the agenda within the ministry.

At both, federal and provincial levels of government currently, children's issues are again becoming more prominent in the political policy arena. The issue of supporting children through expansion of childcare in Canada was a hotly contested political issue in the last federal election of 2006. Both Liberal and NDP platforms proposed increasing universal funding to augment the numbers of available licensed daycare facilities with qualified and educated staff. Conservatives, on the contrary, argued that there should be freedom of choice in childcare and proposed "The Universal Child Care Benefit" (UCCB), an allowance providing parents with resources to balance work and family as they like, whether that means formal childcare, informal care through neighbors or relatives, or a parent staying at home. Most recently on August 28, 2006, Mr. Taylor the Saskatchewan Minister of Health spoke with the College of Nursing Faculty and announced that children were again priority for the provincial government and that program initiatives, such as the "Children's Provincial Hospital within a Hospital" and

the Premier's "Project Hope", were just two of several policy initiatives that the government was undertaking.

While there appears to be "a political will" to do something about improving the health and well-being of children, there has been and continues to be a disconnect between words and action. The Saskatchewan Government carries on supporting the underlying assumptions contained within the philosophy of the welfare state, and in some cases developing and implementing novel social policy agendas and programs in this area, recognizing also that government will never meet the diversity of needs of all constituents. What is disconcerting within the public policy forum is that policies and the resulting programs depend heavily, or even exclusively, on one or a few individuals with a mandate to bring these programs into being and to sustain them. It is at this important juncture that we as a country, a province, and a community must pledge a stronger commitment to a new generation of children with "paper rights" in order to transform these into "lived rights" under the Charter of Rights and Freedoms and the UN Convention.

### *Policy Analysis*

Policy analysis has its historical beginnings firmly embedded within the rational and empirical modes of analysis found in the positivist tradition (Fischer et al., 2007), which constitutes a collection of approaches emerging from the empirical scientific method: cost benefit analysis, survey research, mathematical simulation models, experimental design, input-output studies, multiple regression, and system analysis (Fischer, 1980). From this collection two contrasting approaches of policy analysis

emerged (Evans & Stoddart, 2003; Lomas, 2000; Manzer, 1994; Pal, 1997; Rice & Prince, 2000). The first approach is concerned primarily with the assessment of policy formation, implementation, and the particular effects thereof, beginning with the statement of what a particular policy was intended to do and the analysis considering the resources and measures associated with implementing the policy (Evans & Stoddart, 1990; Lomas, 2004; Shortt & Shaw, 2003). The second approach focused on the 'how' and 'why' a particular policy developed, so the policy, rather than its effect, is considered the outcome (Esmail & Walker, 2004; Mullens, 1998). While both approaches serve and continue to serve a valuable purpose in the development and evaluation of social policy, there has been increasing discourse about the limitations inherent within empirical methods in the study of normative political and social phenomena--particularly with its separation of facts and values (Fisher, 1995). Pal (2001) presents his critique of the positivist origins of the policy 'movement':

The standard definition of policy analysis therefore clearly carries with it some cultural and historical baggage. Even if we substantially relax the definition to include a wider variety of ways of knowing and thinking, it is hard to escape the core assumptions that analysis will demand, at minimum, (1) expertise, (2) reliance on western science, (3) deductive logic, (4) measurement, (5) clear and replicable steps or stages. For the last fifty years, this model of rationality has been challenged and criticized for what it leaves out. So what's wrong with being rational?" (p. 21)

He continues his discourse by presenting three perspectives that continue to challenge the model of rationality. Firstly, the perception of a lack of rationality within

the policy process wherein the act of policy-making is described as an incremental process and decision makers ‘muddle through’ the challenges of the real world (Pal, 2001, p. 21). Secondly, policy processes are value laden, which is a limitation largely ignored by the rational model. Thirdly, the process of policy analysis has “relatively little influence on policy-making” (p. 22). Pal’s position is influenced in part by Fisher’s (1995) previous assumption concerning the intrinsic limitations with the fact/value separation scheme. A scheme based on positivism’s adherence to the metaethical theory known as *value non-cognitivism*, which is predicated on the belief that value judgments are essentially emotional responses to life conditions and contain no verifiable truth content. To qualify as objective knowledge, statements must be verifiable only through formal empirical methods; thus value judgments within this paradigm fall beyond the reach of rational methods practiced and defined as the formal rules and procedures of the scientific method (Fisher, 2000; Poland et al., 1998; Rice & Prince, 2000).

There can be little debate over the reality that public policy is by its very nature laden with value judgments. However, Fisher (1995) and others (Forester, 1993; Pal, 2001; Stone, 1997 & Yanow, 2000) suggest that it is challenging from a methodological perspective to clearly delineate and separate facts and values without distorting the basic purposes. Some policy scientists have solved this dilemma by simply electing to ignore the fact/value separation, which is a position that does little to control for what positivists would describe as threats to internal validity. Still others (Fischer et al., 2007; Lund, 2002; Manga, 1998; Pal, 1997; Rist, 1989) will treat values as normative relationships that are regarded as static, non-complex relationships rather than changeable, dynamic multi-dimensional dialectical process. Normative statistical analysis is limited to

prescribed empirical scientific processes of logic and verification, a process that limits and rules out informal discursive process that mediates the construction of social reality. According to Fisher (2000), this has led positivists to either reject or ignore the study of normative discourse in everyday life, which he describes as an “epistemological limbo” (p. 3).

Increasing interest in the pedagogy of policy sciences and limitations associated with the traditional positivist paradigm has served as an impetus for the development of new models emerging from philosophical paradigms situated in post-positivist (Fischer, 1995; Pall, 2001), interpretive (Yanow, 2000), and post-modern (Forester, 1993; Stone, 1997) thought. Inherent within each of these models are basic assumptions associated with critical social theory. More specifically, normative argumentation is not considered an irrational process, and deliberation about goals and values is not considered an inferior pursuit to scientific discourse, but they are seen as rather different approaches of equal value. In the words of Horkheimer, a critical theorist must form “a dynamic unity with the oppressed class, so that his presentation of societal contradictions is not merely an expression of the historical situation but also a force within it to stimulate change.” (1972, p. 215)

This shifting emphasis towards qualitative methods in the search for an alternative to the positivist model within policy sciences has drawn attention to the unique dimensions of the social world (Kincheloe & McLaren, 2000; Lavalette & Pratt, 2001). A new paradigm is energized and committed to explaining value-laden social issues within the subjective realm by positioning the researcher to “get inside” the situation and understand the meaning of the social phenomena from the informant’s own goals, values,

and point of view. Positivism has failed to capture the reality that social action “has in itself a directness towards knowledge of the good”, including the good life or society (Strauss, 1959, p. 24).

This new discourse and cognitive *lane change* in social policy circles has validated and encouraged researchers to listen and emancipate voices that in the past have been silenced or marginalized. The personal narrative is now becoming valued within the domain of empirical inquiry and makes a significant contribution to an informed and evidence-based decision-making process. Mullan, Fickln & Rubin (2006) assert that the reporting of life events remains a powerful tool for re-focusing the human mind. Dan Fox (1993), historian and health policy commentator, offers his opinion by suggesting that the plural of anecdote is policy. The multiple complexities of health care-giving it, getting it, administrating it, teaching it--are a contextualized realm of human enterprise that is often personal, frequently dramatic, and always controversial (Aronson, 1993; Labonte et al., 1999; Riley & Hawe, 2004). Documenting the personal narrative has been described as an indisputable and compelling vehicle for transporting perspective and opinion about health policy issues (Martin, 1996; Murray, 2000; Ricoeur, 1980; Riley & Hawe, 2004; Roe, 1994).

Human beings have long been involved in telling and writing of their personal stories. Health and health policy has been described as a quintessentially human realm that makes stories as vivid and revealing as those from any other area of human endeavor (Frank, 2000). While there remains a need to place the process of decision-making in health and health care policy on a firmer, more quantitative base (Canadian Institute for Health Information, 2006; Dobuzinskis et al., 1996; Brooks & Miljan, 2003; Gil, 1973;

Twigg, 2002), there is an equally compelling need to maintain perspective and promote wisdom in the search for meaning through the use of narrative, which serves as the underlying perspective of this dissertation study (Aronson, 1993; Bury, 2001; Hatch & Wisniewski, 1995; Labuschagne, 2003; McCorkel & Myers, 2003; McWilliam, 2000; Sawatzky & Fowler-Kerry, 2003). Such an examination was inspired by contributions of the critical theorist Jurgen Habermas (McCarthy, 1978) who offers an epistemological base for a critical theory of society by combining practical discourse with an assumption of communicative competence. A Habermasian position allows me to deconstruct and uncover systemic inadequacies inherent in our value system that serve to underpin current priorities and decisions (Agger, 1998; Foley, 2002). It is my contention that such an approach will provide an opportunity to explore perspectives that will lead to greater social justice in social policy. Through this process I will further make visible the tangible cost and consequences to those who have a child with palliative care needs--a position that strengthens my resolve and serves as the basis for this critical naturalistic inquiry.

## CHAPTER THREE

### RESEARCH METHOD

#### *Design*

In this naturalistic inquiry, which seeks to study people in their own environments, I use critical ethnography (Carspecken, 1996) and Habermas' critical theory framework (1984) as the tools for analysis. Together they provided a broad framework from which to delve beneath the surface of everyday appearances and to produce theoretically informed accounts of social phenomena grounded in parents' perceptions of caring for children who have palliative care needs. This framework also takes a critical approach to the categories and forms in which everyday life is experienced; by unlocking silent discourses, emancipating voices, and empowering families, the resulting narratives provide a vehicle for transporting personal perspectives and real life accounts to people usually removed in time and space from those involved in these day-to-day struggles. This is a course of action that is consistent with Habermas' practical discourse as an area of epistemological inquiry about "what ought to be done" rather than descriptive knowledge simply about "what is the case". The preceding point of view serves to maintain perspective, promote wisdom, and help focus future policy deliberations.

Lincoln and Denzin (1994) and Vidich and Lyman (1994) suggest that through qualitative research discourse there has been a refocusing and shifting away from the more traditional grand narratives to single overarching ontological, epistemological, and methodological paradigms. This evolution placed the humanistic commitment at the "elusive emerging center" where researchers examine the world from the position of the

gendered, historically situated, interacting individual (Habermas, 1996). From this orientation, all share a common belief that a politics of liberation must begin from the perspective, desires, and dreams of those individuals and groups who have been oppressed by ideological, economic and political forces of a society or a historical movement (Carspecken, 1993; Guba & Lincoln, 1982; Lincoln, 1998).

The current state of pediatric palliative care most certainly represents a compelling case for unfairness and injustice within the current Canadian context of a civil society. There are a myriad of unanswered questions about why the majority of children and their families do not receive palliative care services, and, recently, there has been some recognition by government that there is a dearth of programs and policies directed at developing and improving pediatric palliative care services (personal communication with Senator Sharon Carstaris, December, 14, 2005; Canadian Institute for Health Information, 2007). Due to the very nature of the problem, there has been, and continues to be, little communication between those in government and families in need; these constituents are often too depleted to make their voices heard (Steele, 2002; Darnill & Gamage, 2006). Additionally, the subject of pediatric palliative care remains taboo in our death denying society and creates an unacceptable level of discomfort and a deafening silence (Kane & Primono 2006).

### *Critical Ethnography*

*Critical ethnography*, with its genesis in critical social theory, is described as field studies directed towards understanding the ethos or culture of a group or society (Guba & Lincoln, 1982). While ethnography is a qualitative method, Gille (2001) advocates that it

is also an epistemological position. Whereby doing ethnography becomes a commitment to study an issue at hand by understanding it from the perspective(s) of people whose lives are most affected by it (Giddens, 1987; Kincheloe & McLaren, 2000; Lincoln & Denzin, 1994). Critical ethnography emphasizes the particular notion of experience that analytically links the lived worlds of individuals to social structures (Carspecken, 1996; Foley, 2000; Kincheloe & McLaren, 2000), individuals whose voices are not formally attached to constituencies and are generally considered to be outside of the mainstream and are not heard or recorded (Koehler, 1981; Levi–Strauss, 1967; Murray, 2000; Punch, 1994). Silenced discourses, which continue to be influenced by the effects of economic restructuring, globalization and the neo–liberal ascendancy in political discourse and practice beg the question: who really counts in the current neo–liberal era (Gille, 2001; Lyotard, 1984; Noblit & Murillo, 2004; Patterson & Monroe, 1998, Twigg, 2002)? Because what is personal is political and policy is personal, eliciting narratives of experience from parents serves as a means for the researcher to use multiple and gendered images (Denzin & Lincoln, 1994). The product derived from this approach is described by Denzin and Lincoln (2005) as “a complex, quilt like bricolage, a reflexive collage or montage, a set of fluid, interconnected images and representation. This interpretive structure is like a quilt, a performance text, a sequence of representations connecting the parts to the whole” (p. 6). Critical ethnology provides the essential optic to study social life under globalization.

## *Conceptual Framework*

Critical theory has become what Giddens (1987) would describe as a shorthand reference for a variety of attempts to break with the theoretical molds presented by the dominant strands of liberalism/neoliberalism (Habermas, 1975; Torgerson, 1996). Emerging from the Frankfurt School, dissident Marxists gathered together to reformulate Marxist theory as a means to overcome the limits of positivism (Flyvberg, 1998). This movement linked these scholars with Immanuel Kant's critical philosophy, where the term *critique* or *critical reasoning* was considered to be a philosophical reflection on the limits of claims made for certain types of knowledge and an emphasis on moral autonomy (Habermas, 1979; 1986). Critical theory at this time was perceived as a new philosophical approach extending the possibility of revolutionary agency (Best & Kellner, 1997; Croft & Beresford, 1998).<sup>1</sup> For additional background on the evolution of critical theory please see notes on page 60.

Habermas vehemently maintained that there is a general "theoretical lack of democracy in Marxism in which bourgeois democracy [the will and interests of the people] has never been treated either fairly or seriously" (1986, p. 98). As a result, he constructed a position about social formation under capitalism and established a Marxist social theory that had significant emphasis placed on communication rather than revolution of production, on persuasion rather than domination, and on intersubjective legitimacy rather than objective administration. The communication of knowledge, according to Habermas, acts as an instrument of social control since social and environmental norms influence and affect our system of beliefs and values. It becomes a critical imperative to deconstruct how members of society are exposed to or limited from

knowledge by the hierarchal, powerful elite and to recognize that from this position social structures developed within society are inseparable from social action. For example, as mentioned previously, we live in a death–denying society and as such the subject of pediatric palliative care creates a source of uneasy dissonance among and between health care professionals, policy makers, the public, and parents of children who have palliative care needs; this current context results in the vast majority of children diagnosed with life–limiting and life– threatening conditions not receiving or having access to comprehensive palliative care services.

Habermas further illustrated how empirical theoretical knowledge and practical social knowledge are aimed at two fundamentally different purposes. Theoretical knowledge was designed to explain causal relationships that govern objective reality, namely “what is the case?” Whereas practical knowledge addresses the norms of social action with the question being “what ought to be the case?” Habermas (1970) contends that there has been a failure of these two epistemological spheres of thought to transpose theoretical causal knowledge into practical life–world meanings (McCarthy, 1978; Fischer, 1995). Theoretical knowledge, validated by the rules of positivist scientific procedure, must be endorsed in the practical “lived” world through a process of normative discourse carried out by the relevant participants (Kincheloe & McLaren, 2000)—a discourse that involves a dialectical interaction between facts and values and is considered a core process of representative institutions aimed at discursive formation of public will. Science according to Habermas (1979; 1996) must be anchored to what he coins as a “pragmatistic model” of decision–making that governs practical discourse between scientific experts, politicians, and the public (Freire, 1970; Giddens, 1987; Gille

& Riain, 2001). Without the process of practical discourse, science is tacitly planned and controlled by the dominant ideology of the hierarchical decision structure and by the experts who direct it (Fischer et al., 2007).

For the purpose of this study, I made use of Habermas's idea of critical reasoning which extends empirical theoretical knowledge and practical social knowledge. In this way critical reasoning involves evaluating society when it does not function democratically. Critical theorists provided the framework which lead to a critical awareness where social change is necessary to encompass the principles of a just society and transforms its institutions. Critical theory informed by choice of methodology. Most fundamentally, "methodologies based on a critical theory perspective provide a critique of ideology, attempt to reveal hidden power imbalances to achieve emancipation, and endeavor to ensure that knowledge is available in the public domain" (Mill, Allen & Morrow, 2002, p. 115). Critical ethnography, as a methodology, permitted me to deconstruct power structures and relationships for the purpose of revealing and redressing oppression by giving voice to marginalized groups, which in this case were parents of children with life-limiting and life-threatening illnesses (Best, 1997; Carspecken, 1996; Fay, 1987; Gille, 2001; Lyotard, 1984).

### *Research Question*

The overarching research question framing this study is: "What impact do social policies or lack thereof have on parents caring for a child diagnosed with a life-limiting or life-threatening illness?" To do this, I described and interpreted the constructed

realities of families who are living or have lived with a child with a life-limiting or life-threatening illness.

### *Procedures*

#### *Ethical Approval*

This study received ethical approval from the University of Saskatchewan Behavioral Science Ethics Committee consistent with the policies governing research with human participants. Ethical considerations included ensuring that consent from all study participants was fully informed and completely voluntary with the protection of the anonymity of participants and the confidentiality of information. Due to my work in the field of pediatric palliative care, the first study participants were approached by me to participate. Thereafter, past participants contacted other families who then initiated contact with me expressing an interest in this study. The resulting *snowball sampling technique* was very effective and the sample of six families was recruited in a very timely fashion. Each potential participant was sent an electronic consent form and asked to contact me, either by phone or e-mail, after reading and signing the consent to grant permission for me to contact them and to arrange a convenient time and place to conduct the interview.

In addition to interviewing families, I contacted and had discussions with key informants within government circles to cross-reference information and gain further insights into the current state of policy as it relates to children in general and more specifically to pediatric palliative care. These participants were selected on the basis of their experience in health policy. This strategy is known as *intensity sampling*, wherein

“one selects participants who are experiential experts and who are authorities on a particular experience” (Denzin & Lincoln, 1998, p.23).

To further protect the confidentiality of the data provided by participants, my transcriber signed a confidentiality agreement prior to initiation of the transcription process. All tapes have been stored securely. Participants’ names and any other identifiers have been removed from the transcripts and replaced with code names. Transcripts have been stored securely and raw data have not been, and will not be, made available to anyone but my supervisor. All data have been reported in aggregate form or under code names. Any identifying information in quotations that may be used in future manuscripts, reports, and presentations has been replaced with generic terms to avoid any breaches of confidentiality.

### *Setting*

All study participants, parents of a child with a life-limiting illness, live or lived in Saskatchewan with their child. Data were collected and transcribed from April 2007 through to June 2007. In one case, the child with the life-limiting illness died. Due to the geographic locations, some interviews were conducted via phone and others were completed in sites selected by participants. These included private offices, coffee shops, and local eateries.

### *Data Sources & Collection*

Data were derived from three main sources: semi-structured interviews with parents; key government informants--government documents, policies, media and other

documents; and literature related to the current political, economic and social contexts of policy-making.

Three sampling strategies were incorporated in the recruitment of participants for the naturalistic inquiry. The first was *purposive sampling*, where according to Gillis & Jackson (2002) individuals are recruited who have experience with the phenomenon of interest, who can inform the study according to specific criteria for inclusion, and who are representative of the specific population. *Snowball sampling* was also used and considered a type of purposive sampling, in which participants with whom contact has already been made use their social networks to refer the researcher to other people who can potentially participate in or contribute to the study (Denzin & Lincoln, 2005). The final sampling strategy known as *intensity sampling* was used with government and policy participants, wherein, “one selects participants who are experiential experts and who are authorities on a particular experience” (Denzin & Lincoln, 1998, p. 23).

I used the term *purposive sampling* in this study to reflect the recruitment of participants who were first approached to participate, based on the criteria that they had or have had a child diagnosed with a potential life-limiting/life threatening illness. Identifying potential subjects was not difficult due to my clinical practice and contact with other health professionals in the province. The subsequent snowball sampling technique then became the primary source for potential subjects. Intensive sampling was incorporated into the study as I recruited key government policy informants who could provide additional data that could not be extrapolated from existing document sources.

Documents were sourced from a variety of sectors, including journals and electronic and print-published government documents. Reviewing some provincial

government policy proposals provided additional insight into the perspectives of the government participants. The identification of these key documents was an iterative process, wherein participants also identified and alerted the researcher to sources of information that were relevant to purpose of this study. A wide range of opinions about sampling exists in the qualitative research community, where there is a considerable body of literature available that discusses the appropriateness of theory, design strategies, and procedures for sampling (Denzin & Lincoln, 2000; 2005; Field & Moore, 1985). Important contributions have been made by research devoted to identifying and describing the nature of sample universes and the relevant analytic units for sampling (Field & Moore, 1985). The concerns with sampling in qualitative research focus on discovering the scope and the nature of the universe to be sampled. Lincoln & Guba (1994), point out that the basic building blocks of qualitative research are not fixed, constant objects with immutable traits. Rather as Guba and Lincoln (1982) suggests, meanings and identities are fluid and changeable according to the situation and persons involved, and researchers ought to sample for meaning. It is self-evident that those not familiar with the “sampling for meaning” approach often raise concern over the aspects of sample size.

Sampling for meaning has four distinct assumptions. The first is the notion that responses have contexts and carry referential meaning (Denzin & Lincoln, 2000). Secondly, individuals often actively interpret experiences, which is not a fixed response. Thirdly, certain types of data do not have a separable existence apart from their occurrences embodied within the routines of everyday life. Qualitative research provides a context and facilitates a process of collaboration between researcher and participant.

Fourthly, the research interview serves as a means of interpretation of experiences, and it makes reference to both the socio-cultural standards and the ongoing matrix of individual experience.

The sampling frame used for the purposes of this study indicated that sampling for meaning occurred in relation to individuals as representatives of experiential type (Field & Moorse, 1985) The goal was the elucidation of meaning or experience through inquiry about, discussion of, and conversation concerning experiences and of the interpretation of events elicited through verbal narratives. The question of how many subjects remains a perennial question, and clearly there is no formula or gold standard; rather, the sample size is reflective of the specific aims and methods of this study.

Based on the guiding rationale that the primary objective of sampling within the qualitative paradigm is the discovery of the insider's view of cultural and personal meanings and experiences, my study sample consists of 6 parents, who all had or have a child diagnosed with a life-limiting or life-threatening condition. In addition, three key government informants were used to further situate the discovery-oriented goals of this study. After the completion of the fourth interview, it became increasingly clear that distinct categories had emerged and were becoming saturated. At that point, there were another two potential participants identified who had demonstrated significant interest in participating. I proceeded with their interviews; however, when questions arose about additional contacts for the study, I thanked them for their interest and explained that at this time no additional participants were needed but, should this situation change, I would certainly contact them.

I commenced data collection in April 2007 and continued until the end of June 2007. Prior to each interview, I again discussed the consent form and study purpose, which allowed participants another opportunity to ask questions or clarify any assumptions (see Appendix A for “Letter of Information and Consent”). I pointed out, again, that they could request and receive their transcribed interviews to review and edit, but all respondents waived their rights to this. Before the tape recorder was turned on, each participant was advised that they were free at any time during the interview to ask that the tape be shut off if they did not want sensitive excerpts recorded.

Throughout each interview, I used both semi-structured and in-depth conversational interviews as data gathering tools. Semi-structured interviews, interviews in which the same general questions or topics are raised, provided an opportunity to collect comparable data across participants using a list of general questions. Open-ended questions were employed as a probe to gather a wide range of perspectives, which were deemed significant to the study’s purpose. In-depth interviewing was designed to elicit a rich understanding of the participant’s way of thinking; these interviews are less structured than a typical interview and involve the researcher probing into topics that the participant may bring up. Semi-structured interviews are the method of choice when a researcher is aware of what she doesn’t know and can then frame appropriate questions to find out. The conversational interview is used to elicit discussion about opinions or values that the participant deems relevant or meaningful to the topic (Gille & Riain, 2001; Guba & Lincoln, 1982). Such conversational questioning alerts a researcher to aspects of their topic that otherwise are overlooked.

Each taped interview lasted an average of one hour, and, in keeping with respectful research, participants were all given the opportunity to read the transcribed interviews for clarification and sign a Data Transcript Release. If quotes were to be used, participants had the opportunity to read what is said about their participation and identify information that would be excluded. All of the participants waived their right to read their transcripts. Jot field notes, which included my personal thoughts and observations, were completed following each of the interviews.

### *Questions*

During the initial phase of the interview, profile information was formally extracted from all of the participants. As the investigator, I restated the purpose of the study and offered a comprehensive explanation of the methodology adopted. Once the preliminaries were completed, I presented a list of “grand tour” questions (see below), which were prepared prior to the interview. Additional questions did evolve from conversation and the use of probing techniques. These grand tour questions were useful in soliciting an overview of relevant categories from each of the participants:

- “Would you like to tell me about you and your family?”
- “Can you provide me with some understanding and overview of your child (insert child’s name)’s health history?”
- “What impact has your child’s health had on you and the other members of your family?”
- “Thinking about social policy, would you please put into words what this term means to you?”
- “Now moving back to your child’s health needs, would you highlight for me the health services you have had or are currently using?”

- “Did you encounter any barriers to access to any of these services?” “If so, can you elaborate further about this?”
- “Can you describe the types of services that were available to you, your child and family?”
- “Why were these services so easily accessed?”
- “Now thinking about the services that were easy and those that were not easily accessed, do you believe that this was the result of policies or lack thereof?”
- “Now let’s talk about pediatric palliative care. What does this mean to you?”
- “I will read the World Health definition of Pediatric Palliative Care to you. Does your perception change on hearing this definition? If so, why? If not, why?”
- “Do you think any of the services you and your child has received, would be classified as palliative?”

Each of the three policy participants were interviewed and audio-taped during in person interviews. Due to their positions within government, they all felt that “their word was part of the public record” and therefore all waved their right to sign a consent form. During these interviews, I inquired about their understanding of the most prominent policy issues in child and youth health. Further, they were asked about the policy process, including their own beliefs about issues that were and were not on policy agendas: inclusiveness of decision-making and influences in policy process in general and more specifically to children and their families living with palliative care needs. I was aware that studying health systems during a time when health and health care issues including contract negotiations were in the public spotlight may have had the potential to create some level of trepidation or concern. Surprisingly, this was not the case, and participants,

at both federal and provincial levels of government, were very willing to share their thoughts and insights and were keen to learn more about issues of pediatric palliative care. Once I received the transcribed manuscripts for each of the interviews, I read each and cross-checked the tapes and transcripts for accuracy and added jot field notes and personal reflections. This was a useful exercise to situate myself as the researcher and provided a deeper perspective and understanding about each parent's personal context.

### *Data Analysis*

I was concerned that perhaps the telephone interviews would limit the participants. However, I found them to be very forthright in the interviews, and they answered questions openly. The collection of data appeared unaffected by the telephone; the richness of their data was similar in nature to that provided by other participants. Documents and interviews were grouped according their source and organizational affiliation. Analysis was ongoing as the researcher sifted through the data looking for patterns and connections while using a constant comparative methodology. Through analytic induction, I was able to infer that events or statements were instances of the same underlying theme, all the while keeping the research question in focus. As a researcher, I asked, "*Is this code similar to or different from other codes?*" A similar technique was used in looking for patterns between the codes and categories by using the researcher's insights and knowledge of the subject area. I used *Atlas-ti*, which is an open-ended software program that facilitates the systematic, inductive coding and grouping of large amounts of primary data.

After the transcribed primary documents were entered into the Atlas-ti program, the data bits were electronically coded using themes that the researcher identified from a reflective study of the data and by reference to the literature review of the area under study. Coding was used to make intuitive sense out of the masses of data, to cluster related data into groups, and to discern connections among these clusters. In the manner described, integration of diverse and multiple fragments of data were achieved. Global themes and patterns emerged inductively from the data; however, it is the researcher from a position of scholarly, intuitive familiarity with the area of study who selected the themes to be coded. The grounded theory that emerged was based on the interviewee's inside view, and the original voice of the interviewee is never abandoned nor compromised, which is so important in cross-cultural research methodologies. Using critical ethnography as the frame, this study analytically linked lived worlds to social structure. The results of this study will further illuminate how policies, or lack thereof, affect how private decisions are made, and how lives are lived. This approach is seldom studied as part of evaluating policy impacts. Knowledge that is not documented appears often not to exist. This study provides an optic for both policy-makers and clinicians.

### *Interpretation*

More intensive than the summary of the patterns is the rendering of the interpretation of the study, which requires the researcher to think in new and dialogical ways. Interpretation involves redesigning old categories, formulating new relationships by combining elements in novel ways, projecting beyond what actually exists, and conjuring up probable connections. The interpretive practice of sense-making is both

artful and political. In this project, the extended engagement in the field and the involvement of research will provide triangulated data for trustworthy and authentic interpretation. It is critical that the findings are integrated with those of related and relevant studies to establish how these results relate to broader theoretical frameworks, to explicate what the study means outside of the one context, and to make recommendations and transfer knowledge to the community, local schools, and policy-makers. Giving voice to those impacted and currently living through this experience, voices that have remained silent, is a crucial element in this process. This act will yield important baseline data to provide policy-makers, politicians, and health care professionals with a new optic to see how the current state of affairs impacts human lives, and, in so doing, challenge the current liberal ethic of justice with a view to changing the current status quo as it relates to pediatric palliative care.

## NOTES

<sup>1</sup>Emerging from the first phase, the Frankfurt School eventually evolved through four phases. The second phase was characterized by two works that were considered classics of twentieth century thought and authored by Max Horkheimer and Theodor Adorno (Wiggershaus, 1995). Their analysis of reason appears to be a fusion of domination and of technological rationality, suggesting that all of external and internal nature exists under the power of the human subject (Flyvberg, 1998). The third phase extended from the post-World War II period into the mid-1960s, and critical theorists such as Marcuse recognized that the structure of capitalism had changed in this era as did modes of oppression, and the industrial working class no longer remained the determinate negation of capitalism (Jay, 1996; Wiggershaus, 1995). Moving away from the concept that the individual subject was the locus of criticism set the stage for the fourth and final phase, in which Habermas located conditions of rationality within the social structure of language use and thereby shifted the locus of rationality from the autonomous subject to subjects in interaction (Habermas, 1975; 1979; 1996).

## CHAPTER FOUR

### FINDINGS

We can succeed only by concert. It is not, “can any of us imagine better?” But, “Can we all do better?”  
Abraham Lincoln

Capturing and articulating the effects of social policies on people’s lives is important in countries like Canada that have a welfare state tradition. Within the field of policy analysis, the practice of relating the quality of life of citizens to the existence of certain types of policies is seldom contested; the challenge is to both conceptually and methodologically illuminate the dimensions of this complex relationship. In this dissertation, I feel as though I have picked up the gauntlet and thereby assumed the challenge to capture the impact of how social policies affect the lives of people as individuals, as members of a family, and as citizens in a country where many enjoy a relatively high standard of living. More specifically, I have come to gain further insight and understanding about the impact social policies have on parents caring for a child diagnosed with a life-limiting/ life-threatening illness. Drawing on interviews conducted with six parents between May and June 2007, this dissertation captures and presents a critical discourse concerning outcomes of the operationalized welfare state within a liberal paradigm that celebrates the autonomous individual as the appropriate unit of political analysis (Rice & Prince, 2000).

In the global context, increasing wealth disparities and economic and social crises are emerging in many nation states, while there also appears to be increasing interest and attention directed towards building what the World Bank (2000) describes as social order as a means to buffer societies against social disengagement. As the discourse of

commodification continues and the effects of market economies become more global, policy discourse about citizenship rights continues to include discussions of universal entitlements that include health care services (Brooks & Miljan, 2003). The results of this research begin to capture and decontextualize the complex local and personal effects of the liberal paradigm as it operates under the aegis of globalization, which is important within this study context because globalization is credited with being the *raison d'être* for economic restructuring and the ideological reorientation regarding state provisioning and social citizenship (Ruggie 1996). *Restructuring* and *globalization* have become code words for summarizing a number of trends: (1) the emergence of an economy based on activities of transnational corporations; (2) the rapid introduction of new information technologies that are revolutionizing communications and the international dissemination of culture; (3) the formation of regional trading blocs, such as the North American Free Trade Agreement (NAFTA) and the European Common Union (EU); and (4) the development of supranational institutions, such as the World Trade Organization and the World Court (Hankivsky, 2004; Manga, 1998; Pal & Weaver, 2003) . These trends are now revealing a portrait that clearly demonstrates that the powers of individual nation states are circumscribed by forces of globalization and, at a micro level, that the changes resulting from economic restructuring, in this study, equated into personal discourses around income insecurity, employment, and limited or disappearing programs that would be considered pivotal components of the social safety net.

Within the context of globalization and restructuring, the notion of citizenship has emerged as a central concept. According to T.S. Marshall's theory (1965) of citizenship, this construct informs the majority of Western society's thinking and assumes the

existence of a nation wherein a welfare state operates to redistribute, through taxes and social benefits, some of the resources that accrue disproportionately within different sectors of the populations (p. 26). Ruggie (1996) contends “that the mere existence of the welfare state is a sober testament to the fact that contradictions exist between the ideals of democracy and equality and the operation of a market-based economy” (p. 114). Policy scholars maintain that civil rights can and should progress to entitlement rights, such as education, employment, and health care (Keating & Hertzman, 1999). For Canadians this translates into citizenship rights, which have been linked to successful participation in the market economy, but unfortunately there emerges a segment of the population that is excluded de facto from participating in the paid labour force, rendering invisible the mechanisms of social control by which they have or continue to be disenfranchised (Pal et al., 2002).

Through the process of eliciting personal narratives, another facet of globalization and dialogue on citizenship emerges and demonstrates that the realignment of the welfare state has resulted in more restrictive definitions of equality, merit, concepts that are based within the tenets of neoliberalism (Lavalette & Pratt, 2001). Individualism is sanctioned and merit becomes not only the basis for economic and social rewards but also for inequalities. Definitions of what constitutes “genuine need” serve as the basis upon which to claim state support, while more rigid tests are incorporated to empirically validate the need (Lund, 2002; Pal, 1997). Neoliberal concepts of citizenship reward self-sufficiency, criticize dependence, and sanction limited state intervention and greater privatization, and a striking example within this context is the assignment of care-giving responsibilities. As recently as November 21, 2006 on NBC’s *Today Show*, there was a news segway

highlighting the amount and types of unpaid care-giving work being done, particularly by women. Contained within this report and supported throughout the literature (Arskey et al., 2004; Brodhead, 2003; Cheung & Hocking, 2004; Romanow, 2002) are references to the continued off-loading of health care into the informal realm of family; a practice confirmed by parents in this study. Inherent in this dialogue are assumptions regarding who is considered independent versus dependant, taxpayer versus welfare recipient, or in other words the “us” versus “them” mentality, which serves as a powerful instrument of social control to further marginalize and silence competing discourses. Tronto (1993) describes this context as “privileged irresponsibility”:

Those who are relatively privileged are granted by that privilege the opportunity simply to ignore certain forms of hardship that they do not face. Plus, the social programs they do access, along with benefits such as increased tax breaks, elide their own dependence on the state. The dependency is constructed; however suggests that relatively advantaged groups, i.e. those who are included, will not support more inclusive types of policies. (pp.120-21)

Understanding the unequal and compounding effects over time of policies across specific sectors of the population is essential if there ever is to be any meaningful engagement of citizens achieved (Evans & Stoddart, 1990; Habermas, 1986; Labonte, 1993; Mustard, 2005). Transformative possibilities can only be envisioned and carried out in the lived experience when alternative information and perspectives are engaged; this validates my choice of a research methodology embedded within the pedagogy of critical theory and is a shorthand reference for what has come to represent any attempt to break away from the theoretical frameworks developed and subscribed to by the

dominance of liberalism and neoliberalism paradigms (Habermas, 1975; 1979; 1986; Torgerson, 1996). Political and theoretical paradigms espousing the virtue of passive intolerance have come to symbolize the principle that truth is only valued as an outcome of positivistic methodology, which is a position juxtaposed with critical relativism. Like Habermas, I have come to understand through personal reflection that in order to gain a deeper comprehension of the human condition one requires a critical epistemological perspective that transcends the limits of modern social science. The epistemological position is located between philosophy and science or between interpretation and empirical validation--the position that Habermas (1996) has described as the methodological *moment* upon which critical theory is constructed.

The classical question contained within critical theory is the relationship of knowledge to power, which is seminal to this research and has received considerable theoretical attention within the body of scholarly literature, where it may also be referenced as *coercive harmony* (Fischer, 1990; Habermas, 1970; 1975; 1979; 1986). When translated into practice or real life experiences or citizen to expert, our knowledge about these power relationships is disturbingly inadequate. Fischer (2000) describes this situation “as unfortunate given that in our highly complex technological societies the role of experts or power brokers has moved to occupy center stage” (p. 407). By including experts in this discourse, it transforms the original question to additionally address the relationship of power between knowledge and competence.

Questions, Habermas (1986) would suggest, are the basis of tension between experts, using sophisticated analyses to understand a policy question, and citizens, arriving at their own judgments--including their understanding of the experts themselves.

The ritual trappings that adorn legal hearings, committees in government, and panels of “experts” in their solemn hearings with their weighty reports are all ceremonies that demand and receive a degree of public support, respect, and gravity within the empirical, positivist paradigm. What level of influence and or power should the views of the general public carry when compared to the aura of authority on results derived from groups with such ceremonies? Who then becomes most capable of judging the needs of parents who have children with life-limiting or life-threatening illnesses, parent or “expert”?

Moving this discourse to another level, scholars including Ellul (1964), Fischer (2007), Habermas (1970; 1975; 1979; 1986), propose that the prophets of our information society “conflate morality with instrumental rationality”. Technology is arguably the means that enable humans to achieve their desires, and technology exists as a means to serve our needs and desires (Fisher, 1995). Within this framework, our high tech, information-dependent society has created a global environment in which questions of social choice lose out to the influential thrust of the techno-economic system (Fisher, 2000). In other words, our society’s moral and political questions have given way to the logic of a positivist science that has come to increasingly dominate our public and private lives. The result is that scientific and technical experts have become further isolated from general citizens and the interface of communication between these two groups has overtime become increasingly strained.

Inviting, listening, and including the voices of citizens is an occupation contained and valued in our democratic process; it is an essential element within all public administrative structures, which includes our Canadian health care system. Adopting this

philosophical principal has created a multiplicity of issues. John Dewey (1927) posed a cogent question when he inquired about how citizens could deal with increasingly complex problems dominated by complex technologies and expert decisions. He went on to question how citizens could actively participate in policy and political decision-making that had become over time so dependant on the knowledge of experts. He went further pointing out a very intriguing paradox:

As the importance of the citizen grew in the political realm--thanks to the expansion of basic rights in the nineteenth and twentieth centuries--the phenomenon was paralleled by the growth in power of large corporate and governmental organizations directed by managerial and technical expertise. Thus in just that period in which the political influence of the citizenry was taking shape, it was undercut by the rise of bureaucratic organizations and technical expertise. (p. 23)

Fischer (2000) expands further on Dewey by revealing that while Western democracies have exhibited increasing interest in group involvement, levels of individual citizen participation, as demonstrated in political and sociological research, have declined rather than increased. Fischer's position is substantiated by examining voter turnout in the last decades at all levels of the elections process. Dahl (1989) argues that this trend was both predictable and expected. He contends that, "the increasing complexity of social problems, giving rise to increasing specialization and the expansion of "elite" public policy specialists, "puts the Western polyarchies in the position of being replaced by a 'quasi-guardianship' of autonomous experts, no longer accountable to the ordinary public." (p. 337)

I agree with Habermas (1986) that experts alone are themselves incapable of answering and “fixing” the multiplicity of social problems that currently exists in our society. Not only do they, the experts, lack all of the answers to these complex problems, but often expertise itself turns out not to be the neutral, objective phenomenon that it is purported to be. Underlying the expert technocratic approach is a basic positivist principle that dictates rigorous separation of facts and values, and one where empirical research must be conducted without reference to normative concepts or implications (Fischer, 2000). Attempting to separate facts and values reflects an intense lack of insight and a misunderstanding and distortion of the nature of the social world, and the separation also represents a profound paradigm shift and, for me, a source of uneasy tension. My apprehension stems from a well–entrenched positivist framework rooted in my undergraduate and graduate training programs and has become much more dominant as I have maneuvered the pervasive positivist milieu of academia.

Over 21 years of working and researching in the area of pediatric pain and palliative care, I found that I was challenging and being challenged more frequently by the “fact/value” dichotomy seminal within positivism. I resisted and gradually came to understand and appreciate what Fischer (2000) succinctly describes as the “organized universe of meanings” (p. 93) that normatively constructs the social world. Strauss (1953) contends “positivism fails to capture the fact that social action has in itself a directness towards knowledge of the good, including the good life or society” (p.43). Thus according to Strauss’ position, value discussions can no longer be considered unprovable, irrational, subjective responses, and facts then do not just exist out there in the social world for researchers to collect and quantify, nor are political and social problems

independent of subjective attitudes and values (Fischer, 1995; 2000; Habermas, 1970; Strauss, 1959). Through this personal journey of self discovery, re-invention and emancipation, I have come to appreciate that listening and including voices of those living with or without policies is more a question of personal values, attitudes and practices than a matter of scientific methodology. Like Dewey (1927), I have come to realize that there must be a collaborative division of labour between citizens and experts (community development)--a paradigm shift that Habermas (1975) makes clear as being more about power relations than an issue of knowledge production. It should then come as no surprise that the approach selected for this research deviates from the positivist mainstream single-issue policy perspective, which proposes that policies are developed and implemented as discrete entities. As this study exposes, through the examination of personal narratives, policies are not experienced in isolation, and it becomes a social and moral imperative that we come to better understand the unequal and compounding effects of policies experienced by citizens within multiple sets of social relationships.

The analysis will proceed in two stages. Firstly, I will provide a brief context for each participant in this study by outlining the multiple, cumulative, and interactive effects of social policies on the lives of the participants and their families. Each of the participants' narratives together with the rich contextual data will demonstrate how policies in a number of areas affect individuals differently depending on the family structure, social location, and the stability of resources available. Secondly, the key themes that emerged will be highlighted and linked to conceptual and methodological paradigms.

## *Tess*

Tess is a young woman living in an urban center in Saskatchewan with her husband and three children. Britt, their first child, was born healthy and robust and described as a good and contented baby. Pregnant with her second child, there seemed to be some changes in Britt's normal growth and development that bothered Tess. Soon after, Britt began having seizures, and, after an extensive work-up, they found that he had a malignant and rare brain tumor. The news was devastating to this young couple and their extended family:

*Hearing this news for the first time was surreal. I can remember thinking that this is a bad dream and when I wake up this will all go away. Over the next few days, I realized that this was really happening, and I felt physically ill and nauseated. My husband was just really angry and did not want to talk about it. And remember, I was 8 months pregnant with Jessica at the time, so I just couldn't live in a cocoon, I had to come out and face the facts.*

Britt underwent surgery followed by what would be a course of many rounds of chemotherapy. Due to his young age, the odds were not good for his short-term survival. Brett was sent early to Toronto Sick Kids' Hospital to a surgeon specializing in children's malignant brain tumors, and in this environment they felt increasingly confident that Britt would get the best care available.

Britt's diagnosis did change the family, but Tess mentioned many times that because he was so young at diagnosis, they, as parents, had not experienced any other reality. The fact that he had such a serious diagnosis meant that they look at life differently, long-term goals were not part of their life plans and they found themselves

focusing and living for the moment. There is a significant body of literature describing how parents live and project many of their personal hopes and dreams through the lives of their children, and, as a parent, I have acquired a greater understanding of what this truly means. For Britt's family, having their dreams snatched away and replaced with tremendous uncertainty, creates an ongoing sense of loss and bereavement. Tess feels that her son's health status has not really changed her career aspirations because she always wanted to be a stay-at-home mom. However, she quickly added that Britt's health needs have prevented her from returning to casual part-time work, which is a situation that has at times created financial strain for her young family, and, as she also pointed out, working the odd shift "just sort of expanded my personal horizons".

Introducing the term *social policy* did not mean much to Tess until I gave her an explanation, and even then she was unclear as to whether or not any social policies had impacted her and her family directly. She then confided that she has a brother working within the health care sector, and while she doesn't believe that Britt's care would have been any different because of her brother, she did agree that perhaps she may have been better informed or maybe informed earlier about some of the programs and funding relationships that have come to ease some of the emotional and financial burdens for her and her family, "*For example, I was put in touch with an agency that will pay for travel back and forth to Sick Kids in Toronto. Parking in the hospital is also covered so that helps.*"

Assessing acute medical services has not been too much of a challenge for Tess, due to the seriousness of Britt's diagnosis, but there have been occasions when they wanted to take him to Sick Kids' in Toronto for a second opinion, and the doctors here would not

support their requests. These situations, while rare, did result in them flying at their own personal expense to Toronto on one occasion where their fears were substantiated by the medical team at Sick Kids' Hospital. Their costs were not fully reimbursed, but Tess explained that they have family on both sides that were able to assist them paying for those costs not covered. Nevertheless, Tess believes that in general they have had a good relationship with the medical team here in Saskatoon but on occasions have felt frustrated that they have not always been listened to because as she explains, *“There are times that you really cannot explain what is different or what is wrong, but you just feel it in your gut, and you know each time this has happened and I have been right and something was really wrong.”*

Tess reveals that Britt has outlived the projected life expectancy and is now even going to school--something that no one ever predicted would happen. Tess stated that at times they have stumbled not knowing what services were available and what services they would actually need. An example she uses is the need for a special aid person to assist Britt in school because he's legally blind and has some sensory motor deficiencies. No one informed them at registration that they would be entitled to this service, and after several weeks at school and a parent-teacher conference, the teacher inquired about why they had not applied for an aid. Once they were made aware, Tess made several phone calls and filled out the necessary forms and Britt had his aid. They have been so pleased with the relationship this aid has with their child that they have made a conscious choice not to move, or at least not move from the school district, because they do not want to take any risk of compromising this situation

The question about what *palliative care* meant to Tess caught her a bit by surprise. She very quickly informed me that this was a service for adults who were going to die very soon. I then read her the WHO definition, and she instantly recognized that Britt would be a candidate for such a program, and, up until now, no one had ever mentioned palliative care to her, including the oncology doctors. She admitted that the word *palliative* had initially conjured up some negative stereotypes, but since hearing what it means for children, she cannot understand why it is not practiced. She then brought up the need for respite and again there had never been any offered to her and her family:

*It's hard to say that any services up to now would be seen as palliative, but it's hard to know. I like the idea of someone coordinating services so that you would know exactly what is out there and know how to get them. We are probably luckier than some because we have my brother, and we do have family to help us out when we need it. It would be nice to sometimes just talk with someone about what is happening and, you know, have some insights. Talking with other moms in the Cancer Clinic is good, but it is also really hard because everyone has their own issues and every kid's diagnosis is so different. I do think because Britt is a cancer patient, that we probably get more assistance than a mom who has a child with let's say a genetic problem, but I'm not sure.*

*I know that his diagnosis has been hard on both me and my husband. He does not want to talk about it much at all, and I know he keeps it all inside. I think I've learned to accept it more and, even though we share in raising the kids, I have spent more time with him and researching different treatments and stuff. And*

*I do a lot of the talking with the doctors, for example, because of his job, he has not always been able to take the time off to go to Toronto. So stuff like that.*

*While I wish things were different, I feel blessed because we have had him longer than anyone ever expected and I feel that the more time that goes by the closer we are to a cure. He is really close to his siblings, and I do worry about what is going to happen if Britt dies.*

I found that while I was listening to Tess tell her personal story, I was in the presence of someone with strong conviction and inner strength. She was so very matter-of-fact and mentioned several times that Britt's life will be short, and never once did she lose her composure. She talks openly about the fact that their struggle with Britt and his illness is not over, and she again says that what keeps her sane is learning to take one day at a time.

### *Jessica*

Jessica has been married for over 13 years and has a Master's Degree in the social sciences. Her husband is a full-time minister and suffers from a severe congenital heart condition and recently suffered a massive M.I. (heart attack). Jessica and her family had lived in rural Saskatchewan and recently moved to the interior of British Columbia. Sam is the second oldest of three children. She and her twin sister were born prematurely and spent the first 6 weeks of their life in the neonatal intensive care unit. This unexpected experience was described as a time of enormous stress, but luckily both twins gained weight and transitioned successfully from hospital to home with no apparent residual problems. Three years following the birth of the twins, these parents, who had originally

been told that they would never be able to conceive, were now expecting their third child, another daughter, and absolutely ecstatic about the good news.

Sam's diagnosis followed the classic textbook case for Type I Diabetes and occurred just weeks before kindergarten started. Mom felt that:

*We missed the early, early signs looking back because that was when Sam was first being diagnosed with sensory issues, so the summer before kindergarten we were doing really intense therapy trying to address things, and so when Sam started wetting the bed we thought, oh well, it's probably being triggered by some of the therapies. There was also a heat wave that August, so were all drinking a lot. So we missed that piece until one afternoon when it was so hot I just plugged a show in for the kids, and all of a sudden realized that she went to the bathroom 13 times in an hour and a half.*

Jessica contacted the doctor as a result of her observations, and the following day Sam was admitted to hospital and the diagnosis of Type I Diabetes was confirmed. It was a shocking diagnosis since there is no family history of diabetes on either side of the family. Right from the initial diagnosis, it has been and continues to be extremely challenging trying to manage Sam's blood sugars, which often swing from 1.9 to 25 in less than 24 hours. The news of Sam's diagnosis was in Jessica's words:

*Shocking because we were just getting used to the fact that there were other issues with her, and then all of a sudden to find out that your kid has essentially a life-threatening disorder is overwhelming. I went through about 48 hours in shock, I couldn't even begin to think what life was going to be like, and I was also working at the time.*

Sam's admission and diagnosis occurred on a Friday going into a long weekend. This meant that for the first 3 days, there was almost no teaching or support. Once the weekend was over, the nurse educator for the diabetes team was back on duty and the situation as described by Jessica changed dramatically:

*The nurse educator just walks in and kind of goes, well, here is where we are at and we are going to get you all through this. She formed a team with us and we became very aware that you are now part of team and that her expectation was that you can do this and she would support you to make sure you could do it. That made a world of difference because you are no longer powerless. All of sudden you are recognized as being a part of this team to look after your kid, in fact you are going to be the main part of this team and that felt really good.*

The transition from hospital to home was surprisingly not a stressful situation for the family because they felt very comfortable, secure, and supported in the management of Sam's care. Jessica sums up the transition very well:

*We were ready to go home. I think that we were at the point where we were not afraid, we knew what to do, and we knew if we didn't know we had the team behind us. I think for the first month we talked to Dr. X on the phone every morning at around 7:15 am, my husband would call. These calls were not very long, but you knew that if you were messing up that weren't going to go to far wrong. The nurse educator had a phone and a pager. So you could call her any working hours and then outside of working hours you could call the hospital and get a pediatrician on call.*

The account of Sam's transition experience reaffirms for me that the system can work effectively especially if communication pathways are open and accessible to patients and their families. However, I am left to wonder why there is such disparity between and among service units, as you the reader will come to see through the following narratives.

Sam's unstable diabetes coupled with a diagnosis of autism has changed and significantly impacted this family. Jessica mentions on several occasions that she feels the person most affected by this situation is Sam's twin sister because of the amount of time and energy needed to keep Sam healthy. While Tabitha is the oldest child in birth order, she has assumed what Jessica describes as the *lost* or *middle* child position, so special time and experiences have been allocated just for her in order that she feels and knows that she is an important person in her own right:

*She has a sort of sixth sense about Sam. She knows when something is wrong. For example, one night she came and got us in the middle of the night and just said Sam needs help. We asked her what was wrong and she said that she didn't know, but that she needed help. I checked her blood sugar and it was like 1.6. Somehow this twin knew something was wrong with her sister. On the two times when she has had problems at school and on the verge of collapsing, it was Tabitha who identified the problem, not an adult.*

Jessica recognized early that due to the amount of extra care required for Sam, she could not be in a position to return back to the workforce. Not having a second income did, and continues, to create a financial strain on the family unit. She used the example of only being able to afford one car, which her husband uses extensively for his job. This meant that she and the children were very isolated and had to plan ahead for any trips that

were needed. Also, the reality of owning only one car created major problems when she had to administer all of Sam's lunchtime insulin injections at the school. She also pointed out that it was a little scary knowing that if something happened to any of her other children, she would not be able to move quickly.

When I approached the subject of social policy and asked Jessica to describe what *social policy* meant for her, she had a very quick response:

*Social policy, for me, is a way of avoiding having to provide people with services they need. And I think in the best sense, to me, social policy is trying to figure out how to put services and concepts in place that help make people's lives work better. But I think sometimes they get put in place to protect budgets.*

I was a bit surprised by Jessica's answer and I asked if she could expand a bit more on this. She mentioned that this would be easy, especially since they had just moved from rural Saskatchewan to British Columbia, and she was in a good position now to make comparisons from her perspective. Moving back again to the period where Sam was entering kindergarten just prior to her diagnosis, they lived in rural Saskatchewan and the commute on the school bus for the twins would be a 30-minute ride each way. This was not an issue for the family prior to Sam's diagnosis because that was just the way things are when you live in a rural area. What made the distance an issue was the fact the Jessica, who was home with her young toddler, had to drive this same distance everyday at lunch time to give Sam her insulin injection. This situation taxed the family both financially and personally because Jessica had to make this hour drive daily with a toddler and also with only one car that needed to be scheduled around her husband's job, and the increased costs became what she described as a "nightmare".

The family doctor attempted to intervene to find a remedy for this situation. What he found was that home care did not include going into schools as part of their scope of practice and that Public Health was involved only in prevention programs not treatment programs. This situation continued for over seven months with no remedy or proposed plan of action:

*It was our problem, and no one had asked for this type of assistance before. Then one day at the diabetes clinic, I found out that there was another school district in southern Saskatchewan where home care was helping. Once I got that information, then I just really got direct and went right to the top manager and said that this situation is happening somewhere else, and there is now a precedent and I want it to happen here before I crack up. This manager was actually very open; she said that she had not heard of our situation and that it was obviously being dealt with at a lower level. She asked me how many needles a week you give your son. I said, well, six needles a day times seven days works out to 42 injections. And she said, you are asking us to do two needles a week for respite? I said yes, and she said well that sounds perfectly logical and three days later all of a sudden there was somebody coming to the school to give Sam her needles.*

Assistance with administering the medication did a lot to improve the quality of life for Jessica, however her problems were not over. Sam has a very unstable form of diabetes and has very dramatic changes in her blood sugars. After several episodes of her blood sugars crashing and the school staff not being allowed to give her glucagons, Jessica felt that she needed a teaching assistant at school to be present and pay attention to Sam's behavioral signs because the teacher could not take this responsibility on in

addition to her teaching duties. The school district refused and informed them they should transfer their child to a larger urban school that was closer to a hospital. This option meant that this 5 year old little girl would be separated from her twin sister and bused for over an hour both ways with high school students to school. This solution was not an acceptable option for Jessica and her husband.

Jessica commented several times that she did not consider herself, prior to Sam's diagnosis, an assertive person, but that Sam's diagnosis changed this, and she often found herself having to advocate and justify her family's needs; a situation she assumed as part of her role as mother and primary care giver, but she points out it is not a role that she enjoys:

*We were very lucky to have a lawyer for the church and diocese who did pro bono work for the families of clergy. I phoned him up and told him what was going on, and he hit the roof. For starters he gave me some language to use with the superintendent of the school district. So I did, and they refused my request again, but I got a call from the principal the next day saying that the superintendent called, and he says you are talking in a different way, and I guess he is worried that you are going to sue the school district. Well, I told him I might have to. He said, well you need to know that the school board is fully aware that they have more money for lawyers than you do. I said, well you tell him that Mr. ... is going to work for us pro bono, and Sam had an EA the following Monday morning.*

As I listen to Jessica's story, I am reminded over and over again that it seems that for each of the mothers in this study, not only did they willingly assume the responsibility to become primary caregivers to their children, but most describe situations where they

had to go to extraordinary lengths and become assertive advocates for the rights and needs of their child to the point where they refer to this behavior and themselves as “bitches” rather than “supporter”, “activist”, “promoter”, or “advocate”. The system maintains a very adversarial position, especially when women must resort to describing their advocacy behavior as one of “bitchiness”. Jessica suggested:

*It's horrible to say, but when men are assertive in their workplace or in other settings, they are seen as just that, assertive, and we women are viewed as crazy or bitches or both. Just being a woman, mom or not, can work against you. We are accused of being driven by hormones not logic a stereotype that still works against us.*

This family has just recently moved to British Columbia, a move that certainly created a lot of discomfort and concern due to Sam's needs and the levels of care and support this family had acquired in Saskatchewan. Their concerns were realized immediately when they had to wait for seven months to get an appointment with the pediatric diabetic team. This situation was made even more acute because they could not find a family doctor willing to take new patients for over two months. With no team and nobody to contact in British Columbia should a problem occur, they “held their breaths”. The waiting period passed uneventfully and school was about to start. Then, as Jessica describes it, “*out of the blue*” she received a phone call from a community support nurse who introduced herself and asked what Sam's health needs are at school and in the community. Jessica made frequent references to this nurse throughout the interview as “their guardian angel”.

When I inquired about how this nurse came to contact her, she couldn't remember that she herself had asked for or initiating any referrals. Upon reflecting she thinks that perhaps it was made through the school, which would have had Sam's records, transferred from Saskatchewan. The role of this nurse has come to be play a seminal role in the lives of all the family members:

*It's been incredible. The week Sam was to start school she came to our home, did a complete medical history on her, and had also taken the time to listen to me say that we were having her investigated further for autism. So she had gone and done some research to try and figure out how diabetes and autism might go together, which was the first time anybody had even tried to look at that.*

*Her job is to go in and advocate for Sam at the school as to, you know, you guys have gotta change the way recess happens here for this child. It was her job to train school staff, which was different for me because in Saskatchewan it is the parents' job to train the school staff. So that was very different for me because I am used to being the one in charge. It was a hard transition, but now I like having somebody else in charge of that. I can now have a relationship with the Educational Assistant and the teachers about Sam as a person rather than focusing on the diabetes. As well the other way she has been helpful is when my husband had his heart attack, and I phoned her to let her know what was going on, and she just went into action and arranged all sorts of other supports for our family in terms of home support. She arranged for homemaking services to come into the home and childcare support services to be in place. I didn't even know that we were eligible for all these services.*

It was at this point in the interview when I asked what *palliative care* meant to her, and she very clearly articulated that this nurse and her role are their “palliative care program”; a program of services that Jessica believes are imperative for every family with a child who has a life-limiting illness. The services from this nurse provide emotional and physical safety and security—services that every family who has a palliative child needs. While not paying for this service directly, she believes that the services of this nurse have saved the health care system and themselves significant amounts of money by preventing situations from escalating and creating additional costs:

*All I want for Sam is for her to have an opportunity to grow up and be her own person, to be healthy as healthy as she can be. I know that if her environment is not stable and she is anxious it is going to affect her blood sugars and it is ultimately going to affect her heart, kidneys and circulatory system. So we, can not afford to have this child getting stressed out because of the long-term consequences on her health are going to be huge. Some people in the systems like education and health care just don't seem to get it. Yes, Sam's needs cost more than for the average kid, and yes, it costs dollars now, but if it is not done the costs are going to be a lot more for the system to pick up. She is really an amazing little gal with lots of talent, talent that she could use to give back to society, if she is given a chance.*

There may be some who wonder why I would include a child with diabetes in my study. Up until several years ago, I would have asked this same question. As I have continued to learn more about the philosophy of palliative care, I have come to realize the scope and breadth of need for these services. Sam's diabetes is unstable and is an ongoing

challenge to manage her blood sugars. The result of poorly managed blood glucose levels in a young child can be the early onset of cardiovascular diseases, which are manifested through renal insufficiency, vision loss, neurological complications, and of course a host of other cardiac-insufficiency disorders. Together and individually, these can significantly shorten a child's life expectancy and also lead to increasing costs to the health care system, which are only just beginning to be felt. Jessica is absolutely correct when she states, "*Sam's life expectancy is directly related to how effective they and the health care system are in preventing complications, but once they occur there is no fix.*"

#### *Angie*

Angie is a mother of three children; Steve, aged 17 years, Jenny, aged 15 years, and Tamara, aged 8 years. After completing high school, Angie married and enrolled in a secretarial training program working full-time prior to the birth of Steve. Her husband is a tradesman working in construction and, over the years, has had periodic layoffs due to shortages in jobs. This has meant that they have not been able to enroll and pay the premiums in any supplemental health insurance programs. Steve's birth and prenatal period was described by Angie as uneventful or normal. However, Angie felt right from the time she brought him home that something was wrong; she called it "*mother's intuition*". When I probed her about this feeling or intuition, she was not able to describe or pick out anything specific it was just a feeling that she had. I probed about whether she brought this feeling to her physician or public health nurses involved in the post-partum period. She responded with a "*no*", and explained that because she was a first-time mom, they would just "*all think I was nuts*".

Around 6 months of age, Steve had his first of what would become many seizures. The medical team couldn't find any pathology to explain his seizure and felt that it might be just a random event that occurs with some infants. Steve continued to suffer seizures that became increasingly frequent, and with each event there was a subsequent trip to the Emergency Room (ER); finally, the diagnosis of severe myoclonic epilepsy also known as *Drabat's Syndrome* was confirmed. It is a very rare, genetic condition that results from a mutation on one of the sodium channel genes. This condition seriously impairs a child's intellectual development, and, in addition, the seizures will continue resulting in a very high incidence of early death before 16 years of age. The diagnosis for Angie was both a relief and a "*punch in the gut*":

*I remember feeling that at last people know there is really something wrong with Steve, but I felt like I was going to be physically sick at the same time. I remember thinking if only I had said something sooner then maybe it wouldn't be so bad. My husband wouldn't talk about it for weeks and still doesn't like talking about it.*

Because the condition is very rare, the treatment plan was experimental. The focus of his treatment was to try to limit the number of seizures he was having every day. Over time, the family got to know the staff in the ER and pediatric ward very well because Steve was frequently brought back to the hospital due to uncontrollable seizures. Due to the fragile nature of his medical condition, Angie was forced to quit her job and stay home to care for Steve full-time. She assumed the responsibilities of the primary caregiver and the voice for Steve, while her husband became the primary bread-winner-- a role that was at times a source of significant financial instability due to dips in the building market. Angie also reveals that her husband has never been good with hospitals

and medical things and really had a hard time especially early on coming to grips with Steve's diagnosis.

The diagnosis has changed the family, but as Angie repeats many times, "*it's just normal for us now because we don't know any different*". Angie announced that they had two other children after Steve's birth because she always wanted three children. When I inquired about what it was like to have two more children and not know if they would have the same genetic issue, she said that she wasn't as worried as her husband. But she also just needed to take that risk to have "normal" kids. She repeated several times that she just knew that the other two children would be "OK". She did confess that anytime that either of the two other children even had a jerk or twitch, her heart would miss a couple of beats.

The severity of Steve's medical condition and his complex health needs changed Angie's plans to return to work. She had thought that she might be able to work part-time after Steve's birth for the extra income to help pay bills and put a little bit away for special occasions and emergencies. However, that notion of part-time employment evaporated when both she and her husband came to realize how challenging caring for Steve would be. She also interjected throughout the interview that if she even entertained the idea of working part-time, she was not able to find anybody willing and/ or able to look after Steve. She also added an interesting caveat when she stated that there were no caregivers able to take Steve, she also had to know and feel that she could trust this person with his care because his condition was so fragile.

I then inquired about what the term *social policy* or *local health policies* meant to her. She chuckled several times before she answered:

*Social policies, well, I would hope that there would be some support from social policies. Now don't get me wrong, when I say support, I am not asking for money, I am asking for help. Help looking after my child, help getting him the things he needs to enjoy life and help with managing the entire bureaucratic red tape in the system.*

I noticed that Angie kept emphasizing the help needed for Steve. I invited her to expand and tell me more about what she thought about help for her and her family. At this point she stopped and paused for a moment and then looked straight at me and said, *“Quite frankly, Susan, no one has ever, and I repeat never, asked me that question before.”* Her answer surprised me because it seemed an obvious question. She then explained that she spent so much time and energy on making sure that Steve and her other children got what they needed that she herself has never stopped to think much about what she or her husband might need. She went on to say that because money has always been tight, she and her husband have never given any thought to doing something for themselves because movies, dinners, etc. cost too much money. Their limited financial resources have also led to conflicts with programs of respite care because they were not able to “go out” and do the sorts of things that are expected of parents when they received these services. Over the years, her husband has often taken on extra shifts and overtime to ease some of the economic burdens. His extra hours have translated into her often assuming the role as sole parent for all of the 3 children.

She explained that prior to Steve's birth she would describe herself as a very quiet, withdrawn sort of person who would never speak out in public let alone confront anyone. Over the years of caring for Steve, she would now describe herself as a very

assertive and outspoken mom who is constantly trying or fighting to get the help for Steve that he needs. She used the following example to make her point:

*I know that I asked and asked them to have a conference with all the specialists and therapists that worked with Steve because it gets really complicated for me to manage his care. It took a few months to organize, but we finally got it. Some issues came up then, such as the communication between the specialists and what we needed as a family. Finally, someone said that we should look into the Para program. I did not even have a clue what this was. But we were discussing the high cost of medication, and whatever, and the fact that Steve has major problems with mobility and trying to walk. I said boy it would be a real help if there was a program out there to help us with these costs. Well, said somebody, I cannot remember who it was, for the Para program the kids are usually in wheel chairs and with a certain type of spasticity. Because Steve was not totally confined to a wheelchair, he probably would not qualify. Anyway, we were referred to another specialist, and it turned out Steve had the same type of spasticity that is required to get on the Para program. This program covers a hundred percent of all his drugs and because he is incontinent, it covers his pull-ups and wipes.*

*This all happened when he was around 6 or 7 years. Prior to this we covered all of these costs. I know it sure would have been nice if someone had connected us to this program sooner.*

Angie told me a social policy should involve making linkages--to link people to the social programs such as the Para program, program that may never have been brought to her attention without her demanding a team conference. She then stated, “*you know it*

*just would help if someone would connect all the dots for you because you are just too damn drained.”* In addition to being drained physically, she then discusses what financial costs are for them as a family. The financial drain has been significant and she then goes on to describe what this has been like for them:

*The cost of Steve’s drugs were unbelievable, I know there was one drug that he was on that his neurologist actually wrote the drug company to see if they would provide it to us because it was so expensive and it was working for him, his seizures were being relatively well controlled. I think it was over a thousand dollars a month or something. It was not on the Saskatchewan Drug formulary, so insurance would not cover it for us. You know he is on another drug right now from Japan. He has been on it for about five years, and I am just praying they don’t approve it in Canada because Para will not cover it if it is on formulary because it is an incredibly expensive.*

We continued to explore the term of *social policy* and what it means. She again stated that social policies should be in place to help families, such as theirs, from the point of initial diagnosis in order to minimize their stress and also the financial burden. Angie also pointed out, using several poignant examples, that support must also consider and include the voices of those they are supposed to be helping; an example about transition funding illustrates a situation that occurs when a child transcends from child to adult:

*You ask about other supports, and, I guess, I should include respite help, although it has never really been of much assistance. Because Steve is soon going to be 18 years old, we will lose our respite funding through community living division, but*

*they have cut that back already now. We haven't used this service for quite awhile, and home care is no longer allowed in my home because they were really critical of us and Steve. Critical of his behavior and what we as a couple chose to do when we had respite. For example, if we did not go to dinner and a movie, or something like that, then we were not using our time right. If we went out and did yard work or went for groceries, then this was poor use of their services. We were supposed to use this time like we were going out on a date. Well, dates cost money, and we did not have any extra money for that. Besides, maybe we like doing yard work together and getting groceries. Who are they to decide what we are supposed to do? The issues with home care started to get really bad when they pulled out the nurses and gave us LPNs. I can only imagine what it would be like now if we used this service because the LPNs have been replaced with aides.*

*I found other services usually by accident from talking to other parents; another example is the Saskatoon Association for Community Living, they have been great, and they also have a list of people who will provide respite. I have also used this group for advocacy issues, and they have been great. The Community Living Division through Community Resources, formerly known as Social Services, are not that helpful. I don't know if it was intentional, or not, but they make families feel guilty for accessing services through them. It is just some of the questions they ask, and, like, you have to validate why you need a break, and it is almost like you have to make your kid worse than he is in order to get the services. Because if you don't make it sound really bad at home, then it's well you don't really need it.*

*I phoned this mom one day because I heard that her daughter had seizures. I never met the woman before, and I just phoned her out of the blue because I got her phone number, and she told me about the disability tax credit. At first I remember thinking, somebody would have told me if we qualified, so they will probably say no. When I phoned we got on right way. If I hadn't phoned this mom, I would never have found out about this program.*

At this point in the conversation Angie told me she has never cried in public in front of nurses or doctors, she has always gone home and cried because she didn't want people to judge her and think that she was not able to cope. This behavior, she believes in retrospect, may have contributed to her and Steve not being referred for support and services, which is an interesting assumption on her part:

*Well, you know every time the social worker came in and went and talked to another family, I would think, well, she is going to come and talk with me soon; She will come and tell me what is available, and she never ever came. I did not get to see the social worker until I asked to see her. She is the one who told me that she gets the referrals from the nursery when they don't think that families are coping. Or for any of the families who are coming from out of town. Steve was probably about 3 or 4 before I was in contact with a social worker.*

I now approached the question of *palliative care* with Angie, and after relating the pediatric definition to her; she said that she felt comfortable saying that Steve should be receiving this service. No one had ever put in plain words what *pediatric palliative care* was, and she openly admitted that this type of service would be the answer to her problems and was surprised that if such a program existed, why was it not available here

and now. Angie then explained to me that the only time that someone, in retrospect, may have come close to bringing up the issue of palliative care, the situation and context in which it occurred was extremely traumatic:

*I need to tell you again that it did not take me very long, with Steve being in the hospital, before I found that I could be quite confrontational if need be because it was affecting his care. Once in the ER, I was there alone with him, and things were bad like they usually were when we headed for the ER. This doctor just came up to me and said you should think about signing a DNR (Do Not Resuscitate) for your son. I was freaked out by this. I can guess, but I won't. It could be something to do with some people's perceptions on quality of life, and it is better off for someone like Steve to not be alive than to be alive, but I think my family is better for having him. I know that talking about what to do close to the end is probably part of palliative care. In this case, I don't think they were thinking about palliative care. I mean there I was all alone standing outside in the hallway where people were walking back and forth, and there were other patients in wheelchairs, and somebody, I suppose was a Doctor, was asking me if I wanted my kid to die.*

As I mentioned previously, Steve is a 17-year-old adolescent, so I now approached the subject of what the teen years were like for Steve, herself and the family. She laughed and informed me that, could I believe it, Steve has a girlfriend now. My response was a simple, "well yes, he is old enough", and Angie then explained that his girlfriend was also a special needs child. The school has contacted Angie on at least two occasions over the school term regarding this relationship. Steve, in their opinion, has been caught by the teachers and aids touching his girlfriend in appropriate places. I then

asked her what they wanted her to do with this information. She shrugged that she had asked the same question, but there was no response other than they wanted her to know what he was doing. Steve has suffered significant brain damage, and, due to the frequency of seizures, he does not have the ability to make purposeful fine motor movements. His neurological limitations make it difficult to visualize how he could make any deliberate actions to touch inappropriately. When I explored this thought with Angie, she admitted being both surprised and a little embarrassed by these calls from the teacher:

*I mean, what I was supposed to say to do after a call like that. In the past couple of years, I have asked his dad to do more of his personal care, because he is trying to touch himself, and he is also having erections. I just feel a little uncomfortable about the situation. I mean how you are supposed to talk to Steve about the birds and the bees.*

I then asked Angie if she had actualized Steve as a sexual being. She really had to stop and think about her response. She said, *“I guess I really didn’t, but on the other hand why wouldn’t he be. Touching or at least trying to touch his girlfriend then may not be such a bad thing”*. I asked her, is sexuality a bad thing? Again, there was a giggle, and she looked up and said, *“I guess that makes Steve a normal human being. The only difference is he has not learned to be discrete, I guess, or at least he needs to be a little smarter about where and when.”* I then inquired of her if she knew if Steve had ever had any sex-education; her response was a quick *“no”*. I wonder why, I asked? Angie again just said, *“I guess when kids are mentally or physically challenged or both, they must think that they would not be able to think about it or do it. The more I think about it, it would be*

*useful to have some help with this. I mean it can be tough enough, but I wouldn't really know how to approach it with Steve."*

The interview was coming to an end, so I invited Angie to add anything else she might like to add to this interview. She again paused and asked me if any important government or policy people would ever read this document. I restated that it was my primary intention to get these stories out to those who could and would make a difference. She told me:

*You know, it might be surprising to some that I would never change Steve. God made him, and that is who he is. I know that I am a stronger person because of Steve. My two other kids haven't known Steve to be anybody other than who he is. He is just Steve. They get mad at him. He gets mad at them. They love him. They know exactly when he is having his seizures. They know the breathing sound, even if they are in a different room. We as a family have not been able to enjoy some of the things that other families take for granted. We took our first family vacation two years ago. We had a week at a lake and the weather was cool and rainy, but we had a great time. Steve had a seizure the first night and fell out of bed and broke his shoulder, but after a trip to the ER we were back at the lake.*

*I would really, really like to tell every one that the system has to be more understanding of families, respect where families are coming from, and respect what we say we need. We want to be a family just like everybody else. We love our kids, and we want them to become whatever they can and yes Steve will never be a brain surgeon, but no one ever guessed that he would be alive today. He has outlived everyone's timelines and you know his seizures are starting to let up and*

*he is now even walking once around the indoor track on his own pushing his walker. No one even thought in the beginning that he would ever walk.*

### *Sanford*

Sanford is a father of four children, married to his wife Pat for 16 years, who due to Randy's medical needs now stays at home. Sanford is a Treaty member and currently enrolled in a graduate program. His wife Pat is not of aboriginal descent but is of English-Irish heritage. There are four children, Robert, 13 years old, Clara and Junior, 10-year-old twins, and Randy who is now 8 years old. Sanford has been employed with the same organization for over 16 years and is now in a senior management position. Sanford describes Randy as an unbelievable character:

*I say that about all our children, but there is a unique spirit and gift that he has got. A huge character, he is larger than life in terms of character, all 28 kilograms of him. He looks like a small child, I mean people would think that he is 3 or 4 years old but he has a huge vocabulary and we always include him in all the conversations.*

Two days prior to Randy's birth, the doctors noticed some irregularities with the baby, and he was delivered by an emergency C-section. This news came as a total shock to Sanford and his wife, and there was little time to think about what it was going to be like for them as parents and for their unborn child. Immediately following his delivery, Randy spent the first two months of his life in the Neonatal Intensive Care Unit (NICU), and it was during this period of time that the impact of having a child with such acute medical needs was beginning to be realized.

During his stay in the NICU a diagnosis of Diamond Blackfan Anemia was confirmed; a rare genetic condition where the child is born with no precursors to create red blood cells, and to survive these children must receive blood transfusions every three to four weeks. In addition, this type of diagnosis means also that there are numerous other anomalies, in Randy's case, he is legally blind in both eyes and has only one functioning kidney. In addition, Randy also has defects in his central nervous system which cause paraplegia and a hydrocephalus. At Toronto Sick Kids' Hospital, doctors informed the family that there are levels or gradients of severity with this genetic condition and that Randy would be in the 95<sup>th</sup> percentile in terms of complexity or severity of his condition. This genetic condition is described as life-limiting, and doctors initially estimated his life expectancy to be around 15 to 18 years, but due to the severity of his syndromes that timeline was considered to be a very optimistic assessment.

Randy's diagnosis made what Sanford describes as a "huge" impact on their family, and he says it has been tough, but having Randy has also had a very positive effect as well. He explains that his wife made a great number of sacrifices both personally and professionally to stay home with Randy, and, while they have been life-altering, they have also been very positive for his family. He goes on to explain that sometimes it is not just a disease that changes a family, but sometimes it is having two or three children, a 10-year window, and suddenly another child, a scenario that he believes can also create tremendous stress on marriages:

*There have been tension points in our relationship, but I think there would be in any relationship, My wife, Pat, spends all day, every day, she spends 24 hours a day with him; she is with him around the clock. I work very long hours, typically*

*seven in the morning until seven at night—that is a typical day. This makes it hard to connect, and I have gotten better. I think if you were talking with my wife, she would say that I am not perfect, but I am a heck of a lot better in terms of recognizing the intensity in my work. I know that I meet many people every day, interesting people and all sorts of interesting things, whereas Pat takes care of Randy's needs. It is valuable work, but it is very monotonous and thankless sometimes. So I try to make sure that I provide breaks for my wife and make sure that we go out and do things. We go on short dates, but we go on dates. I recognize as well that I need to take responsibility for Randy and let Pat go with her friends. She had a really tight group of other moms that have special needs kids. They socialize and go out on Saturday nights once a month.*

There are three other older siblings in the family, who also have been affected by Randy's medically fragile condition. Up until very recently, Sanford felt that the greatest impact on his other children was the fact that they worry a lot about Randy. This is made more acute by the number of hospital admissions that he has every year due to his low immune status and ongoing problems with his VP shunt blocking:

*My two sons are Randy's protector and would do anything for him and my 10-year-old daughter is the nurturing mother figure at times but also a little more competitive. You will hear her say sometimes that Randy gets all of the attention. There is an edge to it where you can tell that maybe our middle daughter sometimes feels a little marginalized due to the attention the Randy gets.*

There is another issue that has very recently surfaced for both him and his wife that will have another direct influence on their three other children. He prefaces this issue

by restating that Randy's condition is a genetic anomaly, and while he and his wife believe that there is no person to blame for Randy's condition, there is no escaping the reality that it is genetically transmitted. While they have been encouraged over the years to have genetic testing, they have both resisted because, in their opinion, it does nothing to change the current reality, "*Randy is Randy, and he is who he is supposed to be.*" His philosophical orientation he believes is part of accepting their child and not looking for someone or something to blame. Recently, doctors at Sick Kids' Hospital in Toronto have again raised the issue of genetic testing, which they are now both considering. In consultation, a new specialist introduced a new element in the discourse that neither had up to this point thought much about. He mentioned that while their other three children are still young, their childbearing years are fast approaching, and they, as individuals, have both the need and right to know whether they are carriers of this specific genotype and what then what would the implications for them as future parents.

Sanford points out that this recent conversation caught both he and his wife totally off guard; never had they given any thought up to this point about this disorder in relation to their other children and their child-rearing. Continuing along on this topic, he further disclosed that the specialist, during this visit, had also informed them that due to the types and amounts of medications Randy was currently taking, these drugs in combination would precipitate the early onset of puberty. Stanford revealed that no one had ever even entertained the notion that Randy would survive to reach puberty or become a sexual being. So much energy has been expended just trying to sustain his life and trying to keeping him healthy, that making these normal developmental milestones had never really been actualized.

Interviewing Sanford allowed me a unique opportunity to garner some additional insights and understandings of the lived experience from both a man's and also a First Nations' perspective. I inquired of him as to whether he would like to comment on how his treaty and/or social status has impacted social policies either negatively or positively with regard specifically to Randy's care:

*Because we are First Nations and Randy is a First Nations treaty citizen, we enjoy the sometimes limited but benefits of that status. For example being a First Nations family, if one entity will not pay for something, then we go to the other entity and get coverage. So in eight years, we have never hit a roadblock of something that has not been covered or that we not able to cover it ourselves. The way First Nations health works is they say you need to go to your provincial health or private health carrier first and if there is anything residual that needs to be covered then you go to First Nations health. I resist this and go directly to First Nations health because I think that is a disappearing right, and I view it as a right, an extension of the medicine chest from our treaties.*

*You may not know that there are certain elements of Saskatchewan. Health programming that are not available to treaty First Nations citizens on reserves. One example is the Para program for paraplegic children. It may sound trivial something like wipes are covered under the Para program, but not under First Nations health, but you cannot register in Para if you are First Nations. I have spoken to MLAs and the Minister of Health about this because I think it is a matter of principle not a matter of resources. As a taxpaying citizen of this province, I pay lots to the government each year and expect that that would buy*

*me all the rights of citizenship for me and my family. Because we are treaty First Nations, Randy, a dual citizen of Saskatchewan and Treaty Six, cannot register for the Para program. A bureaucratic and jurisdictional rule that makes no sense, but probably has some financial implication.*

*Going back to your original question, getting First Nations health supports, you have to be a very strong advocate; we have a hot line to our worker in Regina, and a very good relationship with them. We can get whatever we need out of them. You definitely need an advocate, and that is where the system is flawed in that it is not standard that all First Nations peoples nets you certain services. I call from my work phone, and I hate to say it, but I push my status around a bit, and then I get what I want. We talk with other First Nations families with ill children, and they do not get that level of support. They ask me for help, and I have ended up doing a lot of advocating for other people. I have talked with FSIN and told them they need to establish an advocacy program. I daresay that would not have the level of support in terms of services for Randy from First Nations with out strong advocacy.*

Sanford's examples provide a very vivid and detailed account of how social policies have impacted the care and support his family has received. He is very cognizant that his education, employment, and off reserve treaty status have provided him with opportunities to leverage and make policies work. All the while, he is acutely aware that for other First Nations children and their families, policies are not universally applied, resulting in additional emotional and financial burdens for some families living in similar situations with children who have a life-limiting diagnosis. Most recently a case

supporting Stanford's position was published in the Canadian Medical Journal by MacDonald and Attaran (2007), illustrating what they refer to as, 'government paralysis'. A state of affairs that may have contributed to an earlier and most certainly a more difficult death for a young First Nations child, Jordan, living on the Norway House Cree Nation reserve in Manitoba. This case very cogently points out additional barriers to care that many First Nation families encounter who have children diagnosed with life-limiting or life-threatening illnesses. Jordan's case, which can at best be described as an unnecessary and tragic set of circumstances is now referred to as Jordan's principle.

Prior to the start of the interview, I was unaware that Sanford had any previous knowledge and experience in palliative care. So once this was established, we entered into an informative discourse about how he perceived pediatric and adult palliative care services as similar or different. He was very quick to respond with an affirmative that children were not little adults and that they required a different menu of services, similar in some cases but very different in others from adult services. In his own words, he remarked that palliative care was "*about focusing on living, and dying is only a small part of that*". This sentiment is articulated throughout the pediatric palliative care literature in the message that palliative care is not about adding years to one's life, but life to one's years.

Respite, he felt, was a very important component in palliative care and had particular relevance to other children like Randy. He very succinctly pointed out that it was far more complex than just finding "*any old baby sitter*" who would agree to look after your special needs child. Firstly, these specially-trained babysitters, as he suggests, just don't exist out there; secondly, if they do, you have to have the ability to find them

and then get to know and trust them before you can, in good conscience, leave your child in their care:

*I mean how are you to have any respite if you spend all the time worrying, and, if there is a problem, you own it and have to deal with the fall out that comes with it. What we found with respite, was that it was funded through social services and that you had “X” number of dollars you could consume a month and you could go out and buy services... But how do you find someone qualified to look after your child? We are very particular about our care and not that other parents aren’t, but even in the hospital we catheterize Randy because we know the routine, we want to make sure that it is always a sterile technique. The service was valuable, but we were not able to secure someone with the level of care to take care of Randy.*

*I think respite is about letting a family be a family. So, it is not always about getting a qualified babysitter. It is about taking a break, and sometimes that break can even include Randy. We know some single moms with spina bifida (kids) and my goodness their hands are full. We have even taken another child in to give the mom some respite. We are lucky to be a team in the marriage to take care of Randy’s needs, but if you were alone doing that I can not even imagine.*

I queried Sanford to reflect and identify what he believed to be some of the biggest barriers or challenges faced in the management of Randy’s care. This would of course include polices, some of which he had previously described. He stopped and paused for a moment before he answered:

*I have come to an easy answer to that. It is people that think that it is a burden to*

*raise a special needs child, and that is the most difficult thing to deal with. I have an anecdote here, someone I hadn't seen in a while said 'how is your son?' I said he is fine. He replied, 'he is fine!' and I said yes, he is. He questioned me again and I said, he is great, he is healthy, and he is fine. He said, 'oh, my goodness, I am happy to hear that I thought he had a lifelong illness.' So my saying, he is fine, he assumed that he didn't have anything wrong; it had all disappeared. That is limiting in that we have built a context of hope and achievement, and it is not about what Randy can't do, it is what he can do.*

As the interview was coming to a close, I asked if there were any other messages he wanted to relay. If he could say something to the government and policy-makers, this was what it would be:

*I have really enjoyed talking with you about Randy and palliative care. I doubt very much that many pediatric health care practitioners understand or know that. Maybe they do and they just haven't articulated it, but I do see a willingness to look more at family wellness in the whole child. I would appreciate policy-makers to come to know that health care is holistic; it has as much to do with family and community as it does with available resource dollars and hospital beds. Palliative care in your words, about giving a big hug, needs to be holistic in nature, needs to work inter-agency and allow room for family and community to make decisions and influence what is happening. It may mean going into a realm of care that is probably less scientific and less defined but equally as important, maybe even more so.*

*Randy has unique gifts and that is what he is here to do and to teach our family. We always say he has taught us patience, taught us understanding, taught us that the value of life is not in longevity or years or wealth or potential or anything else. The value of life is in character and spirit and our ability to transmit love and that is what he is all about. He had done a lot for our family but he has also been a real mediating influence and he helps us keep our balance.*

*Nancy*

Nancy is a Registered Nurse and the mother of two children, Micheal, aged 20 years, and Denzel who is now 18 years old. Nancy has been married 24 years to her husband, Jeff, a geologist, and has lived in Northern Saskatchewan all of their married life. Micheal is their first-born child, and her health problems started in the summer between high school and university. She was a very active baseball and soccer player who first started complaining of extreme pain in her leg, which did not respond to the traditional forms of intervention. She was not the type of girl to complain of pain unless it was quite profound. The pain continued and became more severe and, two weeks prior to the commencement of University, she was diagnosed with a giant cell tumor, osteosarcoma of the leg. The period of time from onset of pain to the definitive diagnosis of cancer was a journey that Nancy would later recall as “living hell”. During this time, several doctors inferred that Micheal was acting out with attention-seeking behaviors, and one doctor suggested that it was late, growing pain. Nancy explained that Micheal was extremely fortunate not have broken her leg during this period of time because over 60% of the bone mass in her leg had degenerated as a result of the tumor.

On what was to become there last of many visits to a medical clinic, Nancy stated that on that particular day, *“the gods were smiling down on us that day”*. Without knowing the context, I found the statement a little puzzling since a diagnosis of osteosarcoma could hardly be considered something positive. Up until this point in time, there had not been any X-rays ordered. So on this day, the doctor on call was a young doctor who had just completed his orthopedic residency. He immediately ordered an X-ray, and within two hours they were seen by a specialist and also had a referral to a doctor in Calgary because, initially, the thought was that she had a giant cell tumor, and no one in Saskatchewan specialized in removing that type of tumor. I now understood Nancy’s earlier statement--the diagnosis of a giant cell tumor meant that the tumor was more than likely benign, a diagnosis much more palatable than cancer.

The specialist in Calgary was away, and this meant a wait of several months before Micheal could be seen. This frustrating time was made more so by this doctor’s secretary stating that:

*“This isn’t cancer so you are not a high priority.” I’m going, well what chance is there that this is cancer and was told 5-15%. I’m thinking, these odds, any odds, could mean cancer, and I want her seen now. The secretary at one point told me that I was overreacting. She actually came and apologized directly to Micheal when it was all said and done. Anyway, just spending those two months just totally trying to research what these giant cell tumors were, what else it could be, how it could have occurred, how long it could have been there, was totally draining. Finally, when we got the appointment, they had also scheduled surgery as well. We were told that the surgery would last about three hours and after*

*about an hour and a half they paged me, and I just knew right away it was cancer. The physical pain, I felt in that instant was unbelievable. You want to run but you can't because it's your child. The diagnosis was traumatic for all of us, but especially for Micheal.*

*In addition to the emotional costs to Micheal and us as a family, there were other costs, some financial. For example, it came down to even having to negotiate just to get an MRI. We had to arrange for MRIs outside the province; this meant that we had to get prior approval, and then we were left having to pay for the dye. We have figured that her illness has probably cost us personally over \$20,000.00. I, of course, took an unpaid leave, so I could be with her all the time. My husband's employer was really supportive and let him take extra time. But in the end, I have lost seniority, benefits, and pension. We are lucky to have had two good wages, or I don't know how we would have managed.*

I have heard this same type of story too many times during my career, and hearing it just once is one to many in my opinion. My emotions after hearing Nancy's account caused me to vacillate between feelings of embarrassment at being part of this type of health care system to an anger, which is most probably fuelled by being a mother myself. I continue to pride myself, although at times my convictions are tested, on having a system of health care in Canada that is premised on values of compassion and the worth of each individual; this philosophical commitment is not echoed in the American system and, having lived and worked in Washington D.C., I learned quickly who the haves and have-nots were.

Nancy then said to me, “*Well, you think you have heard it all, Susan, here is something else I bet you haven’t probably heard before*”. I had mentioned previously, Micheal was 18 years old when diagnosed, and, in the Province of Saskatchewan, she was legally still considered a minor, but this is not the case in Alberta where the legal age is 18 years:

*Because we were moving back and forth between provinces, this created an issue due to her age, and it focused primarily on consent. In Alberta, they said she is an adult, and we will only discuss things with her. So Micheal had to actually say each time, I want my parents here in the room discussing everything with me. Several of the team in Calgary really did not support us being in on the consultations and decision making. I mean, this is this young girl, being thrown a life-limiting diagnosis that is changing her life forever, being told she could not have her parents in the room, I mean, really.*

Nancy was absolutely right, I had never heard of this type of situation happening before. Issues of transitioning care from child to adult services are now just beginning to receive some attention in the pediatric palliative care literature. These scenarios are about the challenges faced in this transition and about how difficult it is for everyone involved, including the pediatric teams who have worked with these children in some instances, for the child’s entire lifetime. Less than a decade ago, this concern was never voiced because these children simply were not surviving long enough for transition care to occur. However, this is certainly not the case today, where this issue is becoming a frequent occurrence and one for which the adult world is not prepared. Again, this and other scenarios continue to point out the multiplicity of challenges that these families must face

in the light of severe adversity. If health care professionals, like Nancy, are finding the system difficult to manage, then you can only wonder what it is like for those families who are not so lucky and don't have a family member on the inside. Interestingly, Nancy at this point in the interview, stopped and said to me, "*Susan, you and I both know that had I not been a nurse and a little bit aggressive and bitchy, in my own little way, that we would probably not have Micheal here today. I not only believe this, I know this. What about all those other families, what happens to them and their children*". The old saying that "ignorance is bliss" has its place, but not in these situations:

*I honestly, firmly believe that if I had not been there advocating just every minute, even with her surgery, there would have been far more problems. For example they told me that her second surgery would take 12 hours, and they swore up and down she would have no pain, she would have no pain. This is just another example, and she comes back and she's hallucinating, because she is in so much pain. I'm going, 'she is in pain, do something', and they are suggesting to me that I am overreacting. I'm going, 'no, I am not, she is in pain and this is my daughter'. Well, it turned out that the epidural did not take; it was working on the non-operative side. So, basically, it took me going up to the desk and saying, 'Call the Administrator of the hospital, and I don't want to speak to anybody else - you promised no pain.' So, I'm a bitch, and guess what happened, somebody came down from the pain clinic and assessed her, and they had her on a morphine drip within minutes. How would a regular person have dealt with this problem?*

*Everyone going through this maze needs an advocate. You know you're first a parent and always a parent, and you are suffering in a different way from*

*your child. Then you are forced into being an advocate for your child, and then, of course, you are labeled a Bitch, or you're neurotic or something. I mean what do they expect? I know that Micheal would not be here today if I had not done what I had done.*

While listening to Nancy's story, my thoughts went back in time as I recalled my own personal story, and all the anguish a sick child brings to a parent. Over ten years ago, my youngest daughter was hospitalized with a dangerously low platelet count, a situation that has only two reasons for occurring, one was leukemia, and the second was an autoimmune condition, called Idiopathic Thrombocytopenia, (ITP), with the latter being the better of the two options. As I put these words to paper, I feel a flood of emotions as though this nightmarish event had all just happened over again. I remember in vivid detail the night before her bone marrow aspiration, a test used to confirm the definitive diagnosis. I remember sitting up all night on a hard chair in her hospital room, watching and listening to her breathing and watching her sleep; so absolutely innocent and precious, she lay there deep in sleep totally unaware that her life could be turned upside down tomorrow with the results. I battled with my conscience that whole night: that this whole thing was just a bad dream that this could not possibly happen in my family, that this was real and I tried to imagine what life would be like without her. The night seemed to drag and yet sped by, and I felt at times like I wanted to just put on my coat and run, to where, I don't know, but there was just this overwhelming feeling of just wanting to run.

When the doctor came in early in the morning, I again tried to manipulate him into saying that it likely wasn't going to be cancer. This, of course, did not happen, and he was truthful but blunt. As I think back to that time, it seemed rather harsh, but he kept

saying there was no room to bargain with the two options until we had looked at her bone marrow, and he was right. However, I was willing to do anything just to have someone give me some room for *maybe*.

The morning of her bone marrow, they heavily sedated Chelsey, and she became very aroused and irritable, and she was moved into the observation room. I climbed into bed with her in part just to hold on to her but also to try and calm her down. Electing to get into bed with her did not endear me to some of the staff who stated, “Was this really needed”. I remember just wanting to scream out, as loud as I could, “this was my child, damn it, and I would do whatever it took to protect her”, but instead I just lay and held her with tears streaming down my cheeks. I learned a very valuable lesson that day about what parents need and about who gives us, nurses, the right to judge, especially, since we have never walked a mile in their shoes.

My journey into this hell ended with a diagnosis of ITP and a sense of relief that remains indescribable. Her treatment was successful with no relapses. During her hospitalization, I initially resisted using any of my power and privilege as nursing faculty; however, when situations arose, like several nurses not being able to re-start her IV and her screaming for mommy to help and make them stop, I just acted and, in this case, paged an anesthetist I had worked with years ago in the OR. He came immediately and had the IV restarted in a blink. At this point, I knew in my heart that I literally would have moved mountains to protect my child.

Reflecting back on this personal experience, I was again reminded of the concept of *surviving cancer*. The question that continues to resonate is what does this concept mean both literally and figuratively to those who live with it? Over 20 years ago, I

received my first externally funded grant, as a new faculty member, to investigate “*adolescent survivors of cancer, recollections of past experiences*”. Children, due to the aggressive nature of cancer in childhood, are subjected to arsenals of dangerous toxic chemotherapy drugs and radiation necessary to achieve “the cure”. As well, they endure endless numbers of invasive procedures that are well-known to be a source of immense pain, fear, and anxiety. Should a child survive the treatment phase and make it out of the “tunnel” to return back into the world as “cured”, there is an intriguing and disturbing assumption permeating society that once cured, these children will pick up with their lives and move along as if nothing happened. This is not so, as my study discovered.

All ten survivors’ in that study (Fowler-Kerry, 1989) believed they would develop cancer again during their lifetime. Only one said that he/she would consent to treatment again, and the others said never again would they elect to endure treatment again. While death would be certain with this option, the idea of going to “war” again was just too horrific to consider. With survival rates improving dramatically over the last decade, not only for children with cancer but for those with other life-limiting and life-threatening diagnoses, another milestone emerges that is not well described or discussed in the literature--the surpassing of the projected life expectancy and all that this means for the child and family. Nancy brought this issue to the forefront again by talking about how Micheal has outlived her life expectancy in this way:

*There is great discomfort to talk about the “S” word (sex), but also within this population there is some bad luck to talk about this. And yet they are all living it in some way or other, and, in addition, they as human beings are sexual beings too. Another example, eight years down the road... she continues to have her*

*hormonal levels monitored, then her blood pressure takes off and then discontinues the birth control pills to see if that is contributing to her blood pressure problems. Wow, all of the sudden her body has woken up, and she is having periods. She is told that this is really rare, but she has no one to talk to. Then she is told by her surgeon that perhaps she could even get pregnant, but they didn't know how long the window will last.*

*She also was told that she was not expected to live, and so the leg she was given was only expected to last 10 to 15 years, but it seems now that she will outlive her leg, and they don't know how to fix them. If she was to get pregnant that would cause some additional stress to her leg and shorten its life expectancy. Oh yes, because they don't know how to fix her leg, she has been advised that they might have to amputate if they can't figure out another way of putting in the prosthesis. My point is that it is ongoing. You just don't survive cancer, it's ongoing, and the system doesn't accommodate this. As you get closer to those survival dates, you cannot even begin to describe the flood of emotions, and you just keep wondering what tomorrow's going to be like, like what is tomorrow? My parting words are, from the day your child is diagnosed, you need someone, somebody to say, 'okay now, so here is your next step and this is what you should expect.' And when you tell parents what to expect, then you also have to follow up on that. It is just so mind-boggling and so much pressure on the family.*

### *Alexandra*

Alexandra is the mother of three children, Drew who died at 9 years, Bridget who is now 20, and Mica who is 14 years old. Alex received her degree in Physical Education and taught very briefly until the birth of her first child. Her husband continues to run and operate the family grain farm and livestock operation in rural Saskatchewan. Alex's story is unique from the others because her son is now deceased; I was keenly aware this particular interview might take on some different nuances. Alex was very composed throughout the interview and remarked on several occasions that it had been a long time since she had thought about many of the memories, and she found this opportunity to reflect and talk with me about them very cathartic. She commented that it felt good to talk with someone about Drew because, now that he is dead, no one ever engages her in conversations about him.

Drew, like all of the children in this study, was described as a very special and unique child. He was Alex's first, and she believes that some of her misfortune with him was due to her lack of experience in the birth process, during which she describes significant bleeding and thinking that this was just normal. Drew was obviously in significant distress during labor, and she and her husband remained unaware that there were any problems with their new baby even when he was whisked away right after the birth. Within 24 hours, it was evident that he had been hypoxic at birth, and there were already profound neurological consequences. As the seizures progressed, he was transferred to Saskatoon where the medical team in the NICU immediately put him in a drug-induced coma to relieve some of the stress and swelling to his brain. Alex

commented that he was an eight–pound baby and that every square inch of him looked normal, especially as he slept in the drug induced coma.

The medical team informed this young couple that there was brain damage, the full extent of which remained unknown, but they already had a good idea it was going to be severe, and they were not even sure he would be retrieved alive from the coma. I asked Alex if at any point in this critical phase anyone ever discussed treatment options with her, including a DNR order. She replied quickly that she couldn't remember any conversations of that nature:

*At the time, all you want is your baby to live, I mean you have absolutely no idea, nor do you know all the ramifications of what it's going to be like in the future. No one ever talks to you about that. When I left the hospital, I can remember being terrified because one minute we were in the hospital with him and the next minute we are at home alone. I was even scared that he was going to even starve to death. Because I was nursing, I would see his sucking reflex was not all that good, and so he would nurse for hours. I ended up getting a breast infection, because he did not have a strong sucking reflex. It was so scary, and at the time I had absolutely no idea that he was going to be handicapped or how bad it was going to be.*

*When he was five months old, he started to have really bad seizures all of the time. That was frustrating because when I took him to the doctor, the first thing they said was that kids do that. They set up a referral, but that was going to take a couple of months. I couldn't stand it, and I did not know what was happening. So we put him in the car and just drove to Saskatoon and presented*

*ourselves at the ER, I mean we did not know what else to do. He was admitted immediately.*

*During that admission I started to understand that he was not developing normally. We were discharged, and he continued to seizure, and they were getting worse. My husband was really upset that we were discharged home in worse shape than before the admission. We had somebody from Early Childhood Intervention come out to our farm for the first time following this discharge. She was a very nice lady, but I was so tired I couldn't even tell her what I needed. In the end, she was like the public health nurse who told me when I had the breast infection to try getting out more and take some walks. I was so goddamn sick, how was I going to take a walk, and who was going to look after Drew? We had an active farm, so who is going to help?*

Becoming a new mom is a difficult transition, but the additional fatigue, fear, and frustration that this new mom was experiencing is articulated through her narrative. Because they lived in a rural farming community, obtaining services for Drew was made more difficult as the majority of programs are located within the large urban centers. More children followed Drew, which exponentially increases the parents' work load. Alex mentioned that her husband was reluctant to have more children, but she stated that she needed "normal", and more children were necessary for her, a sentiment that was also shared by Angie.

As this family became increasingly more aware of the nature and scope of Drew's disabilities, they tried to make decisions that reflected their concern for his rights as a person and to balance that knowledge by not allowing him to suffer unnecessarily. The

system often didn't support their position, and Alex recalled that in these situations the medical teams made them feel guilty for refusing, for example, the insertion of a gastroscopy tube to feed him. She elaborated further that the staff kept saying that Drew has the right to be hydrated:

*We understood that right but on the other hand, why were we keeping him healthy, for what, so he can live longer, have more surgeries and pain and so on. I mean at what point do you just sort of say 'enough is enough' for someone. If he had had cancer, I mean if there was hope that he would get well, or that he would have a reasonable quality of life that would have been a different story. But if the plan was just to make him live longer so you can feel you've done everything; it doesn't seem right because sometimes there is some kind of plan or something in place, and we just seem to ignore it.*

I asked if at any time they had ever asked for, or received any respite. Alex replied *no*, but as Drew got older, he became very involved in the development of a group home within their community. Prior to the establishment of this facility, respite consisted of putting him in the small rural hospital where the staff would leave him, for long periods of time, flat on his back, and he would come home usually with some type of respiratory problems, significant loss of weight and even bed sores.

By the age of seven, the local school bus became equipped with the necessary equipment to transport a wheelchair, and he was able with special care aids to attend school:

*Drew was 24-hour care, so when he was gone for a few hours, I could sit down and have a cup of tea or a few minutes to myself, and I was a better mom when he*

*came home. Respite became a kind of mixed bag, the school experience was generally good, but leaving him in the hospital, or eventually the group home, always came at a physical cost, because he would come home so sick. They really did not know how to manage Drew because he was a heavy patient to look after. It got to the point that they would turn us down for respite because he was such a heavy patient.*

There is some irony embedded within this situation--if the system found him too heavy to care for, how did or could they expect this family to manage 24-7? Drew, like many other children suffering from a severe neurological disorder, experienced a steady and progressive deterioration of muscle tone, which made his care increasingly more complex over time. This progressive deterioration also meant that the family was forced to become more isolated. Alex talked about not being able to attend church at a certain point because she and her husband could no longer carry him up the many flights of stairs, and the church could not afford to build a ramp to help this family. It is intriguing to me to try to deconstruct how a medical system and a community could not see the impact and the immense struggles this family was being expected to endure. At no time during the interview did Alex ever suggest that they regretted having had Drew; their only regret as parents was that they were not better informed and able to protect their child from a system of care that they came to perceive as not considering his needs nor his family's.

Alex, like the other moms in this study, voluntarily removed herself from the workforce in order to provide the necessary care to her child. I continue to marvel at the commitment and sacrifices these moms have made, all the while stating how much their

special child has meant to them, and, in no way, was there any discussion that the state owed them anything but the essential services to maintain their child's health. They gave up their future livelihoods and careers to make their child's life more complete, made choices that had various levels of financial impact, and some, like Alex, had fewer financial resources to buffer this effect. Alex does not hesitate to say that while her other children dearly loved their brother, they paid a heavy price as children with limited resources due, unable to become involved in both school and after-school activities, such as hockey, Brownies, or Boy Scouts. All siblings had to do a lot of extra work around the farm because of Alex's extensive care commitments to Drew. As she continued to talk, I began to wonder just who is this person, a mother, a wife, a sister, daughter, an individual who just wants the right to live, laugh and love. However, due to very unfortunate circumstances, the life she imagined, living on a small farm and raising a family, changed forever. She re-told her story so calmly, and at times she told humorous thoughts in a life that was filled with what I would have perceived as unimaginable stress. Just as the birth of Drew made an indelible imprint on Alex and her family, so has his death. She misses Drew as do all the members of her family, and there is no regret, only sadness and at times the hint of relief--not for her, but for Drew in that he is no longer suffering:

*No matter what the tragedy is or what the issues are for you, you have to look outside and keep going. Life does not stop, but there are times that it feels like it is stopping for you. If it wasn't for my other kids, I don't know what it would have been like for me. When Drew died, my youngest son was only months old. There have always been little kids around, which has been good. But I mean life is good, look how beautiful it is out today.*

## *Findings*

The narratives in this chapter document that each family unit experienced the separate and interactive effects of existent and non-existent social policies while simultaneously dealing with their child's unique and complex health challenges. To unravel the stories within the stories, which were embedded in the rich contextual data, I utilized an inductive process that involved reviewing the written transcripts and re-listening to the taped interviews. Using each participant as the centre of my analysis and critical theory as the overarching framework, the interviews were then reduced to thematic categories, which facilitated the discovery of recurrent categories in the data within and between individuals. Critical to the development and emergence of categories was the ongoing process of coding, or giving meaning to all units of information while making sure that the specificity of each participant's experience was not lost. As new datum emerged, codes were refined or refocused and then aggregated and clustered. These processes revealed many associations that were not previously evident to me.

Critical theory formed the overarching framework for the data analysis and provided the optic with which to expose the reality of policies, the tensions in their ideological underpinnings, and, also, the lived experience. An action I would describe as the most important task inherent in critical social theory, that of social critique, occurs when restrictive and alienating conditions of the status quo are brought to light, and through giving voice, provide a means to free and emancipate those who have for too long been silenced. The impact of this process became increasingly evident as interviews were re-read and then separated into thematic categories. Through the process of deconstructing the interviews and themes, I found the discourse and tensions in ideology

to be an important first step in securing an agenda for change and reform that will be discussed further in Chapter Five.

Four recurring and significant themes emerged from the individual and collective voices of the participants: *Mother as Caregiver*, *Respite*, *Surviving Past Expectancy*, *Getting on the Same Page*. While each family's experience was unique and personal, I was astonished at how quickly the same issues and themes emerged during each of the interviews. Three themes, *Mother as Caregiver*, *Respite*, and *Getting on the Same Page*, have previously been documented within existing literature, but there are new nuances raised in this discourse that add yet another important perspective that must be considered in proposing new policies directed at minimizing current injustices. The third theme, *Surviving Past Expectancy*, while not entirely new, is becoming more critical as time advances and as the critical mass of these children transitions into adulthood. This is an observable reality that neither health education, nor practice is prepared to manage successfully, and one that will cost both the system and families significant financial and personal grief.

### *1. Mother as Caregiver*

The role of *mother as caregiver* follows logically from the historical position women have assumed as healers. Florence Nightingale herself was quoted as saying, "Every woman is a nurse.", which is profound statement that captures the reality where over 80% of workers in the health care system in North America are women (Rachlis, 2004; Romanow, 2002). Achterberg (1991) describes a thread of consciousness that weaves its way through the centuries connecting one era of women as healers to the next;

“she suggests that this is due to the existence of the feminine myth epitomized in behaviors, abilities, and belief systems that have traditionally been associated with women. Whether or not this myth has its genesis in culture or biology remains debatable and somewhat irrelevant because it simply is” (p. 21).

For each of the mothers in this study, there was only one option, which was to assume the role of caregiver and follow the historical tradition of women as healers. The subsequent rearrangement of roles and responsibilities within the family unit was regarded simply as a natural extension of simply “being mom”. While the decision to be the caregiver was made willingly, the effect was frequently described as having a profound impact on every dimension of family life: emotional, physical, financial, spiritual impacts supported in the literature (Knafl et al., 1992; Martinson et al., 1999; Sawatzky & Fowler-Kerry, 2003; Steele, 2002; Vickers, 2006). The full extent of these positions was never outrightly comprehended, and now, having lived the reality, they all explain that the effect was more profound than ever imagined, and they now begin to interject a little about how this has also personally impacted them. The majority of discourse on this topic was primarily focused on the collective impact rather than on how it has impacted them as women and individuals.

There is now a considerable literature replete with documentation demonstrating that the long-term care for children with life-limiting and life-threatening illnesses rests on a vast network of informal female caregivers, described often as the growing invisible army of unpaid workers (Baine & Rosenbaum, 1995; Baldwin & Carlisle, 1994; Brannan, 2001; Buebond-Langner, 1996; Davis, 1996; Enskar et al., 1997; King, King, & Rosenbaum, 1996; Kirschbaum, & Knafl, 1996; Steele, 2002; Votroubek & Townsend,

1997; Vickers, 2006) . Achterberg (1990) describes them as “wounded healers” (p.3). I repeat that at no point did any of these mothers voice any qualms about assuming the role of caregiver. It was seen as natural, the right thing to do, done out of love and commitment for their children. Their regrets are revealed through the following discussions and are premised primarily on feeling powerless or actually being powerless.

The choice of keeping their child in the home environment is congruent with the palliative care literature, where the home has been found to offer the greatest psychological benefits to children (O’Dougherty & Brown, 1990; Martinson, Widmer & Portillo, 1999; Sourkes, 1995; Steele, 2002; Wang & Barnard, 2004). The other rationale for maintaining children in homes reflects a major shift within health care financing that had its genesis in health care reform during the 1980s (Martinson, Widmer & Portillo, 1999; Sawatzky & Fowler-Kerry, 2003). From a dollar and cents perspective, home care is a significantly less costly option than acute care (Himmelstein et al., 2004)--less costly for the health care system, but there are significant visible and invisible costs to each family (Dobson & Middleton, 1998). The first noted here was that all mothers in this study either had to quit jobs or go on unpaid leave to provide essential care for their children; unpaid work that has and continues to be overlooked and not factored into any administrative financial accounting, especially that of traditional economic thought, which ignores the realities that people live out everyday. Within each interview, the participants reveal the financial impact and burden that the child’s diagnosis has had on their lives not only from lost income but also due to additional expenses, which they have to assume (Votroubek & Townsend, 1997). For example, Jessica describes how she was forced to drive a half hour each way to her child’s school once a day at lunch to

administer insulin because the health care system was resistant to providing any other alternative until a lawyer assisted with her case. Over the course of several years, there was a significant and added cost for gas, wear and tear on the car, and also of her time; she commented:

*Even if I had wanted to continue working, there was no way I could get from my job, back and forth to her school twice a day, given the distances and time it takes to drive. I mean who would give me a job knowing that I need all this time off”?*

Another issue raised frequently was related to the experience of transitioning into the role of primary caregiver and the acquisition of skills that they did not have. There were numerous references to this new job being intensely difficult. The reference to difficulties was made meaningful as each participant articulated how their individual situations were even more challenging due to the unknown, unavailable, or limited services and supports, and changes to their family’s financial security. Notably, the effects of policies did differ depending upon the *social location* of the participant, as an individual and as a member of a family unit. *Social location* in the context of this study was considered to be more than just social class; it included other dimensions such as gender, age, social networks, race, and ability (Baine et. al., 1995; Brannan, 2001, Corlett & Twycross, 2006). Social location shaped the availability and accessibility of resources for each mother and family unit. This situation was most evident when comparing Sanford to Alex and Angie:

Sanford very succinctly articulated his success, “*straddling two cultures or worlds*” to guarantee that his son received both the necessary equipment and resources. He clearly recognized that from both his First Nations’ heritage and his employment

arrangement, he was afforded a privileged position, which advantaged and enabled him to successfully leverage to meet the needs of his son. He readily admits that being male also inherently gave him power, and people were frequently more willing to pay attention to his concerns. The intrinsic powers resulting from his professional, personal, and economic position equipped him to become an effective advocate not only for his child but other First Nations children. Pal (1997) suggests “the consequences of privilege cannot simply be turned off or on because the various dimensions of one’s social location are not discrete entities, and they intersect transforming into hierarchies of privilege, institutional structures, and discourses that legitimate inequalities” (p. 98). These dimensions are routinely produced in daily life and become part of the common sense knowledge (Dhruvarajan & Vickers, 2002).

For the female participants, navigating through these uncharted and rough waters created a state of affairs where they found themselves at some points disengaging due to a combination of both financial and personal stressors. Fox (1993) put forward “the notion that the mere act of disengagement means that individuals begin to feel disentitled to social goods where entitlement is a core value indelibly woven into the concept of citizenship” (p. 204). Over time, each mother describes moving into and through this state and morphing into yet another new role as advocate for her child. This transition is described as the culmination of growing frustrations and tensions with policies or lack thereof that limited their child’s opportunity to experience a full and meaningful life (Kalbfleisch & Cody, 1995; Sloper, 1998). They called their ascendance “*becoming a bitch*”. Their term and justification was described simply, “*You do what you do because it’s your kid.*” When probed further, each felt that yes “bitch” was also synonymous with

*advocate*. This newly acquired role and skill was perceived in this context as acceptable behavior by members of the health care system. Moving into the role as “bitch”, or advocate, occurred over time as the result of fruitless negotiations over services, rights, and information. This constant and relentless search for the acquisition of services and information was deemed by all to be extremely time-consuming and unnecessary, as well as emotionally and financially draining.

## 2. *Respite & Coping*

Developments in pharmaceutical and health technologies have created the opportunity for increasing numbers of children with complex health needs to be cared for at home and to have significant increases in their life expectancy. However, as previously corroborated, social supports and services for families, who are giving care to these children, have not kept stride with these advancements. Respite care, one form of social support, first identified in the literature as an unmet need over 20 years ago, continues to be problematic in this current study (Canadian Association of Community Care (CACC), 1995; Kirk, 1998; Knoll & Bedford, 1989).

The term *respite* is complex and is understood to be the relief from, the reduction of, the prevention of, or the maintenance of homeostasis (Labonte, 1993; Rachlis, 2004); this term is synonymous with *break*, *breather*, *lull*, *relief*, and *reprieve* to mention just a few. The psychological experience felt from stress and the relief resulting from respite is internally felt and uniquely personal for each caregiver. To date, there exists no certainty or exactness in the measurement of any psychological event, and it remains unrealistic to

assume that respite will totally obliterate stress but it will rather alleviate some aspects of it.

There are two types of respite services, each offering a particular level of relief to the caregiver and family. The first is in-home respite, which allows the child to remain in their home environment. The second type involves moving the child to a facility outside the home for defined periods of time. The optimum service impact for each of these services depends largely on multiple influences and circumstances, and it is important to recognize the needs of both child and family; for example, a conversation I was part of in the United Kingdom included several adolescent boys with Muscular Dystrophy who voiced their need to “get away” from home, so they could do things like talk dirty, drink beer, and eat pizza; things they wanted and needed to do with a peer group but could not initiate on their own due to their physical disabilities. This is another crucial element of respite that is not yet identified within current literature, a type of *reverse respite*, and it certainly has consonance for many teens and young adults. Nevertheless, whatever form respite takes, what is known and well-established throughout the literature is that if respite is used too little or too late in the caregiving experience, *caregiver burden* will not be reduced creating the situation where the caregiver *burns out* or suffers negative health outcomes (Zarit, et al., 1998: Zarit et al., 1999).

The concept of respite has been referred to as a messy business to research (Torjman, 2003) due to its complexity and further complicated by its personal and social context. This limitation has not deterred researchers from a variety of disciplines to examine and uncover issues associated with respite, including dilemmas of in-home respite, exploration of multagency workings, quality in services, and appropriateness of

hospices and care homes. The Canadian Association for Community Care (CACC) conducted a three-part study on respite care for families of children with special needs (2002). The results from this study were integrated into a comprehensive report calling for a complex system of respite services to meet the wide and diverse needs of families who they described as “heavily burdened” with time constraints and financial challenges:

Parents and professionals found that respite services are an absolutely essential aspect of home care for many children with special needs and their families. In particular, respite is a quality-of-life issue in families where children have medically fragile, complex, technology dependent conditions- necessary for the physical, emotional, and social health of all family members and the family as a whole. A coordinated, comprehensive program of services for children with special needs - in which respite is an integral part, - contributes to the health of the community. It does so, by assuring the families who have children with special needs at home are contributing members of their communities, and are able to prepare citizens of the future who are as capable as they can be. (CACC, 2002, p. 5)

Reducing the impact of stress is a normal goal and expectation for every human engaged in any type of work both inside and outside the home. All participants in this study accepted the role of caregiver and the myriad of responsibilities associated with caring for their children. This job required them to be on call, 24 hours a day, seven days a week, which is a commitment to care that in health care institutions would be covered by two shifts per day and 14 per week; in other words, 14 health care professionals employed at an hourly salary could provide the same care that each mother assumed

unpaid over just a one-week period. Certainly, it is not difficult to understand that over many weeks, months, and years with few opportunities for respite, all parents will inevitably experience variable degrees of *burnout* and personal health challenges (Blaine, Rosenbaum, & King, 1995; Baldwin & Carlisle, 1994; Davis, 1996; Kirschbaum & Knafelz, 1996; Sawatzky & Fowler-Kerry, 2003; Steele, 2002; Vickers, 2006). The concept of *burnout* is linked to one's ability to cope (Carver & Scheier, 1994; Carver et al., 1989; Folkman & Lazarus, 1985; Lazarus & Folkman, 1984; Lazarus, 1991).

The ability to cope varies greatly among people, and it is simply not possible to catalogue all possible responses (Folkman & Lazarus, 1985). From a review of the transcripts, each parent met his/her own situation with his/her particular coping history, meanings, and resources. Embedded within each of the stories are reflections about how policies in Saskatchewan affected or impacted their family's ability to cope with the demands of daily living and with a child who has a life-limiting or life-threatening diagnosis. Sanford explained that his son's diagnosis created the impetus for him to go back and explore his spirituality to rekindle his ability to cope:

*From my First Nation's community of elders, they do not beat around the bush when it comes to imparting teachings, and it is up to me to accept them or integrate them into my being. The elders say that my son is a gift, he is in charge of his life, he will define this definition and its duration, and there is even a little bit of caution not to stand in the way or interfere too much. So, from my First Nations teachings what I have come to know and understand is what is in our domain to affect change with and what is not. So, I have come to find peace in these words.*

Each participant spoke about their need for respite to ‘recharge their batteries’, so they could be better parents. This does not appear to be an unreasonable request but within the ethos of individualism intrinsic to Western society. There is a tendency to view problems, such as the need for respite, as personal dilemmas rather than public issues, a sentiment that was certainly reflected in the lack of services available to these families and also by the participants themselves, who very clearly articulated that this was *their* child and *his* or *her* needs were *their* responsibility, not the states. Jessica clearly enunciated, “*respect me and trust me when I say, I need some help. I am not trying to pass the buck; I just really need some help*”. Sadly as each story unfolded, there were many accounts, including acute crisis situations, where these families were left to problem solve and cope on their own and where they too often acknowledged not having the necessary knowledge, skill, and judgment to handle safely; Tess explains, “*I just want to be able to help my son live what life he has been given to the max. I need to be able to help him do that, that is my responsibility to him as his mom*”. Alex describes her situation this way:

*If it was just cerebral palsy, it would have been different, but it just kept getting worse and worse and worse. If it had just stayed the same, I mean we could handle his handicap, it was just the progression that was so relentless, just so... I guess it would have been nicer if the person that came out had done some exercises once in a while rather than just talking to me. ‘Cause you know when you’re tired, like, you think, please just help me.*

Fixed within each story are acknowledgments by each participant that at certain points in the illness trajectory, the need for respite and new ways of coping was most

acute ((Bandura, 1977; Carver & Scheier, 1994; Folkman & Lazarus, 1985; Lazarus & Folkman, 1984; Lazarus, 1991). The initial diagnosis was the first experience that was described as “*overwhelming and surreal*”. For Nancy, the moment felt like an “*out of body experience*” and then a “*feeling of being slowly suffocated*”. Alex explained that it would have been nice if someone had just stayed with them at this moment “*but I know that the doctors and nurses are always so busy*”.

Another critical moment was the child’s discharge home--a transition that only Jessica felt prepared to handle. This feeling of fear was most acute for participants living outside the city in rural and northern areas. Alex’s story is perhaps the poignant here. She was living on a farm in rural Saskatchewan; the farm was the sole source of income for her and her family. The closest neighbor was several kilometers away and the closest hospital one and half hours away. After returning home with Drew, newly diagnosed with profound neurological defects, she believes that, in retrospect, she was experiencing some post-partum depression that was made worse due an infection in both breasts. She was visited in the home by someone who she describes as a “*well intentioned*” nurse shortly following discharge who recommended that to help her feel better, she should “*do something special for herself everyday, like take a walk*”. Alex recalls that she was “*looking a mess and feeling like she was going to be sick due to lack of sleep*” and *she could not see I needed some help, maybe just let me sleep for an hour or two and then have a shower?*” Alex knew intuitively what she needed and was keenly aware that she was not in a position to ask her husband, family members or neighbors to provide her with some much needed respite, either because they didn’t have the skill sets to manage

Drew, or because they were all working on the farms; it was early fall and everyone was harvesting.

Jessica's experience was outside the norm. While she did describe the scenario as unsettling, the experience was not a negative event in fact it served as a very positive episode. She recounted the support received from their specialist, who instructed them to phone him every morning after they tested their son's blood sugars. Having those 4–5 minutes every morning to re-affirm that they had calculated the correct dosages of insulin significantly reduced their stress, and she believes that this early experience was empowering for them as a family, *“We started this journey knowing that we could handle this situation, just knowing that there would be 24-hour help on the phone was so reassuring, and I know it kept us out of the ER”*.

Coping with the cards that were dealt, was a challenge that each family accepted and managed within their unique contexts. Angie expressed, *“you just have to cope; I mean what else are you going to do, it's not like you can take your kid back and return them for something better”*. *“He was a gift and he brought us to better understand compassion”*. Sanford described Randy as, *“unbelievable little character, he's larger than life, he is just a wonderful character... I can not imagine life without him; he continues to teach us all so much about life”*. Expressions of love and caring translated in many ways, most significantly through a sense of duty to care for their children, and not have the state do it. Respite was not viewed as a means to release themselves of their commitment but as much needed relief, so they could actualize themselves more in the role of parent than primary caregiver.

Several participants confided that due to their social location, they perceived that they were more “privileged” as the result of jobs or personal connections, and that these privileges advantaged them. A question that remains and requires further investigation is, how does privilege or the perception of it, impact one’s ability to cope with a child with a life-limiting diagnosis? In a society where disparities in health and income are increasing, what is the role of privilege? These questions require further attention but exceed the scope of this study.

Within our democratic system, engagement in issues within the public realm is essential. However, for the majority of these parents, this level of engagement was difficult or out of the question due primarily to the excessive expenditures of energy and time required to care for a child at home 24 hours a day, 7 days a week. Alex shared that she became active in lobbying for a group home at one point when Drew was older. She openly admits that she was overstretched, but it simply “*got to a point that I no longer could sit back, I had to get involved*”. The facility did open, but the irony of the situation was that she had considerable problems placing her son in this facility because his care needs were so extensive that the staff did not feel comfortable managing his care. When she did manage to secure some respite time, he would:

*Come home in worse shape, usually a respiratory infection, he always lost weight. He didn't have a whole lot of weight to lose. So respite was kind of a mixed bag. In one way you needed it, but on the other hand you were worrying about what it was gonna be like when he came home.*

Angie’s story reveals another concern regarding home care as respite:

*Home care is not allowed in my house. They were really critical of us and what we chose to do when we had respite. Well, if we didn't go out to dinner and a movie or something then that was wrong because that's what we were supposed to be doing. If we went and like did groceries and ...or even if we chose to stay at home and get things done while they could watch our son... well, that wasn't acceptable. We didn't have a lot of extra cash to go out on dates. And, or, yes, because we have two other kids, they wouldn't watch them, so that would also mean we would have to hire another babysitter.*

Issues of respite and the inherent dilemmas associated with this service continue in spite of increased government attention (Arskey et al., 2004a; CACC, 2002; Children and Youth Homecare Network (CYHN), 2002; Decima Research Inc, 2002; Government of Canada, 2002; Health Canada, 2003; Human Resources Development Canada (HRDC), 2003; Keefe, Carriere & Legare, 2004). Each story communicates how each parent has and, in all but one case, continues to struggle with limited or non-existent respite services. Angie sums up her feelings about home care by saying, *"I've decided life is like a wave, you've just gotta learn how to stay on top of it and ride it. Don't depend on anyone or anything to help you balance on that board. You are on your own"*.

### *3. Surviving Past Expectancy*

Death rates in childhood are declining due in large part to successful primary care prevention programs and major advances in medical science; these are sources of hope that newer technologies, drugs, and interventions will avert death even longer. These changes have contributed significantly to the long-term survival of a new cohort of

children diagnosed with life-limiting and life-threatening conditions who in a previous era would have died much earlier. Many in this cohort are prone to repeated exacerbations and remissions making prognostication extremely challenging along with determining illness trajectories including when a child maybe in the end-stages of life.

Through each of their narratives, the parent paints a picture of being in a state of existential limbo resulting from a distortion in their role as parent and in their *time world*, where normal parenthood involves concentrating on and investing in the present as a way of preparing for the future (Hayout & Krulik, 1999; Sources, 1996). Parents in this study were certainly immersed and absorbed in the present not often speaking about a future that includes their child. Tess talks about how she contextualizes the future and its impact in today's reality:

*Brett's diagnosis has us all thinking about what is important in the right now. We know that his life is very time limited, but everyday he lives we know that we are a day closer to a potential cure. That's what keeps us going sometimes. And yet I know that he will not make me a grandmother, and we probably won't have all those other moments as well, like graduation and weddings. It's hard but you just focus on today and all the good things.*

Alex explains:

*When we first went home, I didn't know there was gonna be any limitations. Then after about 5 months, it was at that time, I started to understand, you know, he wasn't developing the way he should. I know I was the first to accept the fact that he was never going to be normal, but the docs never really gave me a straight answer about what to expect.*

As Alex's narrative unfolds, she clarifies the severity of Drew's diagnosis pointing out that with increasing age, Drew experienced increasing numbers of complications requiring more invasive medical procedures. Both she and her husband had arrived at a consensus with regards to how far they would be willing to go to extend their son's life. Alex explained that when she tried to talk with the medical staff about her wishes, she felt they were not listening or they were not satisfied with her decisions regarding Drew's care, a situation not uncommon from a review of pediatric palliative care literature:

*I can remember this doctor, I can remember her not being pleased with us, like, thinking we were not doing everything we could for him. We were made to feel bad about that. I guess I'd feel the same, like, if a kid had cancer or something. I mean if there's hope that this kid would get well or that he would have, like, a reasonable quality of life that would have been a different story. But if you're just gonna make him live longer so you can feel you've done everything or something, it doesn't seem right because, I don't know. Why do you want to keep doing surgery, like put a gastroscopy tube in him? Oh they said he has the right to be hydrated, and I understand that, yes, he did. But on the other hand if you just want to keep him going, for what, so you can make him live longer, so he can have more surgeries, and so, like... you know what I mean. At what point do you just sort of say, 'enough is enough for this kid?' Sometimes there is some kind of a plan or something, but we just ignore it or, I don't know.*

Attempting to establish boundaries to garner further perspective, Sanford recounts two different conversations demonstrating the inherent real life difficulties with

prognostication. Lack of clarity, made worse by contrasting opinions, creates further blurring and confusion for parents trying to make sense of their reality:

*Should Randy's condition worsen we kept asking what we should expect from the medical staff. We asked if this happened and if that what would you do? And the answer to some degree was everything we could medically do to keep him alive, and maybe they were baiting us with the question, unless you've got a different perspective, and we said, yes we do. If the end to life looks natural, and we would want to be part of evaluating that, then the response needs to also be natural.*

In another situation a hematologist from Sick Kids' provided them with his professional opinion during one visit where there was some discussion of a potential bone marrow transplant option for Randy:

*He is in the 95<sup>th</sup> percentile for the severity of his disease, and we'd give him a five percent chance of survival, take him home, don't go down that road, not now not ever. It's never gonna work; it's never gonna be; he's not a viable candidate for a bone marrow transplant; get it out our minds. That's all the convincing he had to do. He had to do no other convincing because we were already there even if we thought it 50-50, or even a 25 percent risk, we likely wouldn't have done it. Now, we will never do bone marrow, unless he's an adult and makes the decision on his own, it'll never happen, and we're fine with that 'cause it contradicts our beliefs that he was given a life and the conditions that come with that, and we are I think called to do what we can around what is realistic but not to be extraordinary.*

By postponing death, many children today are living into and through adolescence, and, for some, there is more than a reasonable chance of transition into

adulthood, which brings with them a diagnosis with its genesis in pediatrics. Adult health care providers have seldom in the past had opportunities to manage care for this population (Association for Children’s Palliative Care, 2007), and may not be prepared for, what I would characterize as, a potential demographic tsunami. In addition, pediatric health care professionals remain ill equipped to deal with “normal” growth and development issues as these children progress from childhood into adolescence—a notable example revealed through this study is the issue of sexuality (Hingsberger, 1999; Bissada et al., 2000; MacEdwards, 2001).

#### 4. *Getting Everyone on the Same Page*

Each of the four themes identified in this study captures something salient about the data in relation to the research question. This fourth theme surfaces in each of the narratives in the context of unmet needs. Interestingly, Nancy, Angie, Alex, Jessica and Sanford all expressed in these exact words the need for “*getting everyone on the same page*”, so it seems fitting that I use their words to label this theme.

Given the complexity of needs for each of the children in this study, it certainly comes as no surprise that each child would require multiple interventions from a vast array of programs, including health, education, social services, housing, First Nations, and benefits agencies. This equates into a significant number of contacts from different workers, and the challenge would be to coordinate services or find services and thereby minimize the confusion for parents. The “*black hole*” that Alex described finding herself in, due to her son’s needs and the constant challenges she faced, really epitomized the need for these parents to find *security* by “*getting everyone on the same page*”.

The concept of *security* comes in a variety of forms within the context of being a citizen of Canada. Security is most frequently associated with a good education and/or maintaining a job and extends to the presence of a social contract and personal supports to access should a crisis occur. Every Canadian household relies on income for security from a range of sources because government legislation and regulations significantly impact what incomes and expenses people have (Fisher, 2000). Social policy, in the broad context, plays a significant role in the creation or undermining of income security. This becomes contextually relevant when you consider that even income from paid work has a degree of unpredictability and coupled with unpredictable income from other sources, including government programs, can make planning, in general, a complex exercise that becomes even more challenging as a result of unexpected costs related to a health crisis, such as having a child diagnosed of a life-limiting or life-threatening illness. This type of diagnosis has a host of different implications for the older adult than for the young child. Likewise, family history, career stage, work demands, and financial resources define the situation for every parent. For the family with heavy financial responsibilities, losing one parent's income has the potential to bring about an economic disaster that can rival the diagnosis in creating additional distress for the family.

All participants in this study experienced some degree of financial challenge, which created a scenario where the quality of life for each family became dependent on a sole income earner, the husband, and to some extent also determined the success, or difficulty encountered, accessing additional resources and supports. Income security influenced each participant's ability to successfully access other resources, which then impacted their ability to "get everyone on the same page". In addition, I contend that in

this study, income security was often just a thin patina covering a fragile structure of formal and informal supports, an observation that is also described in some detail within published reports (CACC, 2002; CYHC, 2002; Decima Research Inc, 2002; Government of Canada, 2002; Health Canada, 2003; HRDC, 2003; Keefe, Carriere & Legare, 2004).

Sanford's circumstance clearly demonstrates how security comes to be defined more broadly to encompass not only salaried income but also one's ability to become aware and connected with other social supports. He provides a unique look at what it means to be First Nations with a child with special needs:

*I'm a single salary earner in our family; I make good money, no doubt about it. And it allows... I mean if we have an impromptu request to come back to Sick Kids' because there is a new therapy to look at or whatnot, it's no big deal. We will buy the plane tickets, get on a plane, and go, where a lot of families have to turn to fundraising and all sorts of things to make that happen if Saskatchewan Health is not prepared to cover the particular trip or expense of what have you. So non-First Nations families sometimes don't have, you know, one entity won't purchase replacement cartridges for the chelation therapy pump for example, we go to another entity, and they typically will. So in eight years, we have never hit a roadblock yet of something that hasn't been covered or that we weren't able just to cover for ourselves.*

Alex's reality juxtaposed with Sanford's paints another picture about the nature and scope of what security means. Concerning income insecurity, as a result of dependence on grain farming, and the fluctuations therein, as the sole source of income, Alex and her family struggled:

*Money was always an issue, and it didn't make things any easier when I couldn't help out with the farm and all the chores because I was just so busy with Drew. I felt so bad because my husband was literally working all day in the fields and then coming home and trying to help me out. Even if we had the extra cash to buy some help, there really wasn't anybody who could help. Drew was really a lot to manage. But, oh, I have some really good friends. I mean lots of times, we would just have to leave because Drew was so ill or something, and our neighbors would come right over to watch our kids. We have really good neighbors. Yah, they would come, like at a moment's notice, they would say, just get in the car and go, they would be there. It probably would have been harder to find neighbors like this in the city.*

The constant and relenting search for help and support was, as Jessica describes, “*frustrating and at times just humiliating*”; she goes on to make what I describe as a seminal observation regarding supports and resources:

*We couldn't afford the \$1000.00 price tag to send our son to camp, and we told them that. They said that we could apply for a subsidy to go, but in order to get the subsidy to go, you have to give them a copy of your income tax, your last year's income tax form, and you have to write a letter justifying why your family cannot afford to pay to go to camp without a subsidy. I think this is wrong. I think they need to assume that all families with a child with serious illness need the support of camp and that all families with this type of child are at a financial risk or a financial deficit because of it. And that if I say 'we cannot afford the whole cost', they should believe us. I think the average person is honest and is only*

*going to use the resources that they actually need. And I think it's much better to say, here's the support that can be offered and what of these would be helpful to your family and easier for you to function. We are so fortunate that we've got the ability to advocate for what our family needs, and we use resources enough to learn what the system might be able to provide us, but I don't think most people, at least the ones I know, are in that situation.*

Each narrative describes an intriguing tale illustrating the journey traveled to secure supports and services to minimize the impact of unmet needs. In Sanford's case, as a result of his professional position coupled with being First Nations, he was able to connect the dots on his own. Alex was not as successful, isolated both geographically in terms of living in a rural area and socially by not being aware of entitlements from provincial social sources. She then relied heavily on supports garnered from her network of family and friends.

Angie, whose income security was tested as a result of her withdrawing from the workforce sums up by stating:

*As soon as it's known, early on, when this is a lifeline condition and life-threatening condition, start offering supports right away. Give families the information where they can get support, where they can go to find other parents who have gone through this. Because right now, you find it on your own, like, I find out about respite through community living through another mom. The disability tax credit is another story. I remember thinking, somebody would have told me if we qualified, so I probably didn't even phone them for another year,*

*thinking that, and I phoned them when I got really desperate. I thought, oh well, all they're gonna do is say 'no', so I phoned, and we got on right away.*

In their words, there was an association between income security and a family's ability to cope and quite literally survive. All participants described how their child's diagnosis compromised their income security in a variety of ways, and if they had been informed or made aware of programs and services, the impact might have been minimized. Situations described within this study are corroborated in published literature (HRDC, 2001; Statistics Canada, 2003) where data supports the fact that children with conditions like severe to very severe disabilities are likely to have parents with unmet needs. The rationale for this state of affairs was either that services and/or special programs were simply not available at the local level, or the parents didn't know where to look for help--reasons that are echoed through the voices of each participant. Additionally, these reports further delineate that informal resources such as family, friends, neighbors, and community were also found to play a more significant role than formal resources in the lives of these families.

The quest to "get everyone on the same page" and, in so doing, achieve a more secure environment was fraught with challenges that further depleted time and personal resources. Angie explained that she "finally took the bull by the horns" with regards to Steve's care and demanded a conference with all the specialists and therapists working with her son--a meeting requiring several months to organize:

*Some issues came up, like the fact that communication wasn't really happening, and I was not feeling like I was involved nor did it seem like they wanted me involved. I found out at this meeting about the PARA program. To get into this*

*program, you have to hope your kid has something else wrong with them, but we were discussing the high cost of medications, and whatever, and Steve has difficulty walking, and whatever, and I said something about it would be nice if there was a program out there to help with this besides PARA 'cause PARA usually means the kids are in wheelchairs and with spasticity. So, someone, I can't remember who, decided at this meeting that Steve should be referred to another specialist, and it turned out Steve had the same type of spasticity that is required to get on the PARA program, which covers a hundred percent of all of his drugs. And he's incontinent, so it covers his pull-ups and wipes as well. It took 7 years of paying for these things, but finally we have the coverage. I wonder who else is out there paying for this stuff that doesn't need to be.*

Jessica's recollections expose another situation of increasing dissatisfaction with her son's care creating the impetus for her to take action. Mentioned previously, her son commuted back and forth to a rural school, and she was expected to come to school at least once a day to administer his insulin injection. This expectation placed more responsibility, time, and fiscal challenges on her and the family unit:

*This whole situation was just exhausting for us; we had Sam and a toddler at home. As well, we were a one-car family due to economics, and my husband needed the car for his work. Our family doctor was helpful. He was kind of, 'Well this is ridiculous. Home care should be going in and helping out'. But home care, their concept was they didn't go to schools and do anything with a needle that was a public health issue. And public health said they don't treat, they just do prevention. It took a look of work but we finally got it to the point where home*

*care would agree to come in and give Sam his needles two days a week, so that we could have respite. Getting this situation to this point took seven exhausting months. No one ever mentioned a conference to try and 'get everyone on the same page'. Rather it wasn't anybody's problem, it was ours, and no one had ever asked for this service before. We found out through the diabetes clinic that there was another school district in southern Saskatchewan where home care was going. Once I got this information, I went right to the top and just said, look, this is happening somewhere else so I need it here before I crack. This gal was very open, she said that she hadn't heard of our situation. She asked how many needles a week do you give your son? I said, well, six needles a day times seven days works out to 42... and she said, well, that's perfectly logical... and three days later all of a sudden there was somebody coming to the school to give Sam his needles.*

Nancy's lived experience illuminates another reality where even those working within the health care system encounter road blocks leading to additional frustration and fear:

*I honestly and firmly believe that, that if I hadn't been there advocating just every minute, even with her surgery, I think it was about a 12 hour surgery, and they swore up and down she would have no pain, she would definitely not have any pain. This is just another example, and she comes back, and she was hallucinating, she was in so much pain, and they're saying she is just overreacting, And I'm going, 'no, she's not, I know my daughter.' ... Well, what turned out was that the epidural didn't take. It took on the wrong side... so this*

*girl went into respiratory arrest... So basically it took me going up to the desk and saying, call the administrator of the hospital, I don't want to speak to anybody else, and you promised me no pain. I'm not, you know, just being a big bitch really. Finally somebody came down for the pain clinic and got her on a morphine drip. How would a regular parent be able to deal with this when I was sinking? After that I was afraid to leave her alone in the hospital.*

Tess provides a similar account where a close relative worked in the health care system came to her assistance. She states:

*If it were not for my aunt and her assertiveness, which I know some would say was, bitchness, I really don't know what we would have done. It makes me feel nauseated just thinking back. My husband and I were just so frazzled; I mean totally at the end of our ropes and with a new baby at home, we were frozen just frozen that feeling of being, I mean just being so powerless. My aunt knew some of the docs, and she just made a couple of phone calls and all of a sudden there is action. I mean, what would have happened; I mean, really, if she hadn't stepped in, God only knows, what would have happened.*

Each participant describes a unique set of circumstances, which taken together depict a collage of unmet needs and feelings of being marginalized and silenced. Some tension could be alleviated with increased communication among and between agencies, including the parents. Habermas contends that communication is power (Habermas, 1979) an assertion that was consistently validated throughout this study and also supported by a growing body of literature (Athens, 1994; Bury, 2001; Carspecken, 1996; Coburn, 2000; Chomsky & Foucault, 1974; Donnelly et al., 2005; Foucault, 1971;

Horkheimer, 1972; Koehler, 1981; Luther & Cicchetti, 2000; Newman, 2003; Sawatzky & Fowler–Kerry, 2003). Reflecting back over each narrative, the solution to this dilemma seemed at first to be so simplistic that it was must be trite; yet, the voices of each participant keep eliciting the same response. Using their shared words, an “advocate” was needed to connect all the dots in order to ultimately “get everyone on the same page”. This action was needed to provide another degree of security within their lives.

The individual and collective needs of these children are complex and evolve over time. Solutions found to be efficacious today may not be so tomorrow or in the future. Coupled with the significant number and range of health care workers impacting the lives of these families over both the short and long term, it is of little wonder that someone might ask “who is in charge”? It is only answered if every party involved, including the parents, are “getting on the same page”. Unfortunately in each case here, the person to take the lead was the parent who was often already emotionally and physically bankrupt.

Jessica’s experience provided yet another interesting view. Having recently moved from Saskatchewan to British Columbia, she was able to make some comparisons between these two provinces:

*Another thing that happened during that time is something that they have here that they don’t have in Saskatchewan, is here they have community support nurses. So, as we were about to enter the school system, all of a sudden, I get a phone call from a community support nurse introducing herself and saying, ‘hi it’s my job to ask you for your child’s health needs at the school and in the community. What do you need’? I don’t know who made the referral, it certainly wasn’t me. I think maybe it was the special ed people in the school district. It’s*

*been incredible. So probably the week Sam was to start school she came to our home, did a complete medical history on him, and had also taken the time to hear me say that we were having him investigated for autism. So, she had gone and done some research to try and figure out how diabetes and autism might go together which was the first time anybody had even tried to look at that. So, that was really interesting. Then her job is to go in and advocate at the school as to, you know, you guys have gotta change the way recess happens her for this child because he needs his sugars monitored. It's her job to train school staff, which was different for me because in Saskatchewan it's the parents' job to train the school staff. This was different for me because I have gotten used to being the one in charge. It was a hard transition, but now I can just have a relationship with the educational assistants and teachers and focus on Sam as a person rather than just focusing on the diabetes... When he goes to summer camp she goes in and trains the staff there. And when my husband had his heart attack, she just went into action and arranged all sorts of other supports for our family in terms of home support. I didn't even know we were eligible for them, but she did.*

The lives of each of these families have been forever transformed as a result of their children's diagnoses. None of the participants voiced in any manner that they regretted having their child. Quite the contrary, all affirmed in a variety of ways how special this person is or was in their lives. Individual medical needs for each child differed significantly as did their health status over time; a variable that did not change was the unrelenting resolve to care for their child at home. It is important to consider in this discourse that in the not so distant past, children with many similar diagnoses would

have required treatment in hospitals or long-term care institutions and/ or would have died shortly after birth. Major shifts, as a result of health care reform coupled with rapid changes in medical technology, make caring for these children in the home possible and the expected norm. It is this situation that challenges me to reflect further about the limits of parental obligations to children versus that of the state—a query that takes me back full circle to the fundamental premise that served as the impetus for this study, to describe and interpret through voices of parents, the lived experience of caring for a child with a life-limiting and life-threatening diagnosis with existing or non-existent social policies.

## CHAPTER FIVE

### Recommendations and Conclusions

“To every complex question there is a simple answer... and it is wrong”  
H.L. Menken

#### *Discussion*

Menken’s assertion presents a paradox, which I like so many others often accept as a truth. We hear daily through media that the world has grown more specialized, and as a result countless experts have made themselves indispensable to find the complex “fix” for our complex problems. I would argue now that this assertion is flawed and has in fact become a barrier to finding novel solutions. In our quest to decontextualize every problem, always assuming a level of complexity that may or may not exist, we have too often lost sight of the possibility that the answer may in fact be *simple*; for example, some economists predict that the escalating costs of health care, if not put in check, will bankrupt the country. Think tanks, royal commissions, and numerous other study groups have been called together over decades at considerable cost to find “the answer”. All the while, the answer to this complex question is *simple* and rests in a model of primary health care.

Children with life-limiting and life-threatening diagnoses along with their families have a multiplicity of complex medical needs, and I, like so many others working in the field of pain and palliative care, have been caught up and obsessed with finding solutions using positivist methods, which too often result in searches for the proverbial needle in the haystack. Not finding any sustainable or realistic answers using traditional approaches, I turn my sights over to what some in academe would describe as

a “non-rigorous” or “simplistic” form of inquiry that has frequently been devalued by the traditional power elite in research environments.

Throughout my research career, I have been mentored, supported, and heavily submersed in traditional, empirical research methods, but, over time, I have come to experience a tension between science and what I have observed in the practice settings. For example, the health care system has developed an array of interdisciplinary teams of “experts” to manage a host of problems, including pain and palliative care, and yet far too many children and their families continue to suffer needlessly. The disconnect between what is known and what is practiced over time was a constant source of tension for me until now. Throughout this research journey, I have come to understand and appreciate that “we”, as the experts, have silenced or not listened to the voices of our pediatric patients and their families for a variety of reasons; this insensitivity, coupled with institutions of society functioning as mechanisms of social control, have effectively stripped citizens of power and their right to speak and be noticed. Providing a context through this study for silenced voices to be heard was, as Habermas (1984) contends, an emancipating process liberating both the participants and also the researcher.

This paradigm shift challenges us in professional disciplines to rethink the professional-client/patient relationship and to learn to adopt more cooperative and facilitative interactions with the citizen client/patient. In so doing, we implement a process that Habermas (1984) suggests shifts the professional role from that of an authoritative advisor to a facilitator of client/patient discourse. The issue of citizens participating in inquiry and policy development may be perceived by some as a threat to their status and authority, but the task before us is both interesting and challenging,

especially for those of us who now have come to understand and perceive the limits of the traditional methods of inquiry.

This study was inspired by many forces, including my personal need to come to terms with what I see as the fall-out from the re-alignment of the welfare state. As we mature and move through life, each of us periodically renews our political imagination, and through this process I have become increasingly committed to the rights and well-being of children, for whom issues of equity, security, and well-being must be addressed if we as Canadians in a civil society are to retain any claim to civility. Children are the least advantaged members of society; all civic institutions have a duty to ensure that our youngest citizens have a fair chance to enjoy health, education, employment, and security. Unfortunately, in Canada this is not the reality for all of our children. There is an ongoing need for a national commitment to a civic framework that underwrites childhood, family, and community with health care, education, and security; so, as O'Neill (2005) advocates, "what is vital in personal and cultural difference is not diminished by hard divisions of life chances constructed by elitism and exclusions" (p. 37).

This study cannot change the reality for these families who have children diagnosed with life-limiting and life-threatening disorders, a tragedy of life events that is most certainly profound and life-altering. Yet, the results from this study provide a unique optic that can make the worlds that these families live in more inclusive and supportive for them as parents to be *parents*, as opposed to functioning 24/7 as a child's home health care worker, and allow for each of these children to self-actualize and be all that they can be; basic rights that each one of us would defend and that make us human.

The purpose of this critical ethnography was to describe, interpret, and link through the voices of parents the lived experience of caring for a child with a life-limiting or life-threatening diagnosis within the context of existing social policies. The overarching research question framing this study was: What impact do social policies or lack thereof have on parents caring for a child diagnosed with a life-limiting/life-threatening illness? It was my professional opinion that because every individual brings their own unique interpretation to life events, the use of critical ethnography would answer the research question and accomplish the purpose of the study. As a methodology, critical ethnography permitted me to deconstruct power structures and relationships to reveal and redress oppression by giving voice to marginalized groups, which were parents with children diagnosed with life-limiting and life-threatening illness. A total of six families were interviewed. Four themes emerged from the interviews:

1. Mother as Caregiver
2. Respite and Coping
3. Surviving Past
4. Getting Everyone on the Same Page.

These themes are summarized in the sections that follow and recommendations are provided for social policies to address the issues inherent in each theme. The recommendations concerning social policy were informed through:

- The six interviews with the families of children with life-threatening and life-limiting illnesses; each interview participant was asked to describe what social policy means to her/him.

- My own extensive experience as a bedside nurse, which brought me into regular contact with children diagnosed with life-threatening and life-limiting illnesses and their families. In addition, my experiences as an academic, which furnished knowledge of the broad philosophical, economic, political, and practical considerations that influence the development of social policy.
- Interviews that I conducted with federal and provincial government officials to gain insight into policy as it relates to children in general and to pediatric palliative care.
- Government documents, including policy documents, research reports, and reports from advisory committees and commissions.
- The academic literature relating to social policy, pediatric palliative care, and health care.

Questions about life and death date back to the origins of humanity and continue to be hotly debated today. It has been my experience that those who appear to have adopted and internalized a strong spiritual faith seem at least on the surface to be content with knowing what resolution death will have in their lives. Thus, the final act of dying, for some in our society, marks the beginning of a new life and journey, and for others death simply represents the end. The truth is that we are all born to die; however, in the 21<sup>st</sup> century this truth is under attack due to rapid changes in technology and science, where the beginning of life can be successfully and artificially manipulated, and death can be and is often delayed. Through the lens of mass media, we observe that politics, science, law, and the circle of life have collided and further complicated the transition

from life to death, a state of affairs that becomes even more difficult when a child is involved.

Within our death-denying society the topic of dying children is simply avoided at all costs. The deafening silence this topic evokes does not change the reality that many parents continue to live with children who have life-limiting and life-threatening diagnoses nor does the silence negate the state and other institutions from their responsibilities to provide support services, so these children and their families can live out their lives to their fullest potential.

### *Recommendations*

The recommendations proposed in this study are supported with the basic tenets advocated by the critical social theorist Jurgen Habermas (1984), who also provided the critical perspective for viewing the lives of parents with children diagnosed with life-limiting and life-threatening diagnoses within their lived sociopolitical contexts. By providing an opportunity for the voices of these parents to be heard, I as the researcher applied the process central to Habermas's theory of communicative action. Thus, communicative action became the process of discourse through which understanding was achieved; a discourse undistorted and unconstrained by institutions or agents of power. Like Habermas, I too advocate for the principles of justice and reason, and I believe that if the security of our youngest citizens continues to decline and that if inequality and disparity continue to undermine individuals' and families' collective potential, then human capital will depreciate, and so will our economy and civil society. The necessary reinvestments to turn this tide will be substantial; in other words, these proposed

recommendations focus on correctly addressing the issues at their onset, when solutions are less expensive and more effective, instead of trying to “fix” things later when problems have become entrenched; this is the core belief of primary health care models.

### *Mother as Caregiver*

For each of the mothers in this study, when their child was diagnosed with a life-threatening or life-limiting illness, there was only one option—to assume the role of caregiver. This role was assumed willingly and lovingly, and it had profound effects on every dimension of family life as the roles and responsibilities changed. The mothers gave up paid employment to care for their ill children, and none of them expressed regrets about assuming the role, it was seen as the right thing to do.

Assuming the role of caregiver had a profound effect on these mothers. Several said that they initially did not have the knowledge, skills, and judgment to assume the role of caregiver and found the role change immensely difficult at first. This change was made even more difficult because there were limited or unavailable services for the child and family and also because of the financial precariousness of the family’s new situation. The literature is replete with documentation demonstrating that the long-term care of a child at home with a life-limiting or life-threatening illness rests on a vast network of informal caregivers, primarily mothers who are unpaid for services (Baine & Rosenbaum, 1995; Baldwin & Carlisle, 1994; Brannan, 2001; Buebond–Langner, 1996; Davis, 1996; Enskar et al., 1997; King, King, & Rosenbaum, 1996; Kirschbaum & Knafl, 1996; Steele, 2002; Votroubek & Townsend, 1997; Vickers, 2006). Angie best summed up her rational

to care for Steve, “*I mean who else could look after my child and his needs better than me. It was what I had to do: he is my very special little angel.*”

Numerous rationales are cited throughout the literature discussing this reality. The most frequently cited reason is that women continue to be perceived in society as the maternal nurturer, best suited to the caregiver role, which is an assumption that also could be considered within a framework that deems the human-to-human aspects of care as a process of decision-making best suited for women.

Some mothers described feeling overwhelmed by personal and financial stressors and disengaging as a result; they felt disentitled to the social goods and services that are their rights as a citizen. They also described gradually moving from this position to the position of *advocate* for their child—becoming a “bitch” in more than one mother’s words. Becoming an advocate occurred over time and as the result of months and years of fruitless negotiations with the health care system over services, rights, and information. This constant and relentless search for services and information was deemed by all study participants to be extremely time-consuming and emotionally and financially draining. The role change to advocate was often precipitated by a significant change in their child’s health status.

Recommendations for addressing issues related to “Mother as Caregiver” include:

1. Assign an advocate to each family immediately upon a child’s diagnosis with a life-threatening or life-limiting illness. Responsibility: Provincial government and health regions.

The advocate’s role would be shaped by the needs of each particular family. In general, the advocate would help the family negotiate the system and would link the

family up to services. When appropriate, the advocate would work within the educational and social services systems as well as the health care system because families' special needs often extend to all these systems. The family advocates would be outreach workers, rather than office workers, and would coordinate services for families by visiting families in their homes and meeting with various services providers. The family advocates might be nurses, but they might also be social workers or administrators who know the system, have tenacity, and good interpersonal skills as well as a deep understanding of the issues faced by families whose children have life-threatening and life-limiting illnesses.

The role of family advocate would be similar to a case manager in the social service or health care system, however the family advocate would work within several community systems, not just one, and their involvement with a particular family would continue for the life of the child. A particular family's needs for assistance from their advocate would fluctuate and change over the course of the child's illness as the child's health changes and the family's needs evolve.

2. Provide financial support to mothers of children with life-threatening and life-limiting illness. Responsibility: Federal and/or provincial government

Every mother in this study gave up paid employment to care for her child, and the family's financial situation became precarious as a result. Financial difficulties were compounded by the extra expenses associated with the child's illness such as transportation and child care for the family's other children when the mother was in hospital with the ill child.

At the current time neither Unemployment Insurance (EI) nor the tax system are appropriate vehicles for providing financial support to mothers, since most are ineligible for EI and have little or no taxable income. A direct grant has the potential to be the simplest and most practical alternative to minimize some of the financial burden. The amount of this grant could be calculated by looking at the foster care system and asking, “what would it cost the government to support this child in foster care?” Foster care placements are sometimes the only option to parents who currently are unable to manage the care themselves at home. The value of the grant to the mother could be the equivalent to the cost of a foster care placement. In my professional opinion, it is a deeply flawed system that will pay for foster care placements, but not provide equivalent support to families so that children with life-threatening and life-limiting illnesses can be cared for and loved by their families in their homes.

3. Provide skills development and training to mothers to support them in their role as caregiver. Responsibility: Health Regions

Most of the mothers in this study said that initially they did not have the knowledge, skills, and judgment to assume the role of caregiver. They lacked skills relating to procedures such as administering medications and dealing with monitors, tubes, and other medical equipment. They did not know which situations could be dealt with at home, which required a routine visit to the doctor, and which necessitated a rush to the ER.

Training and education would better equip mothers for their role as caregiver, give them more confidence, and reduce some of their stress. Training and education

should be provided on a one-to-one need-to-know basis, in which the mother works with an appropriate medical professional when she needs the training or information. The family advocate could link mothers up with appropriate medical professionals, and the professionals' job descriptions could recognize that a certain amount of time will be spent in an instructional role with mothers and other family members. Formal classes would not be appropriate for these families, as every family's needs and situational factors are different.

### *Respite and Coping*

Advances in medical care have created the opportunity for increasing numbers of children with complex health needs to be cared for at home and have increased the life expectancy of these children. Unfortunately, social supports and services for these families have not kept pace with medical advances. Respite care is particularly problematic and was identified in the literature as an unmet need over 20 years ago, and it continues to be problematic (CACC, 1995; Kirk, 1998; Knoll & Bedford, 1989). The term *respite* is complex and is understood to be the relief from, reduction of, prevention of, or maintenance of homeostasis; it is synonymous with “break”, “breather”, “lull”, “relief”, “let-up”, and “reprieve” to mention just a few. The experience of stress, like respite, is internally and uniquely felt by each caregiver. There is certainly no exactness to the measure of stress, and it remains unrealistic to assume that respite will obliterate all the stress, but it will alleviate some aspects of it. Respite is achieved through one or several interventions and only some of them are formal respite services.

Each participant in the study spoke about the need for respite to “recharge their batteries,” so they could be better parents. Tess commented that, “*It’s not that I want somebody else to do everything, I just need an opportunity once in a while to be alone, to think, to plan just to sleep, so I can be a better mom for all my kids.*” All participants described acute crisis situations where no respite or support was available, and families were left to cope on their own. Respite and support are important at particular points in the trajectory of the child’s illness; for example, at the time of initial diagnosis, discharge from hospital, and periodic exacerbations. Several study participants also gave examples of gross insensitivity on the part of health care professionals, who failed to respond to the mother’s plea for respite or help and offered instead platitudes or judgmental comments.

Relief from stress and burden is a normal expectation for every human engaged in any type of work both inside and outside the home. All participants in this study accepted the job and the myriad of responsibilities associated with the care of their child in the home, which required them to be available 24 hours a day and seven days a week, a commitment to care that in the hospital would be covered by two shifts per day and 14 over one week.

Variability in coping among people is great, and it is not possible to catalogue all the possible responses (Folkman & Lazarus, 1985). From the collected narratives, each parent met the situation with his/her own particular coping history, meanings, and resources. In each of the narratives, there are significant reflections recounting how policies or a lack thereof affected the parent’s ability to cope with the demands of daily caring for a child who has a life-limiting or life-threatening diagnosis.

Respite issues, and the inherent dilemmas associated with this service, continue in spite of increased government attention (Arskey et al., 2004a; CACC, 2002; CYHN, 2002; Decima, 2002; Government of Canada, 2002; Health Canada, 2003; HRDC, 2003; Keefe, Carriere, & Legare, 2004). Contained within each narrative is an account of how each of the participants and their family struggled with limited or non-existent respite services. One participant summed up by saying, *“I’ve decided life is like a wave, you’ve just gotta learn how to stay on top of it and ride it. Don’t depend on anyone or anything to help you balance on that board. You are on your own.”*

Recommendations for addressing issues relating to “Respite and Coping” include:

1. Increase the number and type of respite opportunities, particularly in rural Saskatchewan. Responsibility: Provincial government and health regions

In general there is a lack of respite opportunities for families of children with life-threatening and life-limiting illness. This is particularly the case in rural Saskatchewan and in farming communities where families may live an hour or more from the nearest town.

There is an urgent need to extend the existing respite system with measures such as increasing the number of beds in hospitals and nursing homes and providing more hours of in-home respite. There is also a need to develop new and innovative models for providing respite; for example, it may be appropriate to train and fund a community member or extended family member, so they can provide in-home respite care for several hours per week to give the mother a break.

2. Educate nurses, home care workers, and other similar professionals regarding the experiences and needs of caregivers (who are most often the mothers).

Responsibility include: Educational Institutions and regional health authorities

Participants in this study described some examples of major insensitivity on the part of health care workers. One mother said that home care workers were judgmental because she and her husband did yard work during their respite break rather than going on a date. Another said that a visiting nurse urged her to do something for herself every day, like going for a walk, rather than offering the desperately needed help.

All health care professionals, but particularly nurses and home care workers, would benefit from additional pre-service and in-service education relating to the experience of caregiving. Caregivers are in the best position to identify their own needs, and every caregiver's situation and circumstances are different. Health care professionals must learn to recognize mothers' spoken or unspoken pleas for help. As well, they must be cognizant of the individualistic nature of a mother's needs. For some mothers, going for a walk is indeed a relief, but for other mothers getting their housework or shopping done, or sleeping, or visiting with a friend is a relief.

### *Surviving Past Expectancy*

Death rates in childhood are declining; this means the long-term survival of a new cohort of children diagnosed with life-limiting and life-threatening conditions who in a previous era would have died much earlier. Many in this group are prone to repeated exacerbations and remissions, which makes prognostication extremely challenging. It is

also a challenge to determine their illness trajectories, including when a child may be in the end–stages of life. Parents paint a picture of being in a state of existential limbo that results from a distortion in their role as parents, where normal parenthood involves concentrating on and investing in the present as a way of preparing for the future (Hayout & Krulik, 1999; Sources, 1996). Parents in this study were immersed and absorbed in the present and do not often speaking about a future that includes their child. At the time of this study, five parents had children living past their projected expectancy. Nancy refers to this situation as, “*maneuvering into as yet uncharted waters. It’s a place that you want to get to, but then there is the big question about what’s next.*”

This situation brings new challenges and new issues:

- Children with life–threatening and life–limiting illnesses may be subject to invasive, painful, and complex medical procedures over the years to prolong their life, but which do little to improve the quality of their life. This creates the potential for conflict between parents who want quality of life and freedom from pain for their children and medical practitioners who are focused on prolonging life at any cost.
- Pediatric health care professionals are often ill–equipped to deal with “normal” growth and development issues as these children progress from childhood to adolescence to adulthood. One notable example is the development of sexuality in this group of young people. This is a growing issue as the number of young people with life–threatening and life–limiting illnesses who survive into their teens and twenties continues to increase.

Recommendations for addressing issues relating to *Surviving Past Expectancy* include:

1. Focus on quality of life and freedom from pain for children with life-threatening and life-limiting illnesses. Responsibility: Health regions

Traditional palliative care for adults recognizes that death is near and emphasizes quality of life and freedom from pain. Palliative care for children is different in that children are sometimes receiving both curative and palliative care at the same time with the intention of both prolonging life and enhancing quality of life. With children there needs to be a balance between extending life and quality of life. There needs to be a recognition that ongoing, painful, invasive procedures that prolong life but do nothing to enhance quality of life or reverse the course of progressively debilitating conditions may not be in the child's best interests.

2. Provide support to teens and young adults with life-threatening and life-limiting illnesses, so they can experience normal developmental milestones in a routine manner. Responsibility: College of Medicine, College of Nursing, and health regions

Some individuals with life-threatening and life-limiting illnesses who survive into their teens and twenties will experience all the normal developmental milestones: the development of sexuality, an interest in going on dates, a desire to be part of the gang, the need to develop an adult identity, an interest in career planning, and a desire to experiment with risky behavior. These normal developmental milestones are made more complex by the vulnerabilities created by the young person's illness. For example, these young people may be targets for sexual predators, they may lack mobility to go on a date independently, and engaging in risky behavior, such as

getting drunk, may seriously jeopardize their health. Two types of support are needed to enable teens and young adults with life-threatening and life-limiting illnesses to experience normal developmental milestones in a routine manner:

- An understanding and acceptance by health professionals of the normalcy of these developmental milestones and of the manner in which life-threatening and life-limiting illnesses and developmental milestones interact and influence each other. This understanding and acceptance by health care professionals can be developed through both pre-service and in-service education, essential programs to enable teens and young adults with life-threatening and life-limiting illnesses to experience normal developmental milestones in a routine manner.

3. Seamless transition of care between pediatric and adult services. Responsibility:

Federal and Provincial Departments of Health

The transition from pediatric to adult health services is a complex issue that requires close cooperation between these two service sectors and the volunteer quarter. Due to their ongoing and fluctuating medical needs, achieving a reasonable degree of independence is challenging for this cohort, especially since they reach the level of the greatest dependence both physically and emotionally in early adulthood, when the stark reality of a life-limiting diagnosis is realized. Facilitation of the transition to adult services has been identified as a major challenge, and is a challenge that continues to grow each year as more and more teenagers survive into early adulthood.

A three-pronged approach is required to ensure seamless transition between services:

- Provincial departments of health need to develop and implement working plans for transition care that maximizes data networks and communication strategies among provincial health regions and between provinces and territories.
- The Federal Ministry of Health must apply a consistent *age of majority* for this population of teens throughout all provincial and territorial jurisdictions.
- Each jurisdiction must establish a set of liaison advocates whose job will be to oversee all transitions by age or change of geographical location.

### *Getting Everyone on the Same Page*

All of the children in this study required multiple interventions from an array of programs, including programs offered by health, education, social services, housing and First Nations benefit agencies. All parents described difficulties trying to identify the programs that might be available to them, contacting the appropriate workers within each program, and coordinating the various services offered by different agencies. The existence of multiple programs and the lack of coordination among them included supports for parents, such as financial supports. Each program has different criteria, forms, and application processes. Each requires contact with a different worker, and there is little or no coordination and communication among workers and programs. For parents, getting information about the various programs, their criteria, and application

process and then trying to coordinate services becomes an extremely time-consuming and frustrating task.

Angie described how she “finally took the bull by the horns” demanding a conference with all the specialists and therapists working with her son; a meeting that required over three and a half months to organize. Her message to anyone who would listen is:

*As soon as it's known, early on, when this is a lifeline condition and life-threatening condition, start offering supports right away. Give families the information where they can get support, where they can go to find other parents who have gone through this. Because, right now, you find it on your own, like, I find out about respite through community living through another mom. The disability tax credit is another story. I remember thinking, somebody would have told me if we qualified, so I probably didn't even phone them for another year, thinking that, and I phoned them when I got really desperate. I thought, oh well, all they're gonna do is say no, so I phoned, and we got on right away.*

Recommendations for addressing issues relating to “Getting Everyone on the Same Page” include:

1. Implement the Integrated Wraparound (I-WRAP) Process for families whose children have life-threatening or life-limiting illnesses. Responsibility: Provincial government and health regions.

The I-WRAP Process is a holistic approach to the delivery of human and social services that has two important characteristics:

- Ensure that families and individuals play an active role in planning for their own future and have ownership over their support plan.
- Provide a forum through which all agencies that are working with a particular individual or family can come together to coordinate their work.

The I–WRAP Process is used extensively in the human services field in Saskatchewan and other jurisdictions. In Saskatchewan, the Human Service Integration Forum and the nine Regional Intersectoral Committees have been instrumental in leading and implementing this approach. The I–WRAP Process is well documented in the literature (Amankwah, 2003; Associate Deputy Ministers (ADM)s Forum, 1998; Cheesman, 2005) and several training sessions have been held in Saskatchewan.

I-WRAP is a process in which the client, individual or family, and all service providers who work with the client come together in a forum or meeting. The client’s strengths and assets are identified along with their needs and the service gaps they are experiencing. The service providers who are participating in the I-WRAP Process identify ways that they might respond to these needs and gaps, and a written service plan is developed. The service plan identifies the responsibilities of each service provider and the client in addressing needs and gaps. It can identify services to be provided, responsibilities of individuals, mechanisms for communication and coordination, timelines and other matters that will foster coordinated service delivery. Typically, the service plan is revisited every few months to ensure it is working effectively and to identify changing needs or changing services.

The I–WRAP Process is relatively new to the health care field.

Implementing it will require a change in mindset and a change in procedures among health care staff who work with the families of children with life–threatening and life–limiting illnesses. In–service education will be an important tool for implementing the needed changes. Fortunately, models for in–service education already exist. The Saskatchewan Human Services Integration Forum has funded, sponsored, or supported several training initiatives and developed training manuals in this process; for example, the Yorkton Regional Intersectoral Committee has developed a training manual and has held several training sessions over the years.

2. Research, write and distribute an annual directory of services for seriously ill children and their families. Responsibility: Provincial government and health regions.

Families who have children with life–limiting and life–threatening illnesses rely on many services from the health care sector. These families also often need support from the education and social service systems and financial assistance from various provincial and federal programs. A directory of all such services would be immensely helpful to families. The basic framework of such a directory could be prepared by Saskatchewan Health. The framework would describe provincial and federal programs that are common across the province. Then each health region could add to the framework services in that health region. The directory would provide names and contact information for representatives of each service. The directory could be posted online, so it is available to all. A limited number of print copies could also be produced for distribution to families who ask for them.

## *Conclusion*

Through the collected narratives, I have gained a deeper appreciation of the utility of critical ethnography as an instrument to link the lived worlds of individuals to social structures and to see first-hand the limitations of empirically conceptualized tools that policy researchers have historically used. By creating, what Denzin & Lincoln describe as “a complex, quilt-like bricolage, a reflexive collage or montage, a set of fluid, interconnected images and representations” (1994, p.6), I became positioned and empowered as a researcher to challenge the dominate paradigm within the academy—the paradigm of positivism that has been held for to long as the gold standard. Throughout this research journey, I continued to gain a better appreciation and understanding that positivist, empirical approaches can miss as much as they reveal.

This study provided access to an untapped data source that until now has remained silent. Listening to each of participant’s stories unfold, I was constantly reminded of how interlinked we are as global citizens and how our basic human needs are the same everywhere. Unfortunately, there is no impartial arbitrator to determine how privilege and oppression, fortune and misfortune are distributed within and across different sectors of the population, nor is there any fairness about which families will have a child with a life-limiting or life-threatening diagnosis. However, the question we must all grapple with is whether the state should intervene and/or become involved in trying to leverage a more even playing field. That is not to say that the state would ever be in a position to change the reality of a child’s diagnosis, but should all the devastating consequences from such a diagnosis be a foregone conclusion? The harms associated

with such a diagnosis could certainly be lessened through social policies that direct the provision and access of pediatric palliative care services to all to require it.

While it may be said that states have no principles, democratic states such as Canada have a social welfare history of being responsive to the wishes of their citizens, and if past practices continue and Canadians have principles, then they can and will impose them on their government. We all need to be cognizant and mindful that everyone is variously dependent, and, that at any given moment, anyone of us may become life-limited, disadvantaged, or disabled. Becoming so should never place an individual or family in a position of having no choice and no alternative and of being forced to become reliant on unresponsive services or demeaning charity that renders them marginalized, dependent, and voiceless.

It is clear from the results of this study that the change cannot be solely addressed by an infusion of funding capital. Rather, the recommendations proposed here include targeted or strategic investment directed to the enhancement of services for these children and their families. Most recommendations, here, identify a need for new and novel ways for health care professionals to work together to support children and their families in their homes and communities, to support parents to care for their kids, to build stronger community capacity, and to use existing resources more efficiently and effectively.

All of the proposed recommendations contained in this study are constant with basic civil liberties, highlighted throughout a myriad of international, national, provincial and local documents and tenets of law. I am now reminded of Minister Pat Atkinson's words, when she summed up for me that policy change is really driven by several factors;

namely the right time and constellation of individuals who are all on the same page. So are we there yet? Perhaps that answer is found in the voice of Angie, who says:

*You know, no one wants to have a child that isn't perfect, I know I hadn't even thought about it ever, I mean it never occurred to me that I would ever have a child like Steve. But you know he's mine and I love him just as much as my other kids. I know he will never be like his siblings, but he is our special gift. If someone asked me right now if I could change things back and make him so called perfect, I would say no, because he is who he is and has made us all, who we are today. All I wish for is to be able to be more of a mom to him and the rest of my kids. I mean, if I am not giving care to Steve and my other kids, I am trying to get figure out how to work the system, get information or find someone who has some answers to make our lives more normal. I don't want any special handouts, he is my kid and I am responsible for him. But if someone or some office or something would just be available to us when we need answers, help or a break that would be a huge step forward. Palliative care sounds like the answer, but I don't know if anyone will listen and understand, that, that is what we need. All I want is to have the time to give my kids love something I think they all should have. Don't you think that should be a basic right?*

To me, Angie's words echo the underlying premise of this study. There can be no dispute that these special families face many challenges raising their children according to their values and beliefs. The question for me has always been about how we as a society can act together to strengthen these families and enable them to raise their children and protect themselves from influences that threaten to undermine their parental authority. It

is time for Saskatchewan to take the lead again in moving beyond the rhetoric of children's rights by transforming "paper rights" into "lived rights". To make this cognitive lane change, it is an increasing imperative that these children and their parents have as many advocates as possible.

The present state of our children and their well-being is under unprecedented threat and I believe that in Canada this issue represents the single greatest domestic problem facing our nation; a silent crisis that is literally sapping our very roots. Governments at all levels have an important leadership role in turning this tide. Child health researchers (Coffey & McCain, 2002; Hertzman, 2002; McCain & Mustard, 1999; Mustard & Marland, 1999) have long advocated that government must understand that an investment in children and their families is a significant piece of a nation states social investment strategy as are large Council grants to promote development of the high technology sector. Children and their care especially those with life-threatening and life-limiting illnesses should become our moral touchstone. These children, like all others must not be denied a fair chance at a standard of living that includes, good education, protected environments, economic opportunity, health care including pediatric palliative care, because every child in Canada, after all, are citizens too.

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## Certificate of Approval

PRINCIPAL INVESTIGATOR  
Linda Wason-Ellam

DEPARTMENT  
Curriculum Studies

BEH#  
Beh 05-300

INSTITUTION (S) WHERE RESEARCH WILL BE CONDUCTED (STUDY SITE)  
University of Saskatchewan

SPONSOR  
UNFUNDED

TITLE  
The Lived Experience of Palliative Care Social Policy

CURRENT APPROVAL DATE  
18-Jan-2006

CURRENT RENEWAL DATE  
01-Jan-2007

### CERTIFICATION

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

### ONGOING REVIEW REQUIREMENTS

The term of this approval is five years. However, the approval must be renewed on an annual basis. In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions:  
<http://www.usask.ca/research/ethical.shtml>.

APPROVED.

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Valerie Thompson, Chair  
Behavioural Research Ethics Board  
University of Saskatchewan

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Please send all correspondence to:

Ethics Office  
University of Saskatchewan  
Room 306, Kirk Hall, 117 Science Place  
Saskatoon, SK S7N 5C8  
Phone: (306) 966-2084 Fax: (306) 966-2069

## APPENDIX B: LETTER OF CONSENT FOR PARENTS/CAREGIVER

I appreciate your participation in the research study: The Lived Experience of Palliative Care Social Policy. The study will benefit both you and others about how learning how palliative care policies (government and agencies) affect you, your child and family. I will adhere to the following guidelines which are designed to protect the interests of everyone taking part in the study.

1. I will interview you (once, for one hour) to discuss ways policies affect your everyday life. Each interview will be audiotaped. There are no known risks in responding to the questions, but you may turn off the tape recorder at any time during the interview if you so wish. After your interview, the audiotape will be transcribed and analyzed to discover the major themes which were discussed. You will be able to check the transcriptions to clarify and add information in your own words so as to construct the meanings that become “data” for later interpretation by the researcher. You will be asked to sign a data release form. Later, in discussing the data with me, you may delete anything you do not wish to be quoted in the study. You will be able to see a copy of your contributions to the study before the final draft and you will receive a copy of the study.
2. The tape recordings and transcriptions made during the study will be kept in a secure place and will be held with Dr. Wason-Ellam, College of Education, University of Saskatchewan for five years, according to the University of Saskatchewan guidelines, before being destroyed.
3. Participation in the study is voluntary, and you may withdraw at any time without penalty or loss of services. If this happens, the tape recordings and interview data will be destroyed.
4. Since this is a study in your environment, your participation will be anonymous and your contributions will remain confidential. The results of the study will be disseminated at scholarly conferences, in journal articles, and community newsletters, etc. To assure confidentiality, pseudonyms will be used for your name, your child, and all identifying information will be excluded.

The proposed research project was reviewed and approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board in January 2006. If at any time you have any questions about this study or your rights as a participant, you can contact me, Professor Susan Fowler-Kerry, telephone 306-966-6214, e-mail [susan.fowler.kerry@usask.ca](mailto:susan.fowler.kerry@usask.ca); Dr. Linda Wason-Ellam, Department of Curriculum Studies, College of Education, telephone 306-966-7578, e-mail [linda.wason-ellam@usask.ca](mailto:linda.wason-ellam@usask.ca); or the Office of Research Services, University of Saskatchewan, 306-966-2084, calling collect if you are out of town.

I, \_\_\_\_\_, agree to participate in the above study as explained to me. I understand the guidelines outlined above. I have received a copy of the consent form for my records.

Date: \_\_\_\_\_ Participant’s signature: \_\_\_\_\_

Date: \_\_\_\_\_ Researcher’s signature: \_\_\_\_\_

## APPENDIX C: INTERVIEW QUESTIONS

\*Note: Interview Questions will be framed in language that is clear to participants.

1. Would you like to tell me about you and your family?
2. Can you provide me with some understanding and overview of your child (insert child's name)'s health history?
3. What impact has your child's health had on you and the other members of your family?
4. Thinking about social policy, would you please put into words what this term means to you?
5. Now moving back to your child's health needs, would you highlight for me the health services you have had or are currently using?
6. Did you encounter any barriers to access any of these services? If so, can you elaborate further about this?
7. Can you describe the types of services that were available to you, your child and family?
8. Why were these services so easily accessed?
9. Now thinking about the services that were easy and those that were not easily accessed, do you believe that this was the result of policies or lack thereof?
10. Now let's talk about pediatric palliative care. What does this mean to you?
11. I will read the World Health definition of Pediatric Palliative Care to you. Does your perception change on hearing this definition? If so, why? If not, why?
12. Do you think any of the services you and your child has received would be classified as palliative?