

The Experiences of Family Members who Make Decisions for Their Relatives with  
Developmental Disabilities when the Individuals' Wishes Are Unknown

by

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### Abstract

People with developmental disabilities are particularly susceptible to health challenges. If they are not capable of making treatment decisions, they rely on substitute decision makers to make decisions for them. In this research, I examined the experiences of families who have made decisions for their relatives with developmental disabilities when the individual's wishes were unknown. Using a naturalistic, qualitative research design and an interpretive description approach, eleven family members, representing eight families who had made decisions for their relatives with developmental disabilities, were recruited in order to obtain data about their experiences. The data were analyzed in order to reconstruct current knowledge and interpret findings through a nursing theoretical lens. In my findings, I demonstrate that families of people with developmental disabilities are marginalized by the experience. They actively engage in lifelong processes and seek out community resources to support their relatives. The findings suggest that professionals should consider the processes, experiences and consequences of marginalization when supporting families of people with developmental disabilities.

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Finally, my love and appreciation goes to my family; especially my husband, Dave, my children, Erin and Kevin, and my brother, Michael.

## Dedication

Dedicated with love to Dave, Erin, Kevin and Michael.

## Chapter One

### Introduction

With the advent of community integration, people with developmental disabilities are participating more in their communities than in the past (Culham & Nind, 2003). This trend has provided opportunities in areas such as education, employment, socialization, and health that were not previously available to this population. As a nurse who works with people with developmental disabilities, I have experienced some of the challenges associated with the integration of health services for this group. The complex relationship between illness and health in this population has contributed to increased mortality and the under-diagnosis of physical illness (Lunsky, Emery, & Benson, 2002).

In my own experience, I have witnessed many situations where there was disagreement on how to proceed with treatment. This disagreement can occur among professionals, with individuals with developmental disabilities, or with family decision makers. In my practice, the majority of people whom I serve are not capable of making treatment decisions. I have, therefore, developed an interest in how treatment decisions are made for people with developmental disabilities<sup>1</sup> when their wishes are unknown. As a nurse, I am responsible to ensure that the decision is made in the 'best interests' of the individual (College of Nurses of Ontario, 2005). The experiences of family members who make decisions have received little attention among researchers. In this research study, I have chosen to explore the experiences of family members who make decisions for their relatives with developmental disabilities when the individuals' wishes are unknown.

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<sup>1</sup> In labeling this population 'people with developmental disabilities,' I respectfully honour the unique personhood of all people with developmental disabilities.

In Chapter One, I describe the aims and objectives of this study and discuss the significance of this research for nurses. I provide a rationale for the concepts that I chose to explore. I develop a definition of developmental disabilities as related to my study and provide a general review of some of the health issues that are particular to this population. This review provides some context for how informed consent applies to people with developmental disabilities. As I am particularly interested in the 'best interests' standard, I explore social construction of 'best interests,' the context of decision making, and the ethical considerations that may influence the informed consent process.

Chapter Two contains my literature review. I have chosen professional research that examines how informed consent is actualized in populations where a substitute decision maker is engaged to make decisions. I review literature from the areas of pediatrics, geriatrics, and developmental disabilities in order to lay a foundation for what constitutes current practice.

In Chapter Three, I discuss the naturalist method that was used in this study. I use interpretive description as an approach to analyzing the data. I describe the selection of participants, data collection, analysis, trustworthiness of the study, and ethical considerations.

I discuss my findings in Chapter Four. The findings are developed directly from interviews with the participants. After the initial interviews, I analyzed the data for experiences that were common to all participants. I designated fourteen preliminary categories. I developed my secondary categories from themes that I found in the preliminary findings. Five themes emerged that are descriptive of the participants' experiences with decision making.

Finally, in Chapter Five, I compare and contrast my findings with current literature. I examine the legitimacy of personal knowledge acquired by family members who make decisions for their relatives with developmental disabilities as well as the relevance of relational advocacy.

I discuss my findings in consideration of what is known about marginalization, cultivating social supports, advocacy, and reestablishing normalcy and suggest implications for nursing practice, education, and research.

#### Aims and Objectives of the Research

Investigators have shown that substitute decision makers, in long-standing relationships with the individuals who they represent, may not always agree with the recommendations of 'best interests' made by professionals (Cohen, 2004; Stoner, et al., 2005). Over time, many have encountered situations where they received professional advice that has not been in concert with their beliefs. Substitute decision makers' past experiences with professional responsiveness, perceived breaches of trust, and success or failure with previous decisions impact how they receive professional recommendations. Often, families engage in an intense process of self-education about their relative's disability. Knowledge about the disability and the individual's response to interventions increases their belief that they, not the professionals, are more qualified to make 'best interests' decisions.

Nurses are responsible to participate in the informed consent process and ensure that the 'best interests' of the individual with developmental disabilities are actualized. Understanding the definition of developmental disabilities, knowledge about the health realities for this population, ethical implications, quality of life, and the individual views of the substitute decision maker provide a complex maze through which the nurse must determine what relevant information should be considered. While the professional standard is 'best interests', little is known about how substitute decision makers make decisions for people with developmental disabilities. One could ask if 'best interests' is the standard used by substitute decision makers, or do other constructions of reality prevail? Whether proposing treatment or supporting substitute

decision makers as they make decisions, it is important that nurses have an understanding of how these decisions are made. In order to explore what information might be relevant to the substitute decision maker, I examine the experiences of families who make decisions for their relatives when the individual's wishes are unknown. My aim in this study was to explore the perceptions of family members and increase understanding of the relationships that exists between family members and professionals. This information would increase knowledge and suggest how nurses could effectively engage in the informed consent process for people who have developmental disabilities.

#### Significance of the Problem for Nurses

The College of Nurses of Ontario Consent to Treatment (2005) practice guidelines state that nurses are required to obtain consent in three areas of practice: consent to treatment; consent to admission to care; and consent to personal assistance services. Consent to treatment refers to any treatment provided with the exception of emergency treatment. Consent to admission to care covers admission to any care facility except in an emergency. The standard does not require specific consent for the provision of personal assistance. If the professional deems the individual as being incapable of providing consent, consent may be obtained from a substitute decision maker. Nurses are directed to engage a substitute decision maker when the person is unable to provide informed consent for any of these three areas of practice.

The substitute decision maker is entitled to the same information that the individual would have before providing consent. Therefore, it is imperative that the nurse includes the substitute decision maker in the therapeutic relationship that exists between the nurse and the patient. Furthermore, the standard also requires nurses to act as advocates for individuals under

their care. As advocates, nurses are required to “provide the desired information and support required” (Canadian Nurses Association, 2002, p.11).

While the College of Nurses of Ontario (2005) standards for consent direct that decisions should be made in the ‘best interests’ of the individual when his/her wishes are unknown, there is little understanding of what this means to the substitute decision maker. This research was designed to help increase knowledge about the perspectives of substitute decision makers in order to improve the therapeutic relationships required for ‘best interest’ decision making. Ultimately, increased understanding of the complex relationship between nurses and substitute decision makers will positively impact the experience of ‘best interests’ decision making for people with developmental disabilities.

#### Population of People with Developmental Disabilities

While this research examines the experiences of family decision makers, the context of decision making occurs with individuals with developmental disabilities when their wishes are unknown. There are, however, different ways of describing this population. Therefore, I begin with a general discussion of who is included in the population of those with developmental disabilities.

Brown (2003) suggests that mental retardation, intellectual disabilities, and developmental disabilities are almost synonymous terms for the same population. In Canada, the term developmental disability is commonly accepted as interchangeable with the American use of intellectual disability. Intellectual disability is described as a significant impairment of intellectual and adaptive skills that occur before the age of 18. The term developmental disability usually refers to conditions that interfere with development and may or may not be associated with intellectual disability (Brown, 2003). Currently, standards that measure intellectual ability

and adaptive behavior can be problematic for people with limited verbal skills. Furthermore, in those individuals who are tested, many have similar intelligence test scores but very different developmental challenges (Walsh, et al., 2007).

Because of the current debate about how to label this population, for the purposes of this study, I include family decision makers for all individuals who continue to experience child-onset non progressive impairments in physical mobility, psychological functioning, cognition, learning, communication, behaviour, or speech. These individuals may be classified in the broad category of developmental disability without direct reference to their intellectual or adaptive capacity (Decoufle, Boyle, Paulozzi, & Lary, 2001; Palley & Van Hollen, 2000). Challenges to hearing, speech and/or vision, cerebral palsy, and epilepsy that occur in childhood and interfere with multiple areas of major life activity, such as education, socialization, independence, activities of daily living, health, and employment may also be characterized as developmental disabilities (Decoufle & Autrey, 2002). These individuals require a sequence of special life supports for a lifelong duration.

#### Health and Developmental Disabilities

People with developmental disabilities are particularly susceptible to health challenges (Lunsky, Emery, & Benson, 2002). Mortality among children, adolescents, and young adults with multiple disabilities is high in comparison to similar populations without disability (Decoufle & Autrey, 2002). Vaccinations, regular screenings, and health promotion activities are less likely to occur if the person has a developmental disability and, as a result, prevention and early detection strategies are compromised (Lewis, Lewis, Leake, King, & Lindemann, 2002). Communication and sensory deficits frequently compound the difficulty in detecting and reporting symptoms, causing diagnosis and treatment to occur later than usual in the disease

process. A positive association between behavioural manifestations and medical morbidity may contribute to the under-diagnosis of physical illness and an increased focus on psychological interventions (Davidson, et al., 2003). Accurate interpretation of behavioural changes may be a crucial link to the diagnosis and treatment of disease in these individuals.

Once treatment is proposed, the professional must obtain informed consent before proceeding. Informed consent can be problematic for individuals if they lack the capacity to understand the process. In these situations, substitute decision makers become involved to provide consent for individuals who cannot participate. A discussion of informed consent and the nurses' responsibilities provides the context under which family decision makers are asked to make decisions for their relatives with developmental disabilities.

#### Informed Consent

Consent is considered informed if the person is capable of understanding the information provided, critically reflecting on that information, and making an informed choice. When a person is unable to provide consent, a substitute decision maker is engaged to make the decision and provide consent for the individual (McVilly & Rawlinson, 1998). In this situation, family members are usually asked to be substitute decision makers for their relatives who cannot make the decision.

The College of Nurses of Ontario (2005), in their practice guidelines on consent, direct nurses to act as advocates by insuring that the substitute decision maker has the relevant information in order to make the decision. The two dominant standards for obtaining consent from a substitute decision maker are 'substituted decision' and 'best interests' (Moore, Sparr, Sherman, & Avery, 2003). In a substituted decision, the substitute decision maker provides direction for health care according to the individual's known or expressed preferences. If the

individual's preference is unknown, the treatment decision is made using the 'best interests' standard. When a person who has developmental disabilities is deemed by the professional who is proposing treatment to be incapable of providing consent, and the substitute decision maker is unaware of the expressed preferences of the individual, the 'best interests' standard prevails.

People who have developmental disabilities may not have the capacity to participate in the informed consent process. As their disabilities are manifested in childhood, the substitute decision maker may not know the wishes of their relatives and have to rely on the 'best interests' standard.

#### Construction of 'Best Interests'

The process of how 'best interests' decisions are made for people with developmental disabilities has received little attention among researchers. From a legal perspective, directives imply an empirical view that determines 'best interests' decision making using evidence of treatment effectiveness without regard for individuality and quality of life (Nazarko, 2004). Examination of the determinants of 'best interests' reveals a complex maze through which professionals interpret the concept of treatment effectiveness.

Clinicians are obliged to propose treatment that they perceive will achieve treatment goals. Professionals' perceptions, that a treatment would not benefit the person, are the primary reasons for not suggesting treatment (Ardagh, 2000). Benefit to the person that is determined solely by professional opinion suggests that treatment goals and patient goals are the same (Bailey, 2003). Patient goals may differ from treatment goals depending on individual circumstances. The inclusion of the patient's subjective experience when determining benefits or ineffectiveness of treatment invokes a qualitative dimension that includes individuality and the contextual nature of quality of life.

Bailey (2006) cites three qualitative components that account for not offering treatment and quality of life decisions in acute care; the capacity to act autonomously, the presence of bodily integrity including relatively normal body functioning, and the absence of absorbing pain and suffering. People with developmental disabilities who require a substitute decision maker to use the 'best interests' standard lack the capacity to act autonomously. The need for specialized life supports may challenge perceptions of normal body functioning. Furthermore, pain and suffering may or may not be communicated by a person with a developmental disability. Thus, determining effectiveness of proposed treatment for people with developmental disabilities, without regard for unique individual circumstances, may prove to be a difficult standard when deciding what is best.

Another dimension of deciding what is best involves the relationship between disability and ability in Western culture. While autonomy, independence, and inclusion are valued aspirations; dependence and exclusion are considered less desirable (Cardol, De Jong, & Ward, 2002). Caring for those who are dependent and excluded is considered an altruistic expression of compassion. Yet, underneath caring, there often exists an assumption that, given the choice, the dependent person would choose autonomy and independence. While the person with the developmental disability might never express that choice, the presumption that it is 'good' to be autonomous and 'bad' to be dependent guides practitioners to promote independence as a quality of life value. This construction privileges a particular form of personhood over another and devalues those who are not part of the dominant independent group (Clapton, 2003). Assuming that people with developmental disabilities want to be different than they are distorts the context of deciding what is best for each person (Culham & Nind, 2003).

A third dimension to be considered in deciding 'best interests' is the concept of autonomy that, in Western culture, arises from a view that values freedom of choice and action (Cardol, De Jong, & Ward, 2002). There are, however, conditions under which this form of autonomy can be actualized. The individual must be capable of understanding, critically reflecting, and acting on the information provided (Bailey, 2006). According to this traditional interpretation, people with developmental disabilities, who require the use of the 'best interests' standard, are excluded from participating autonomously. I, therefore, consider another perspective of autonomy that provides a different view.

Meininger (2001) describes autonomy as the development of self in relation to others. In this context, autonomy is actualized through the development of one's identity embedded in dependent and independent interactions between one's self, one's environment, and those with whom one shares life. Understanding autonomy can only occur by attending to the values and meanings that are manifested in relationships. In this context, autonomy is a continuum manifested through living in the world. While disability might impede the full execution of an individual's life choices, interdependence suggests that people act autonomously through participation in life (Cardol, De Jong, & Ward, 2002).

Considering autonomy through interdependent relationships locates the concept of 'best interests' as a process of engagement in life. Treatment decisions cannot be made solely on the merits of effectiveness and risk, but must be made in a relational context. As such, autonomy and 'best interests' are socially constructed and depend on particular relationships to be actualized (MacDonald, 2002). Autonomy and 'best interests' do not exist outside the relationship but are situated by the relationships themselves (Bergum, 2004). The nature of the relationship between the substitute decision makers, individuals with developmental disabilities, and professionals has

intimate relevance to autonomy and the effectiveness of ‘best interests’ decisions. Therefore, autonomy and ‘best interests’ are intersubjective experiences that occur within the context of supportive relationships (Sherwin, 1998).

The constitution of supportive relationships is contextual. Each individual in the relationship may hold different perspectives of autonomy and ‘best interests.’ Each encounter may reflect diverse and ambiguous interpretations of supportive relationships. In this sense, autonomy and ‘best interests’ are fluid concepts that constantly evolve with life experiences (Sherwin, 1998).

Autonomy and ‘best interests’ are multidimensional concepts that invoke a relational capacity. They represent, however, only one dimension of how decisions are made. Examining the context of decision making provides a deeper understanding of this complex phenomenon.

#### The Context of Decision Making

In order to understand the context of decision making for people with developmental disabilities, consideration of the meanings embedded in the term ‘disability’ illuminates some of the challenges associated with disability language. The recent movement away from the traditional medical model of disability towards a social model focuses on the interactions between capacity and participation in the context of people’s lives (Smart, 2002). Citing historic limitations to classifying disability in the realm of diagnosis and treatment, the World Health Organization (WHO, 2002) identifies a social model of disability that recognizes disability as a socially created problem that is an equal contributor to impairment. The WHO describes disability as a complex phenomenon that exists through the interaction between people and the context of their lives. Using the term biopsychosocial, the WHO proposes a model that integrates health, the individual, and the social environment as contextual factors in describing disability.

This model encompasses the classification of health, the components of health and the context of individual circumstance (Peterson & Rosenthal, 2005). From this perspective, quality of life for people with developmental disabilities shifts from an individualistic, biomedical focus to one that includes a complex and interdependent view that considers life experience when deciding what is best.

Quality of life is a frequently used term that describes the psychological and physiological well-being of people with developmental disabilities. There is general disagreement in the literature about how to define and measure quality of life. Molzahn (1991) observes that it is difficult to compare and replicate research findings due to the fundamental differences in definitions and measurements among researchers. Objective measures may yield results that differ significantly from subjective experiences.

Studies on quality of life in the field of developmental disabilities tend to rely on objective measurements without addressing the subjective perceptions (Fresher-Samways, Roush, Choi, Desrosiers, & Steel, 2003). Furthermore, most approaches evaluate the delivery of services rather than the impact of these services on individuals (McVilly & Rawlison, 1998). While the quality of care is a critical component of professional practice, there is no guarantee that high quality care produces good quality life experiences or positively affects quality of life.

Zekovic and Renwick (2003) note that measuring and defining quality of life for individuals with developmental disabilities is further complicated by the disagreement among researchers as to whether they should be compared to the general population or if people with developmental disabilities should have a different standard. If people with developmental disabilities are compared to the general population, some unique qualities of this population could be lost. For example, the need for specialized services that are designed to improve quality

of life for this population would not be accurately measured. Researchers also argue that comparison among people with developmental disabilities would perpetuate segregation practices and foster discrimination.

While defining and measuring quality of life is multidimensional and complex in the general population, this process has only just begun in the field of developmental disabilities (Brown, 1989). Depending on the degree of disability, subjective data on quality of life issues for this population are difficult to obtain. When subjective data is not available, information from the individual, family, friends, advocates, and support workers might provide a clearer understanding of quality of life for people who have developmental disabilities.

The context of decision making for people who have developmental disabilities evokes a multitude of perceptions ranging from individual circumstances to the social construction of disability and quality of life. I have chosen to examine disability and quality of life in order to demonstrate the range of opinions that is embedded in two of the contextual aspects of decision making. How context is evaluated depends on the interpretations of those involved in the decision. From this perspective, the context of decision making takes on an ethical dimension where the decision making participants engage in an interdependent evaluation of values, definitions, and measurements. Examining the ethical considerations that influence decision making expands the context under which decisions are made.

#### Ethical Considerations in Decision Making

Understanding what is 'best' from a multidimensional perspective invokes a relational ethic that exists within the subjective experiences of interpersonal relationships (Bergum, 2003). Relational ethics highlight shared relationships where decisions are contextual and attuned to individual experiences (MacDonald, 2007). The traditional biomedical principles of autonomy,

beneficence, and non maleficence are interpreted as connected, reciprocal experiences that exist simultaneously between the person who has a developmental disability and the world in which he/she exists. In other words, autonomy is not an individual endeavor, but a state of being that occurs by sharing relationships with others. When people engage in decisions that are beneficent, they consider the well-being of all participants of the decision making experience. In this sense, 'best interests' exists outside the realm of personal understanding. It is located in a connected world and reified by the relationships of those who engage in the process (McIntyre, 2003).

Relationships founded from a relational ethical perspective are bound by mutual respect (Bergum, 2004). As a result, individuals with developmental disabilities are valued for their worth and contributions to the world. 'Best interests' decisions are weighted by the dignity of persons with the technological benefits and risks being considered as a part of the whole experience. The embodiment of the proposed treatment and the personhood of the individual create an integrated space that connects the mind, body, and spirit. As a result, the individual's 'best interests' are an inclusive process of living rather than a finite decision (Bergum, 2003). As the professional, the substitute decision maker, and the person with a developmental disability engage in the 'best interests' process, they embark on an intimate journey along the path of meaningful understanding (MacDonald, 2007). Examination of current literature illuminates what is known about decision making and the meaning for professionals, the decision maker, and the person affected by the 'best interests' decision.

## Chapter Two

### Literature Review

There is a dearth of published literature about the perspectives of substitute decision makers who make health care decisions for people who have developmental disabilities (Mitchell & Lawson, 1999; Stoner, et al., 2005). Most researchers in medicine, nursing, and sociology examine substitute decision making with a view to investigate the context of decisions made to sustain or terminate life in pediatric or geriatric populations. Some researchers in psychology have studied the substitute decision maker's participation in deciding for a relative with developmental disabilities (Botsford & Rule, 2004). In this chapter, I will discuss literature from pediatrics, geriatrics and the field of developmental disabilities in order to inform my research.

When discussing pediatric literature, I focus on research in neonatology because the wishes of individuals within this population are unknown. Parents make decisions based on their understanding of current health realities, and with a view to how these decisions will affect their children's lives as they age. Authors writing about geriatric clients provide a perspective that reflects that the general wishes of individuals are probably known but individual decisions may not have been discussed with the individual when he or she was capable of making decisions. Substitute decision makers in both populations are concerned with the effectiveness of treatment as well as the quality of life afterwards. While there is limited information available about decision making and developmental disabilities, I review literature in psychology that has addressed this issue. I have specifically chosen literature that informs current knowledge about how substitute decisions are made.

### Literature on Informed Consent in Pediatrics

Pediatric researchers in neonatology strongly suggest that professionals sometimes withhold information from substitute decision makers as a means of sparing families future regret (Duff, 1981; Lee, Penner, & Cox, 1991; Pinch & Spielman, 1990; Martinez et al., 2005; Ward, 2005). Perceptions that family members cannot fully understand the technical and ethical components of decision making, and emotional involvement are cited as the primary reasons for partial disclosure of information (Ward). Cognitive impairment, congenital malformations, poor future quality of life, and futility of treatment influence professionals when limiting information and providing families with options (Martinez et al.). Providing information for decision making that is selective according to anticipated life quality excludes families from participating in decisions that will impact their future (Ward). Family members themselves express concerns that professionals do not share all pertinent information regarding treatment decisions. When asked, parents want active and informed participation in treatment decisions. Furthermore, when Lee, Penner, and Cox conducted a retrospective study they found that families who had children with developmental delays due to low birth weight supported active treatment. The families adjusted well and described themselves as leading normal lives. Accordingly, the investigators suggested that concerns that the children might have developmental disabilities might not have been the only factor that influenced decisions made by family members. In this article, Lee et al. did not speculate on what other considerations might contribute to these decisions.

Pediatric investigators examining informed consent highlight two areas of concern for decision making. First, the professionals weigh information that they provide based on their own perceptions of treatment effectiveness and long-term gain. Bailey (2003) suggests that professionals who withhold information without consultation with family decision makers may

jeopardize the informed consent process. Furthermore, professionals often make decisions based on the assumption that they, not the parents, know what is best for the child.

Secondly, family members may have a different view of treatment effectiveness. If provided with all relevant information, they may make decisions that differ from the professionals' opinions. This potential for disagreement about what information is relevant suggests that professionals who withhold information may place their personal values above those of the decision makers (Martinez, et al., 2005).

These findings have relevance for decision making for people who have developmental disabilities. If pediatric professionals withhold information based on their assumptions that family members are too emotionally involved and cannot comprehend the ethical and technical components of decision making (Ward, 2005), one could argue that professionals in other fields might harbour the same perspectives. If this is the case, there is a possibility that people who have developmental disabilities may not be offered treatment if the professionals assume that the quality of life for these individuals is poor.

Lee et al. (1991) found that parents of children with developmental disabilities, secondary to low birth weight, are satisfied with the decisions that they had made. The findings of Lee and his colleagues suggest that parents might not agree with the professionals in Ward's (2005) study who withheld information because of the possibility of developmental delay. In other words, the perspectives of substitute decision makers may differ from those of professionals. The assumption that professionals have a better understanding of what is 'best' than substitute decision makers impedes the mandate to share all relevant information in the informed consent process. Researchers in neonatology may have perspectives that are not shared by professionals

in other disciplines. My review of geriatric literature on substitute decision making further informs this discussion.

#### Literature on Informed Consent in Geriatrics

While neonatal investigators attend to the relationship between families and professionals, palliative authors in geriatrics refer to the relationship between the substitute decision maker and the individual when treatment is decided (Leichtentritt & Rettig, 2001). Substitute decision makers rely less on the benefits and risks of proposed treatments, and make decisions based on shared values and life experiences with the person that they represent (Hayes, 2003). Memories shared with the individual who is incapacitated guide proxy decisions in light of what the person would have wanted.

As substitute decision makers likely may rely on the substituted decision standard, they may also view 'best interests' as a continuum of substituted judgment (Hayes, 2003). Considering the individual's inferred preferences, the substitute decision makers may override previously stated wishes in favour of the 'best interests' of the person at the time. Predictions about quality of life rather than the likelihood of death influence substitute decision makers towards substituted decisions or 'best interests' (Leichtentritt & Rettig, 2001).

In a study designed to discover factors that influenced decision makers when initiating long-term tube feeding in cognitively impaired elderly relatives, Mitchell and Lawson (1999) found that the substitute decision makers relied most often on the 'best interests' standard of informed consent. The substitute decision makers recalled that they were told about the benefits of the intervention but not adequately informed of the long-term risks such as diarrhea, aspiration, and the need for chemical or physical restraint to keep the tube in place. Most substitute decision makers in Mitchell and Lawson's study believed that tube feeding had not

improved the individual's quality of life. The substitute decision makers expressed satisfaction with discussion on the immediate risks and benefits of tube feeding during the acute phase of illness. They expressed a desire to better understand the long-term implications as part of the informed consent process. The exclusion of information beyond the acute phase of treatment decisions influenced how the decision makers made their decisions. In considering knowledge about long-term consequences, their decisions may have been different.

While the literature in the field of geriatrics cited here does not specifically address the withholding of information based on professionals' assumptions about the geriatric population, it does suggest that substitute decision makers may override previous wishes in favour of what they perceive to be 'best' at the time (Hayes, 2003). In other words, the assumptions held by substitute decision makers influence acceptance of treatment recommendations.

One could assume that substitute decision makers decide on what is best from information provided by professionals. Mitchell and Lawson (1999) found that not all relevant information was shared at the time of decision making. Therefore, decisions made by substitute decision makers are influenced by the kind of information that professionals disclose. In other words, the information provided by professionals, as well as the values of the substitute decision maker, are interrelated components of decision making.

When considering decision making for people with developmental disabilities, studies on informed consent from geriatrics demonstrate that the context of the relationship between professionals and substitute decision makers is central to deciding what is 'best.' This suggests the possibility that, with other professionals and substitute decision makers, decisions could be different when determining 'best interests.' In this context, people with developmental disabilities are vulnerable to the circumstances under which professionals and substitute decision

makers make decisions for them. Authors in the field of developmental disabilities further explore the relationships between substitute decision makers and professionals.

#### Literature on Informed Consent in the Field of Developmental Disabilities

The complex relationship among the substitute decision maker, the professional, and the individual with a developmental disability raises some interesting questions about how decisions are made. Authors in the field of developmental disabilities suggest that repeated negative interactions with professionals, including the withholding of information, can directly impact how decisions are made (Stoner, et al., 2005). Common events in families' lives that influence their stance include; struggles to obtain a diagnosis when the children were young erosion of confidence in professional services, experiences with self education, conflicts during transition, the concept of fighting for services, the need for frequent open and honest communication, and perceptions about trusting professionals.

Researchers in the fields of pediatrics and geriatrics discuss specific phases and settings where treatment decisions are made. Yet, Stoner and his colleagues view decision making for people with developmental disabilities as a process whereby decisions and consequences build on each other throughout the person's lifetime. Substitute decision makers may respond positively to education that addresses specific areas of concern at certain stages in life (Botsford & Rule, 2004). There is little information about timing, context and subject matter that would guide professionals in responding to substitute decision makers' needs.

In summary, researchers in pediatrics, geriatrics, and developmental disabilities found multiple and complex contributors to substitute decision making. Factors articulated in this research literature suggest that the substitute decision makers' relationships with professionals, the kind of information provided, quality of life, personal history, and perceived risks are areas

considered by the substitute decision makers. Confidence in professional services is influenced, not only by the current relationship, but also by the consequences of previous relationships. Quality of life is perceived through the lens of shared life experiences, memories, and hopes for the future. The substitute decision makers' histories, including shared relationships with their relatives with developmental disabilities, their personal education about the disabilities, inferred preferences, and current information contribute to understanding the options. Decisions and consequences build over time. Risks are considered in the context of individual lives rather than immediate threats to life.

The findings of the studies described above indicate to me that future research should explore contextual factors that influence decision making. I have chosen to conduct a qualitative study that arises from the naturalistic paradigm to increase understanding of the experiences of substitute decision makers who make decisions for their relatives who have developmental disabilities when their wishes are unknown.

## Chapter Three

### Methods

The nature of the suggested research arises from the paradigm under which I view the world (Lincoln & Guba, 1985). Decisions about how to best answer questions about the process by which substitute decision makers make decisions depends on the ontological, epistemological, axiological, and methodological assumptions embedded in a question. In other words, I make assumptions about the nature of reality, how I am related to those participating in the research, the role that my values play in the research, and how the knowledge is obtained.

#### Naturalistic Inquiry

In taking a naturalistic approach to research, I assume that reality is a subjective phenomenon that is constructed by mental processes (Lincoln & Guba, 1985). Naturalism arose from a cultural transformation that rejected positivist thought. The naturalist knows reality to be a complex construction that can only be understood through a holistic perspective. The knower is inseparable from what is known. The naturalistic inquirer examines reality by deconstructing the meaning embedded in ideas and structures in order to reconstruct those ideas and structures in new ways. Knowledge is constructed from an interactive process where subjective engagement and researchers' values are intricate components of the creation of knowledge. Using inductive processes, the researcher engages in dialectic processes in order to vicariously reconstruct reality (Denzin & Lincoln, 2005). Naturalists seek knowledge embedded in subjective experience and bound by context.

Context describes how we experience the world. The nature of our experiences is never completely visible to us in the present, but can only be understood in reflection (van Manen, 2003). Context is dependent on the social, temporal, and spiritual world where life is lived. It is

in the lived world where we interpret our experiences to generate meaning. Our interpretation arises, not only from personal experience, but also from the political, cultural, historical, and gender realities in which we exist. In other words, meaning is created through infinite variability. Meaning is a fluid concept that moves with the experience (van Manen, 2005). It is never final or absolute. In this sense, we are only able to generate meaning through reflection on our experiences in a certain moment in time. In another place, at another moment, reflection might reveal a different construction of meaning.

Language is the medium by which humans reify their interpretations of life experiences (Johnson, 2000). Language allows the interpretations to become words and each interpreter will use language as an expression of personal meaning. Every word evokes images that arise out of the experiences of those who share the words (van Manen, 2005). Language is a metaphorical representation of meaning. In naturalistic inquiry, language is deconstructed to expose assumptions and ideological interests that constitute experience in order to gain an understanding of meaning (Patton, 2002).

By using a naturalistic approach to research, I deconstructed the meaning of decision making with a view to gaining new understanding of what decision making for people with developmental disabilities means to relatives who make those decisions. This process was examined for complex and multiple constructs without predicting or controlling the results. Substitute decision makers told their stories, allowing for detailed descriptions that yielded information about how they make decisions for their relatives with developmental disabilities. Patterns that illuminated the experience were identified through individual and collective meanings that were constructed from consensus. Interdependencies and system dynamics were viewed considering the social, political, gender, and historical context that shaped decision

making (Patton, 2002). As naturalism provided a framework for posing questions of meaning, research questions into how surrogates made decisions for their relatives with developmental disabilities were best answered through this world view.

#### Interpretive Description Research Approach

Exploring the experiences of families who make decisions for their relatives who have developmental disabilities when the individual's wishes are unknown is congruent with a naturalistic approach. My perspective arises from knowledge of the subject through experience and literature. Lack of attention to this subject in the research literature has limited my ability to interpret the findings through previous theoretical frameworks. As a result, I searched for a method that allowed for the constructed, contextual nature of human experience while contributing to the advancement of nursing knowledge (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004).

Interpretive description was developed in response to specific nursing concerns about generating grounded research knowledge that pertained to clinical nursing realities. Thorne et al. contend that traditional qualitative inquiries were developed outside the realm of nursing practice and have traditional methodological orthodoxies and traditions that constrain emerging nursing scholarship. They acknowledge that researchers using interpretive description risk blurring the distinctions between qualitative approaches. They state, however, that "interpretive description differs from other qualitative approaches because it is a smaller scale investigation of a clinical phenomenon of interest to the discipline for the purpose of capturing themes and patterns within subjective perceptions and generating an interpretive description capable of informing clinical understanding" (p. 5). Researchers using interpretive description assume that there is some

theoretical knowledge and clinical pattern that forms a basis of nursing inquiry into human health experiences.

Nursing knowledge dwells somewhere between what is known about common health experience and what is unique about each nursing encounter. In finding a research method that honours nursing knowledge, I chose a design that would contribute to the advancement of nursing knowledge in the area of substitute decision making for people with developmental disabilities. Interpretive description research is a generic nursing research approach that arises from the naturalistic paradigm (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). Its purpose is to answer questions that would illuminate knowledge through exploration of participant experiences and interpreted through the lens of nursing knowledge (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997). With similarities to the traditional qualitative research methods of phenomenology, grounded theory, and ethnography, interpretive description is grounded in individual experience. This experience is linked to what is known to nursing practice in both its practical and scientific dimensions. In this way, the knowledge generated can be used to advance nursing knowledge without losing sight of individuality when applying knowledge to practice.

#### Researcher as Participant

As I am also a participant of this research, my personal experience is relevant to the process. My brother was born with a developmental disability and he lives in a group home. Over the years, we have remained very close and I currently share next of kin decision making with my mother. We have found decision making to be challenging at times. As my brother speaks well, professionals have often assumed that his ability to understand is equal to his verbal ability. As a result, we have acted as active advocates for his health care. His ability for abstract thought is limited and we have often negotiated treatment agreements using more concrete

terminology. While we have enjoyed relationships with very caring professionals, in my experience, they often have limited understanding about communication with my brother.

I began working with the agency where my brother currently resides in 1984. I began as a staff nurse and, over time, began to realize that I needed advanced skills in order to work effectively with this population. I began my Bachelor of Nursing at the University of Victoria in 1996. It was during my undergraduate years that I first became cognizant of the difficulties associated with 'best interests' decision making. I was primary nurse for a client who was admitted to the local hospital for an intestinal blockage. During his hospitalization, the physician and the family decided that he had "suffered enough" and, therefore, the required surgery was not performed. Nutrition and hydration were withheld and he was placed in palliative care. He died within ten days. My personal journey to understand how 'best interests' decisions are made began with his treatment and death.

Currently, I hold the position as the Residential Nursing Supervisor of three community residences within the agency where my brother lives. These residences are staffed full time with Registered Nurses (RNs). The 18 to 20 clients in these homes require nursing support to live in the community. There are some clients who live permanently in these homes. Some come into residence temporarily with a variety of health issues, such as rehabilitation, palliation, post operative care, or unstable medical conditions. As supervisor, I have frequently been asked by family members, professionals, and organizational representatives to participate in treatment decisions.

Throughout my personal and professional experiences, I have become acutely aware of the complexities of each decision. As a relative of a man who has developmental disabilities and

a nursing supervisor, conducting research into this phenomenon will increase my understanding and ability to support the people who have developmental disabilities in my care.

### Participants

The Southeastern Ontario Community Research Alliance in Intellectual Disabilities (SEO CURA in ID) consists of a group of researchers interested in influencing families, conducting research, and increasing knowledge about people with intellectual disabilities. SEO CURA in ID currently consists of 42 member agencies that support research in intellectual/developmental disabilities. It is estimated that there are 4000 people with intellectual disabilities known to the agency partners in the six county areas. SEO CURA in ID granted funding for this research (see Appendix I).

Once members of the Human Research Ethics Board of the University of Victoria, Dr. Roy Graham, Human Research Ethics Chair and Eugenie Lam, MA, Human Research Ethics Coordinator, notified me that I had received ethics approval to conduct this study, I approached five representatives of local member agencies and distributed letters explaining the purpose of the research and requesting assistance in recruiting participants (see Appendix II). These letters identified SEO CURA in ID as one of the umbrella agencies that approved the research and included suggestions for recruitment, such as presentations, and the distribution of flyers, pamphlets or letters. Agencies were asked to make the research information available through their contacts and request volunteers. The criteria for participation were; to be a relative of a person with a developmental disability, to have acted as a substitute decision-maker in some capacity, to be English speaking, and to be willing to discuss this experience with me. Members of one agency requested that I make a presentation to their family support group and

representatives of another agency asked me to speak to the research committee. One participant volunteered after these presentations.

I attended the SEO CURA in ID annual conference and distributed flyers about the research project in the conference handouts (see Appendix III). Some of the families who attended the conference approached me to participate in the research. Two participants agreed to be interviewed after contact at the conference. In total, 11 participants, representing eight families, agreed to be interviewed.

Once the three convenience sample interviews began, subsequent participation occurred through snowball sampling. Early study participants were asked to facilitate the selection of participants who could provide appropriate and information-rich experiences. One participant invited me to speak at a family support group. From this presentation, I recruited one volunteer. I asked participants to give my flyers to people that they thought might be interested in speaking with me. Those interested in participating contacted me through the information provided on the flyers. The remaining four volunteers were recruited through contact with the initial participants.

The participants came from a variety of backgrounds. All were parents of children with developmental disabilities. The children ranged in age from six to forty-eight years old. In five of the interviews, only the mother participated. Both parents responded in three of the interviews. Two of the participants had experienced divorce. Of those, one remained single and the other remarried. In this family, the mother and step-father both responded to questions. Nine participants were of Caucasian background and one couple was Asian. This couple's first language was not English but they communicated in English effectively. Five of the children lived at home and three lived in group homes. Three children are still in school, one is in a

supported work environment, two attend sheltered day programs and two have no organized day activities.

All participants who participated in this research spoke English and were capable of understanding the consent, participative processes and questions posed to them. None had physical or medical reasons that affected participation or were members of vulnerable groups. While age of the relative with a developmental disability was not a factor, the participants had to be at least eighteen years of age and were required to have made a decision for their relative in the past.

#### Exclusion Criterion for Participants

While participation in this research was open to all adults who have made decisions for their relatives with developmental disabilities, there were some instances where a person was excluded from this research project. As I have personal and professional ties to the community, people who knew me were not recruited to be participants in this project. As the professional relationships with families I know might be influenced by power imbalances, I did not solicit participants from the agency where I work.

#### Data Collection

Once participants volunteered, they were sent a letter that described the research process (see Appendix IV). Participants were asked to agree to two in-person interviews, each lasting about an hour. I collected data through interviews and observations. Interviews were audio taped and transcribed and observations were recorded as field notes (Patton, 2002). Questions were open-ended (see Appendix V) and informed consent was obtained (see Appendix VI).

In the first interview, participants were asked questions about their experiences with decision making. Data collection and analysis occurred simultaneously. After the first interview,

through the initial analytic process of open coding, I broke down the data line by line so as to compare and contrast the information. As themes emerged, I further explored these concepts in subsequent interviews. In the individual or two person second interviews, I shared my analysis and observations in order to check out my initial theorizing and explore how these ideas reflected the individuals' or couples' experiences.

I examined the data following each interview with a view to coding the data in order to conceptualize a framework under which the data could be analyzed (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). As interviews progressed, I considered new possibilities for organizing data in order to ensure that the framework would include broader conceptual linkages. Through continuous comparison (Patton, 2002), patterns were organized into themes. Themes were compared to current nursing literature in order to find similarities and differences. The interviews continued until I was satisfied that I understood the constructions about decision making as presented by the participants. This understanding occurred when the themes were explored so that no new data emerged and the themes were fully developed (Coyne & Crowley, 2006).

#### Data Management

I audio taped each interview and wrote field notes. Once each interview was completed, I listened to the tapes, transcribed the interviews to my computer, and created a database. The computer and interview files were password protected. I compared the transcriptions with my notes. After comparing the audio tapes and my field notes to ensure accuracy, the tapes were erased and the field notes were shredded in order to maintain the confidentiality of the participants. I assigned each transcription a numerical code to differentiate the interviews. Names were not transcribed during this process. The participants were subsequently identified as 'M' for mother and 'F' for father. The interview number was attached to the identifying code in order to

organize the data. As patterns became explicit, I reorganized the data into codes that captured the essence of the patterns. Using a constant comparative method (Patton, 2002), I developed the code names from the language of the interviews. Summarizing these code names, I conducted second interviews with the participants to discuss my interpretations.

I used the same process for the second interviews. The field notes and tapes were destroyed following transcription. I assigned codes that would link the participants to their first interviews. I used data from the second interviews for expansion, reduction, and rearrangement of the code names found in the first interviews (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). I organized the data from the first and second interviews as follows; figuring out how to support their children with developmental disabilities, life's struggles, the behaviour of people with developmental disabilities, keeping people with developmental disabilities safe, successes, the politics of engaging in the community, wait lists, abandonment, teaching others, professional (expert) advice, non-professional (expert) advice, other supports, taking care of yourself and the future (see Appendix VII). During the data collection process, I began to analyze the data with a view to reconstructing data into broader categories.

### Analysis

In interpretive description, there is an assumption that the researcher will have theoretical knowledge, clinical observation and a scientific basis on which knowledge will be furthered (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). In the earliest analytical stages, I took into account the nature and type of existing theoretical knowledge but, as data collection continued, I moved away from existing knowledge as new concepts emerged. Early data were used to search beyond what was immediately apparent to find linkages that challenged the known theoretical constructs (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). For example, I had developed

my knowledge about decision making for people with developmental disabilities from personal and professional experiences. In speaking to participants, I noted that the concepts of 'best' or 'quality of life' were not specifically mentioned. Instead, participants spoke about positive and negative experiences that changed their perspectives about decision making.

Preliminary pattern categories were compiled and grouped into broader categories to produce secondary categories. As categories were identified, I reviewed literature about the categories comparing research findings with information emerging from the data. Further interviews reflected the findings and data collection followed the previously outlined process. As themes emerged from the secondary categories, I developed theoretical constructs (Coyne & Cowley, 2006).

#### Trustworthiness

In qualitative research, trustworthiness means that the research is authentic and dependable (Lincoln & Guba, 1995). Authenticity refers to the reflective process that clarified the subjectivity that I brought to the research. From my authentic engagement with the process, I provided evidence of dependability by demonstrating a systematic search for meanings embedded in the data (Patton, 2002). The assumption in naturalistic inquiry is that knowledge is socially, politically, and psychologically constructed. Multiple interpretations of meaning may therefore exist.

The trustworthiness of qualitative research begins with the interview (Patton, 2002). In using the interview to gather data, I assumed that the participants' perspectives were meaningful. By sharing their stories, I was able to gather data that was credible and contributed to knowledge about 'best interests' decision making. I valued the quality of listening. As a listener, I was capable of being drawn into the participants' experiences and attending to their perspectives.

While I have both personal and professional experiences participating in 'best interests' decision making, I reported the process by which I conducted a systematic search for divergent patterns and alternative themes that are different from my current understanding. For example, while I had been looking for ways to interpret the 'best interests' standard of informed consent, participants reported that their experiences of parenting children with developmental disabilities had changed their understandings of their responsibilities towards decision making. They viewed themselves as experts about their children. They believed that those without this experiential knowledge were not capable of deciding what was 'best.' They indicated that they had to teach others about their children before considering available options. Using inductive reasoning, I looked for new ways to organize the data. I reported on all alternative classifications that I considered and provided logical explanations for the choices that I made.

In order to ensure that my analysis reflected the participants' perspectives, I asked the participants in the second interview to review my summary of the previous interviews (Holloway, 2005). This review ensured accuracy, fairness, and completeness of the analytical process. As classification of data was obtained through my interpretation of their experiences, sharing this analysis with participants offered them the opportunity to provide context and alternative perspectives (Patton, 2002). While participants identified different areas of my analysis as important to them and offered divergent interpretations in other areas, there was general consensus that I had captured their experiences in my analysis.

Another component of trustworthiness is the credibility of the researcher (Patton, 2002). As a Master's of Nursing student at the University of Victoria, a sister of a man with developmental disabilities, and a nursing supervisor who shares personal and professional relationships with people with developmental disabilities, my experiences with this population

are extensive. I have been both personally and professionally associated with ‘best interests’ decisions. Over the years, my experience in working with relatives who are making these decisions has given me the knowledge and ability to communicate effectively with families. I am able to listen, entering into the world of relatives as someone who is willing to share in the experience.

I also have a fundamental appreciation for naturalistic inquiry and espouse a philosophical view that is holistic and contextual. While I have personal experience with ‘best interests’ decision making, my research experience is limited. As I believe in multiple realities that can embrace diverse views in reporting my findings, I included various perspectives that demonstrated findings that differed from my previous knowledge.

Throughout the descriptions of my findings, I provide sufficient detail to delineate the steps used in the process and demonstrate the logic of the method (Patton, 2002). Trustworthiness of the findings is demonstrated through the use of thick descriptions. Thick descriptions provide details about the rationale for using an interpretive research design; clarification of the research process, including data collection and analysis; and the provision of detail about the raw data that is generated (Curtain & Fossey, 2007). For example, as themes emerged, they were compared to current knowledge about the themes through reviewing the literature. Data were described using descriptive language to ensure that the findings and reported conceptualizations arose from the interview process. In this report, I use direct quotes to illustrate the richness of the informants’ experiences. Decisions about what constitutes data, what data were relevant, and how conceptualizations were structured arose from my own experiences. Thus, an essential element of descriptive interpretation is the acknowledgement of my involvement in the findings (Thorne, Reimer Kirkham, & O’Flynn-Magee, 2004).

I consulted my thesis committee throughout this process, drawing on their expertise in ethics, 'best interests' decision making, research design, research analysis, methodology, and particular knowledge about people with developmental disabilities (Rossman, 2002). In these discussions, I enhanced my knowledge about relational ethics and considered how relational ethics informs decision making for relatives of people with developmental disabilities. My committee members challenged me to expand my understanding of 'best interests' decision making by reviewing current literature in medicine, nursing, and psychology. They assisted me to clarify my research design, analysis, and methodology in order to develop a systematic approach to my study. Finally, my research committee members suggested areas that I might explore in discussions about how current knowledge might apply to making decisions for people with developmental disabilities.

#### Ethical Considerations

Following approval from the Human Research Ethics Board of the University of Victoria, I conducted this research project within the framework of the Code of Ethics published by the Canadian Nurses Association (2002). I respected the participants' rights to autonomy (see Appendix IV). All participants were capable of providing consent to participate and were given enough information to understand the study and its implications. The participants were free to withdraw at any time. This research had a low risk of harm and vulnerable groups were excluded. The potential benefits of the research were discussed with participants. In choosing this research design, I respected the personhood of the participants and, in particular, the individuals for whom decisions are made. I ensured the ethical integrity of the research throughout the process.

## Chapter Four

### Description of Research Findings

As the first interviews progressed, certain common experiences became visible. I have included a summary of these preliminary findings (see Appendix VII) and named these initial patterns “Level One Codes.” The themes that became evident after the first few interviews are discussed below in order to provide context for the subsequent category development that is outlined later as I describe my findings more fully.

#### Initial Identification of Patterns

Participants spoke of ‘figuring out how to support their children with developmental disabilities.’ Many stated that they were unsure of what was happening to their family or who to turn to for guidance. Previous understandings of how children behaved, developed and interacted were challenged by the presence of developmental disabilities. Participants described a process of reflection, seeking assistance, and trial and error that influenced how they made decisions for their children. They learned from the successes or failures of past decisions. As they learned, participants gained confidence in their abilities to make the right decisions.

While participants began to make sense of their new reality, they described a series of ‘life’s struggles’ that influenced their decision making. In addition to the ordinary ‘life’s struggles’ that they had expected, they spoke of difficulties that they believed arose when they became parents of children with developmental disabilities. For example, they stated that their relationships with family and friends changed because other people in their lives did not fully understand their experiences. They also described a general sense of loss as their children did not meet the expected milestones of maturation. In conjunction with the unexpected struggles of parenting children with developmental disabilities, participants expressed a new understanding

of their children, informed by the process of ‘figuring it out,’ as a foundation for how they faced their ‘life struggles.’ In the process of parenting children with developmental disabilities, participants began to realize that others in their lives might not share their views of how decisions should be made. Participants stated that their families, friends, and communities were not always responsive to their changing lives. They expressed a sense of loss, not only because their children had developmental disabilities, but also because some of their important relationships had changed. As a result of these experiences, their way of making decisions became different. They relied on their own sense of right and wrong decisions more than on the opinions of others. Decisions that they may have made in the past were now different because the challenges and consequences were different than before they had children with developmental disabilities.

Along with their sense of struggling, participants learned that the ‘behaviour of people with developmental disabilities’ was different from the behaviour of neuro-typical people. Their children’s behaviour could be puzzling as well as challenging at times. They began to understand this ‘behaviour’ as a form of communication and learned about the non-verbal language that their children expressed. Using their understanding of their children’s behaviour, participants made decisions based on past experiences of what their children would accept and what might increase their children’s challenging behaviours. As they learned to rely more on their own perceptions of what was best for their children, they also learned to listen to the communication behaviours that their children expressed. Participants stated that they believed others did not understand their children’s behaviours. This belief reinforced their view that they, not others, knew what decisions were best for their children who lived with developmental disabilities.

While understanding that others might not know what was ‘best’ for their children, participants also realized that their children’s behaviour could place them in situations where they were unsafe. Participants described three particular areas where they believed that their children were vulnerable; the children’s lack of safety awareness, public perceptions about their children’s abilities, and those who might prey upon their children. ‘Keeping people with developmental disabilities safe’ is a concept that describes the life-long vigilance that the participants believe is essential to their children’s well-being. When making decisions, participants considered dangers that their children might not recognize as well as dangers imposed by others. They indicated that their decisions were not only based on current concerns for safety, but with a view to how those decisions might impact their children’s safety in the future.

While participants described their worries and concerns, they also emphasized the many ‘successes’ that they experienced along the way. They spoke with pride about their children’s achievements and described how they built on these ‘successes’ to increase opportunities for their children. Finding areas where their children thrived, participants eagerly sought out experiences where their children could learn and grow. These areas of growth and learning were built on what the participants had figured out, their life’s struggles, their children’s behaviour and their children’s need to be kept safe. Decisions were made with a view to increase opportunities for success for participants’ children with developmental disabilities.

Finding opportunities in the community was difficult for participants. They stated that they had to become active politically at many levels to ensure that their children were afforded the same opportunities as other children in society. Socialization, education, health, and residential options are some of the areas where participants described their encounters with ‘the

politics of engaging in the community.’ They had learned that their children had unique personalities that were not always congruent with generic community options. They became politically active as they advocated for their children’s access to services. Participants sought out services that could support their children’s communication behaviour, ensured their safety, and provided opportunities for success. Funding issues, service flexibility, and power struggles also ensued. Participants stated that, when accessing services, they considered their experiences with the ‘politics of engaging in the community’ to be a major component of the decisions that they made.

As participants became engaged in the ‘politics of engaging in the community,’ they discovered that, even when they accepted services, they were placed on waiting lists. They described ‘waiting for service’ as an everyday reality. Participants stated that they could be on several different waiting lists at one time. Waiting lists could be several years long. Sometimes, they waited for services that were not beneficial to their children. When a service did not meet their children’s needs, participants either invoked political processes to modify the service or terminated their children’s participation. While none of the participants refused services because of waiting lists, once the service became available, participants considered if their children would still benefit or if they had different needs from when they were first placed on the waiting list. Decisions about services were influenced by the length of the waiting lists, the availability of other services, and the benefit to the participants’ children once the service became available.

Once they received services, participants became aware that services could be terminated due to a variety of reasons. They spoke of feelings of ‘abandonment’ when services stopped before their children were ready to move on. Participants described reasons for the termination of services as the service provider’s efforts to manage waiting lists, changes to funding,

professionals' career changes, or changes in their children's behaviour. While the realization that services were finite did not deter any of the participants from accepting services, it did influence how they managed their children's access. Participants expressed awareness that there was little coordination of service provision in their communities. The combination of waiting lists, termination, and the 'politics of engaging in the community' meant that their children received services without the benefit of overall planning. Understanding this gap in service, participants described themselves as taking on case management roles. They organized case conferences, negotiated transitions, and facilitated collaboration of services in an effort to ensure that their children would benefit from the combination of services. Participants' decision making was influenced by their beliefs that their children required coordination of services. The realization that services could be terminated, access to new services could be delayed, and multiple services may not be compatible caused participants to make decisions based on an overall plan rather than only considering the services individually.

With the experiences that developed self-reliance, listening to their children, ensuring safety, and coordinating services, participants expressed the belief that they were the experts about their children. They viewed their role as one of 'teaching others' about their children in order to attain success. They viewed family, friends, professionals, community contacts, and all others who developed relationships with their children as requiring knowledge about the uniqueness of their children's lives. While they acknowledged that others might be familiar with people with developmental disabilities, they believed that each child was different. Participants assumed that others, who were less familiar with their children, required information that they, as parents, could provide. How information was received by others had direct impact on how participants weighted their decisions. Information provided by others was more easily accepted if

the participants had the opportunity to communicate their knowledge about their children. In other words, people who accepted that the participants had valuable information to share about their children were considered more reliable than those who did not learn from the participants' experiences. In making decisions, participants considered the responsiveness of others as a major factor in trusting their recommendations.

When seeking advice, participants acknowledged the role that professionals played in providing services to their children. While professionals might have taken time to know their children, they were not always knowledgeable about developmental disabilities. This lack of specific knowledge about developmental disabilities caused participants to be cautious about accepting 'professional advice.' They cited physicians, teachers, nurses, and social workers as some of the professionals to whom they looked for assistance. Participants recognized that they required support from the professional community in order to access services. Participants viewed the lack of general knowledge among professionals as an impediment to finding the right services for their children. As such, when making decisions, participants frequently sought out second or third opinions before accepting the recommendations of professionals.

When consulting other sources for information, participants relied on 'non-professional advice' to assist them in navigating bureaucratic systems. Discussing strategies with other families in similar situations, daycare workers, and education assistants provided invaluable support to participants. Participants believed that others, who had similar experiences, offered them guidance that was reliable and resourceful. They stated that, at times, they were more likely to accept advice from non-professionals than from the professional community. Participants stated that, when making decisions, they gathered information from both professional and non-professional sources in order to make decisions that were best for their children.

While learning about their children, navigating political processes, and receiving advice from professionals and non-professionals, participants described the need for ‘other supports’ that assisted them in dealing with family stress and crisis. Whether they were professional or non-professional, people who were responsive to their situations recognized that the family also required support. Participants acknowledged that having children with developmental disabilities increased their families’ stresses. When making decisions, they considered what was best for their children with developmental disabilities as well as the impact that these decisions would have on their families.

Participants stated that caring for their children with developmental disabilities was stressful. They needed to find ways to ‘take care of themselves’ in order to support their children. Finding ways to alleviate stress and maintain a sense of well-being was paramount to success. Participants described figuring out how to support their children, managing communication behaviours, keeping their children safe, negotiating community supports, and receiving different information from professional and non-professional sources as some of the contributors to the increased stress in their lives. When making decisions, they stated that they also considered the ways in which the consequences of those decisions would affect themselves as well as their children. They suggested that ‘taking care of themselves’ ensured that they would have the required energy and patience to continue to provide care for their children with developmental disabilities.

Participants spoke of past and present experiences that informed their decision making. They described a complex maze through which they had learned to care for themselves, their families, and their children with developmental disabilities. They also stated that their hopes and dreams for the ‘future’ also played a role in how decisions were made. Participants described a

process by which decisions built upon each other. They expressed hope that past and present decisions would lead to 'future' successes. They also worried that the decisions that they made might not always meet their children's needs. Participants described the 'future' as filled with hopes and fears that their children would always be recipients of decisions that were made in their 'best interests.'

Participants generously discussed their past present and future circumstances. A summary of the initial coding is included in Appendix VII. The following provides an in depth analysis of the meanings embedded in each category with a view to increasing understanding about how relatives of people with developmental disabilities make decisions for the individuals when their wishes are unknown. In reviewing the preliminary findings or 'Level One Codes,' I searched for broader themes that would illuminate the phenomenon of decision making for people with developmental disabilities. I named these broader themes 'secondary development of patterns.' Describing these secondary patterns, I examined some of the processes that informed participants' decision making.

#### Secondary Development of Patterns

In reviewing the initial patterns, I became aware that the meanings embedded in these processes were pivotal in participants' interpretations of information. I examined the initial patterns for clues as to how these meanings informed decision making. The patterns that became evident to me during my second development of patterns were; difference and isolation, changing relationships, developing advocacy, engaging political action, and finding a way.

#### Difference and Isolation

Participants spoke freely about the complexities of parenting children with developmental disabilities. Whether they learned about the disability at birth or later in childhood, participants

harboured strong feelings about that time in their lives. One mother spoke about her reaction when her physician told her that her child had a developmental disability, “I looked, I mean with horror. I picked [my son] up and I just walked out of the office. It was the worst possible thing. I went out and my husband was there outside so I just...I was crying.”

Participants also spoke about how, once they became parents of children with developmental disabilities, they began to view themselves as different. They believed that their lives had taken new directions and that they could not easily return to their old ways of being. One mother described the experience this way: “And so I wouldn’t talk to them about it. Because you knew that they just didn’t understand it. To some extent, around that time I was moving in a different direction with my life.” One father expressed his thoughts about difference: “She’ll always look different. She is different. She acts different. This makes our family different.”

Participants recalled their initial consultations with medical professionals as unsatisfactory. The professionals’ lack of knowledge about developmental disabilities coupled with a poor understanding of how to support parents caused participants to feel lost and frightened. Participants described feelings of isolation and vulnerability. One father said:

We felt alone. It felt like you were totally vulnerable. It felt like you were falling apart and when you did go and ask for help you had to tell pretty personal stuff, expose yourself, and then you’re denied any help.

Changes in the participants’ perspectives were reinforced by their changing relationships with others. They discovered that, not only did they perceive themselves as different, the reactions of others reinforced their feelings of isolation. Participants stated that, at times, they had to explain themselves to others in order to be heard. They had to remind others that they

continued to be reasonable, contributing members of society. One mother talked about how she perceived that others saw her:

You're automatically pegged like you have a mental disability yourself because your child does. Even by professionals, sometimes. And I actually said, pointed that out to a dentist that looks after, a pediatric dentist and I said that I didn't like the way we were treated in this office. And I said, "We're hard working people and don't like just because [my son] has a mental disability doesn't mean that we have."

Participants struggled with their newfound feelings of difference and isolation. They reconciled those differences by establishing new, more supportive relationships.

#### Changing Relationships

For participants being parents of children with developmental disabilities served as a catalyst for forging new relationships. They found that their old relationships had changed and they actively sought out social situations that were congruent with their newfound family lives. One father said, "And relationships do change. The biggest single thing is your friendships and your family change." Another father described how an old friend questioned the choices that he and his wife had made:

You know what's behind the questions. I'm not stupid. He was condescending.

It's like you're stupid, you could have done something. You know... he thinks you've got a child that's a burden to society. He was looking at us like it was a waste of his time.

We felt we were wasting taxpayers' dollars.

Participants in this study found other families, in the same situation, were the most reliable supports available. They consistently looked to other families for stress reduction, information sharing, and guidance. One mother said:

I belong to a mother's group, and it wasn't organized through an agency, there was just a bunch of women that decided they would get together. I happened to be invited. We would try to get together once a month and we would go to different women's houses and talk about other things other than our kids. It was very social but you found out a lot of different things.

As participants cultivated their social supports, they perceived a regaining of control over their lives. Many turned to support groups in order to formalize their alliance and develop strategies for change. One mother spoke about her experience with a support group:

That was sort of sharing of information, talking about some of the stresses, looking at strategies to influence change, those kinds of things.

Participants reorganized their social relationships and began to feel empowered as parents. The sense of empowerment was reified through perceptions of interconnectedness between themselves and their new social relationships. These relationships strengthened their resolve to make decisions that they believed were 'best' for their children. They understood that their new ways of thinking might not be congruent with the perspectives of people who did not have children with developmental disabilities, but finding others who shared their new understandings validated their positions as experts about their children. They quickly learned that decision making was not always an easy process. They felt empowered by their relationships with other families. While their experiences with empowerment occurred in the context of their

relationships, they needed to reach out to their communities in order to access services for their children.

### Developing Advocacy

Participants discovered that accessing community services was not always easy. Many community members had difficulty accepting children with developmental disabilities into society. Participants found that they could not stand by silently as their children endured rejection from their communities. They raised their voices in protest and evolved as advocates. One mother explained her position this way, “Because you’ve got to be the advocate. You’ve got to fight, to be there, these guys can’t fight for themselves. And sometimes you come out like a real.... But it doesn’t matter.”

As their children moved into the community, participants drew on their personal experiences with their children to guide their way. They believed that they, not others, knew what was best. While they acknowledged that their decisions might be questioned by others, they demanded the right to advocate for their children. As one mother said:

But you know, people will always judge. I judge people, too. That is human nature. It’s when you’ve made a decision that you feel is right and people try to argue you out of it. When you’ve made a decision that you feel is right based on the information, it is not their right to try and sway your decision. No, it is their right to try to sway your decision, but once you’ve made your decision don’t keep knocking people over the head. Whether your decision is right or wrong, it is a decision you’ve made.

While participants viewed themselves as the best advocates for their children’s rights, many expressed their surprise at finding themselves negotiating with bureaucracies. They did not

envision themselves as political activists when they first became parents of children with developmental disabilities. One mother described how she advocated for her child when she believed that the agency where her child lived was not providing a safe environment, “We had to write a letter with our lawyer’s help, stating that if she was harmed in any way that we would have to take legal action.” Another reflected on how her sense of advocacy had changed, “When I started, I never saw myself ending up here.”

Participants described the development of their advocacy roles as their duty. They soon discovered that advocacy was a complex multidimensional phenomenon. Participants described their role as advocates from a different vantage point. Whether they advocated with professionals, services, agencies or government Ministries, they developed their roles as advocates out of the need to protect their children. One mother commented that she felt, “intimidated by the political aspect. I don’t think I am knowledgeable enough to go that route.” She was, however, very active with her child’s school and belonged to a politically active support group. Another stated that she was more comfortable at the systems level, “I think that because I am active and participatory on the board. It’s not that I try to throw that around but I think that it subtly influenced the options and choices that he [her son] has.” A third mother indicated that she advocated with the government Ministry of Social Services:

I’ve been invited to go to the Ministry for meetings from January to June. The government’s vision is what they call individualized funding but it’s not individualized funding that other clients currently have, but to put more money directly to families. Because it’s so much more cost effective.

Advocating for their children was not always an easy process. Participants also spoke about areas where they required assistance. They discovered that accessing assistance could be

difficult. For example, they found funding applications to be complicated. They stated funding administrators, who were usually government representatives, were not particularly helpful in completing applications. Participants believed Ministry representatives did not give them all the information that they required to obtain adequate funding. They stated that the Ministry's objective was to save money and, therefore, their assistance reduced the amount of funding awarded. Participants found that other families were more effective at showing them how to complete the forms and provided direction on how funding could be used. Once approved, these funds were used to obtain home care and respite services that provided the family with support. As one mother observed, 'If you do a funding application wrong then you are cut off.' Another suggested:

What I find is that, you mustn't be intimidated by this form [application for funding]. You have to learn how to do it and be empowered. Because, if you don't know how to do it; you are not going to get what you want.

A third mother described her experiences, "They are not actually helpful because their goal is to save money. [Funding administrators] are not going to tell you, 'If you put that in you are going to get more.'" A fourth mother said:

You're so overwhelmed. You don't know who to talk to and what to do next. So other families helped to guide me. Things like how to apply for support money and how to spend it once you get it. It is really hard.

In conjunction with negotiating funding processes, participants looked to their communities for social networking and resources. They found that communities were not always able to support their children. For example, participants had learned that modifying the environment was more successful than expecting their children to conform to social norms.

Advocating in the community took on new meaning as participants learned the differences between accepting their children and society's expectation that their children would be 'acceptable.' As one mother explained:

Like today, this daycare at the gym. I got called to the daycare because [my son] had climbed up on some tables and would not come down. I think this girl is new but I only have ten minutes left in my gym program but she should have been able to handle what was going on. It wasn't that major, and she said a comment like "How do you put up with this?" And I'm like, "This is what he is like. I deal with it every day. He's usually not this bad." I'm thinking to myself, "Move the damn furniture."

Each of the participants described their experiences with advocacy as central to caring for their children. Whether they advocated at a personal, political, or social level, they believed that their participation improved their children's lives. They soon learned that others may not be as accepting of their children as they had hoped. As others questioned the decisions that they had made, they viewed decision making as an obligation to their children rather than an agreement between themselves and those who presented options. In developing their advocacy skills, participants frequently found themselves in conflict with services that were meant to support their children.

### Engaging in Political Action

As advocates, participants discovered that the available options might not be best for their children. They learned to navigate the political arenas in order to increase opportunities and meet their children's unique needs. Political processes affected funding in education, medication choice, community supports, residential options, social contacts, and many other areas of life.

Participants viewed engaging in a political process as essential in successful advocacy. One mother stated, “Things are going to change. I think parents really must take charge and not be intimidated by them [the Ministry personnel]. If you are not sure, phone another parent up. Then phone the Ministry.” Another described her experiences with advocacy, “So I have chosen to become involved in systems that influence the quality of life that he has and it has worked out to his benefit.” A father expressed his concerns about funding, “It was amazing. Even the cost of drugs, just because we have a handicapped child and are not covered.”

Having developed their abilities as advocates, participants perceived accessing services as a series of political struggles. Access to their children’s services was tainted by the possibility that they had to fight for services. As one mother said:

For the negative experiences are the long wait lists, difficulty connecting with other agencies, the unawareness of others, the lack of collaboration among some agencies, intimidation by school board, stress and guilt, reception by others, and the bureaucracy.

Participants believed that they were experts about their children and used this expertise to ensure that community supports met their children’s needs. They encountered many roadblocks along the way. Bureaucracies, funding, existing policies, and power struggles ensued.

Participants found that they had to participate actively in order to ensure that they received the supports that they believed would be most beneficial to their children. One mother said, “I had a sense of what I thought was right for him and what kinds of supports and services he needed.”

She also described her experiences with the politics of service provision:

I think that I was one of the agitators for changes in the special education system.

I was on the special education committees on school boards for years. I was on

the board of the Easter Seals, the federation for cerebral palsy. I made all kinds of representations through these organizations to the provincial government. My generation of parents were instrumental in many of the positive changes that have happened.

Participants did not always have positive experiences with political activities. One mother described how a school board member tried to teach her how to behave at meetings after she had spoken out about her concerns:

Anyway, I get a visit two days later from that lady to talk to me on behalf of the superintendent, the one trustee and herself on how to handle me. On how to follow the protocol of the committee. First of all I am not to sit at the table. This is a bit interesting. My very first meeting she invited me to sit at the table.

“You’re supposed to sit in the gallery.” Anyway it went on and on listening to her. “I know what it’s like. I have a son who is LD [Learning Disabled].” [I] couldn’t say anything [as a parent] at the committee. At that time, I got another parent to represent me on the committee. So if I had anything to say I had to pass her a slip of paper and she had to speak on my behalf. I was so angry I sat there and didn’t even look at her. I was trying not to cry.

Participants indicated that obtaining the right supports was often a struggle. They began by advocating for their children, but soon discovered that they were fighting for services. Participants stated that decisions made by bureaucrats who were unfamiliar with their individual context were often difficult for their children. They indicated that there was a lack of collaboration among services. Not only did service providers entertain different philosophies on how to support their children, participants felt pressure from service representatives to conform

to the proposed, available options. One mother stressed that she had to “pick [her] battles” because complaining takes time and energy that was not always available to her. Another spoke about the difficulties of coordinating goals for her child:

But even deciding particular goals, his teacher and I had a hard time because we are basing it on this IBI [Intensive Behaviour Intervention] program. We didn't know exactly what they were working on so it's like say, this is my goal for him socially and this is my goal for him playing-wise and safety-wise. And here's where I think I would like to see him go academically but I couldn't tell you what IBI he's working on right now.

Another mother described the pressure that she felt from teachers, “And they warned me that would be the worst decision that I ever made and I kept saying, ‘No, that's what I want,’ and it ended up being the best decision I ever made.” A third mother spoke about the possible consequences of not advocating, “If I hadn't come in with that I think they would just have put him in a regular classroom then probably kicked him out for bad behaviour.” A fourth mother described how she managed disagreements:

You can't fight it all. Don't sweat the small stuff. You've got to really figure out is it really worth it? You really got to figure that out because you don't want to be a complainer all the time. I have found over the years that there is always a battle. You have to pick and choose or else you run out of energy.

Participants believed that their role was to question the status quo in order to ensure that the proposed services would meet their children's needs. Building on their knowledge gained through experiencing life with children with developmental disabilities, participants' experiences with advocacy reinforced their perceptions that they knew what was ‘best’ for their children.

They found, however, that participation in decision making was not always easy. Regardless of pressure placed upon them by others, they based their decisions on what they believed to be right for their children. Over time, they developed their skills as advocates and learned how to negotiate politics and service provision.

#### Finding a Way

Despite adversities, participants described their relationships with their children as special. They saw their children as contributing members of their families. They found joy in accomplishments and agonized over challenges. In this light, they saw themselves as similar to other families. One father said:

I think that we are very fortunate with [our daughter]. She's not downtrodden. She's not sad. She's a happy go lucky kind. It's just like we would want for any of the family. She gets normal treatment. She doesn't get any special treatment.

Another father spoke about his son's accomplishments:

And it's just as important when he says, "Dad" or "Mom look," when he puts a puzzle together or something, that's just as important as when the kids come home and say look, I got an A or whatever, it's all such a reward and it feels so good to see accomplishment, to see that kind of accomplishment.

Participants in this study found joys in everyday living with their children. They described a shift in perspective that incorporated their children's happiness, hope for the future and acceptance of reality. As one mother said:

She's happy, we're happy. Would we change anything? That would be hard to say. We love her for who she is. Would we wish for more? Who wouldn't?

While participants talked about the joys associated with parenting children with developmental disabilities, they acknowledged that there was also a sense of loss. This loss transcended the initial diagnosis and permeated their lives as milestones were reached. For example, one mother described the experience of bringing her child to a group home for the first time:

It's not like you are dropping your kid off at residence at university. It's not like that. It's not the same sense of satisfaction. It's almost like you do it with a sense of regret. It's not something you feel necessarily good about even though you think you need to do it.

Despite experiencing sorrow, participants, in this study, utilized strategies in order to maintain a sense of well-being in their own lives. A mother described how she viewed her own situation, "You take what you get. You don't have an option. You can't pick and choose. When you make a decision to have a child, you support your family and your child."

One strategy participants described involved shifting perspectives and finding new ways to measure success. They also stated that their perspectives continued to change throughout their children's lives. As one mother said:

So, I've kind of moved in terms of my thinking with him. I am comfortable with where he is now. He's happy where he is. I just think I'm fortunate and he is fortunate. [My son] is in a different stage in his life now. He's moving into a more - like I'm not really interested in a lot of high level activity for him anymore, because he has moved beyond that. I'm more interested in maintenance of function, quality of life issues in terms of some leisure, interest, participation, and some kind of psychological well being. Because, I know his physical self is

going to worsen all the time.

Participants learned to think about their children differently and to figure out new ways of understanding them. Figuring out the meaning behind non-verbal behaviours and how to define successes was seen as crucial information that assisted in the development of their new identities.

As one father said:

[My son's] accomplishments, those milestones are just as rewarding to me as the other two [children] even though they are at a different level, the reward, the feeling of pride, whatever, is all the same.

Participants acknowledged that they viewed the world differently as a result of parenting a child who lives with developmental disabilities. While at first they felt lost and frightened, they soon began to make sense of their world through realigning their values. They stated that these experiences had changed them. These changes affected the way in which they made decisions. Their goals for their children shifted, from the generic expectations of children growing into adulthood, to understanding accomplishments in light of their children's abilities. As their goals changed, they modified their decisions to reflect their different viewpoints.

Participants acknowledged both their challenges and successes. They stressed the joys of having children who have developmental disabilities more than the difficulties. They formed alliances with other families in order to gather information, regained their sense of self identity, and garnered support. They made their decisions based on what they believed to be right despite personal anguish. They looked back on their experiences as a foundation for decisions that they might make in the future. They expressed hopes and dreams. They were aware that the future would hold new challenges. While, participants worried about the future options available to their children, they expressed confidence that they had learned from their experiences and were

ready to actively participate in future decisions as they arose. One mother stated, “I think I feel good now about the choices. I don’t have any regrets about the choices I made or the decisions I made. But the process was dreadful.” Another mother said:

You’re talking about making decisions for people and you are giving them the comfort that you are going to make the right decision for them. That they are going to trust you. It’s the time thing again. Just to put them in their comfort zone.

A third mother said, “Yes, I feel stronger. My decision making ability. Whether there is more out there is another story. I feel more confident in myself with my knowledge and how well it will turn out.” Finally, a father said, “I know [my son] and I know what I want. Whether I am ever going to get it or not is another story but...”

While comparing my secondary patterns, ‘difference and isolation,’ ‘changing relationships,’ ‘developing advocacy,’ ‘engaging in political action,’ and ‘finding a way,’ to some of the current nursing literature, I became aware that these patterns could be reorganized into four main theoretical constructs; marginalization, cultivating social supports, advocacy and reestablishing normalcy. In the following chapter, I discuss my findings in comparison to what is currently known, how this information informs nursing knowledge, and make suggestions for practice, education and research.

## Chapter Five

### Discussion of Findings

Making decisions for people with developmental disabilities when the individual's wishes are unknown is a complex, multifaceted phenomenon. While nursing standards suggest that 'best interests' should guide nurses in the informed consent process, family members in this study have demonstrated that determining what is 'best' is subject to interpretation. Participants viewed decision making through a lens of advocacy that transcended all aspects of their decisions. They perceived the individuality of the person with a developmental disability, personal experiences, community responsiveness, politics, and hopes for the future as important considerations. Each of these components is value laden and subjective. Therefore, decision making is not an isolated event. It is a process that is constructed by the relationship between the decision maker and the individual with a developmental disability. In order to further explore the process of decision making, I examined those relationships with a view to develop a new understanding of how decisions are made for people with developmental disabilities.

#### Marginalization

Once participants became aware that they had children with developmental disabilities, they viewed themselves as different from parents of children without disabilities. Their relationships with families and friends changed. They felt isolated and did not know where to go for assistance. In other words, they became marginalized by the experience of having a child with a developmental disability. Vasas (2005) described marginalization as a process by which individuals or groups are socially excluded and, as a result, experience inequities in the distribution of resources and power. Social isolation occurs at two levels. First, the individual or group becomes separated from the mainstream. Secondly, social connections and powerful

individuals identify the marginalized individual or group as different. Being recognized as different reinforces feelings of separation from the mainstream that created the marginalization in the first place (Sanders & Munford, 2007). Compounding the sense of isolation, marginalized people recognize themselves as outsiders. Perceptions of their personal differences reinforce the exclusionary process.

The process of marginalization occurs when there is a separation between the marginalized group and the center of accepted social structures (Vasas, 2005). Vasas describes the center of accepted social structures as an invisible but powerful force that defines the boundaries of social acceptance. Those who fall within those boundaries are not cognizant of the needs of the marginalized group. When members of the marginalized group speak, the center views their voices as unreasonable or incomprehensible.

Participants in this study recognized that they were separate from the center of society by virtue of their relationships with their children. Furthermore, they believed that others saw them differently. These experiences reinforced their feelings of isolation. When they looked for supports in their communities, they found that there was little understanding of their situations. They felt judged by professional and social contacts. Participants also found that they did not always agree with recommendation made by others. Their personal views about what was 'best' for their children were often not shared by professionals, family members or friends. This perceived difference increased their isolation and they became aware that decisions that they made for their children might not be congruent with the beliefs held by others with whom they shared relationships. As a result, participants looked to other families with children with developmental disabilities to find support and understanding.

### Cultivating Social Supports

In society, people tend to belong to multiple social groups. Within those groups, individuals migrate towards those with similar interests and social status (Mehra, Kilduff, & Brass, 1998). Members of small groups with distinct characteristics will use that distinction as a foundation for social identification. Social supports are positive mediators of family stress and well-being (Tak & McCubbin, 2002).

Participants followed this pattern, finding and associating with other parents who had similar experiences. These positive interactions reinforced feelings of competency, strength and encouragement (Gibson, 1995). While the experience of marginalization was difficult, finding new alliances within the marginal group was a source of emotional support and provided a sense of belonging (Sanders & Munford, 2007). Shared experiences were a powerful magnet to draw group members together. Within their groups, participants began to feel empowered as parents and developed strategies that would assist them when making decisions for their children.

### Advocacy and Fighting

Parents of children with disabilities consider advocacy to be a duty with moral implications (Wang, Mannan, Poston, Turnbull, & Summers, 2004). They emphatically argue that it is their role to intervene when their children's welfare is jeopardized. Advocacy has both positive and negative implications. It motivates parents to gain more knowledge about their children's disabilities, know their rights, and access resources. It also increases stress and positions the parent in opposition to the people who are charged with helping them.

Advocacy can occur at multiple levels. While advocacy may begin with interpersonal relationships, it can be used to influence change in systems and government policies (Wang, Mannan, Poston, Turnbull, & Summers, 2004). Participants in this study viewed themselves as

advocates for their children. They actively developed their knowledge about their children, and firmly believed that they knew what was 'best' for them. Parents were cognizant of the stress that advocacy placed on them. They found ways to reduce stress and spoke about taking care of themselves in order to be better advocates for their children. Participants also expressed concerns about alienating others. They realized that they needed community support in order to care for their children. Therefore, they chose their areas of advocacy carefully. At times, they decided to accept decisions that others suggested. In these circumstances, they either agreed with the decision or perceived that the decision was not major. Participants believed that disagreeing with every minor proposal would result in increased stress and alienate those who were there to support them. At other times, they made decisions that were not congruent with the values of the people who proposed the options. Participants found that these decisions could lead to power struggles.

As participants discovered, advocacy can often result in highly charged, emotional exchanges where opposing factions argue passionately about what is 'right' (Copp, 1986). Developing skills as an advocate involves effective communication, timing and negotiation. Yet, effective employment of these skills does not always guarantee success.

For parents of children who live with disabilities, participation and action are key components of advocacy (Dempsey & Dunst, 2004). Participation ensures that parents are engaged, and at the same time increases their opportunities for decision making. Furthermore, participation increases competency as parents develop partnerships with service providers.

Developing partnerships between parents and service providers is fraught with challenges. Shaddock (2003) states that, in order to participate effectively, parents need bureaucrats to listen to them and give credibility to their positions. In the absence of responsive

bureaucrats, parents are charged with gathering information and communicating their concerns in language that bureaucrats will understand. Marginalization occurs when one group exercises power over another (Sanders & Munford, 2007). If bureaucrats are not responsive to parents, they reinforce exclusion by denying access to resources and reducing the parents' opportunities to participate. Without bureaucratic responsiveness, parents remain marginalized and risk increased isolation from the mainstream.

Along with exclusionary group practices, powerful individuals can further impede participation by remaining impervious to marginalized voices. Professionals who insist that they know what is best can impede independent decision making and contribute to continued marginalization (Thorne, 1993). Recipients of such practices feel dehumanized and powerless to participate in changes that they believe are necessary.

Participants in this study viewed themselves as active and participatory advocates for their children. They described emotionally charged encounters that left them feeling frustrated and further alienated them from the people who were supposed to help them. Participants described situations where professionals disagreed among themselves as to which approach might be best for their children. Not only did some professionals espouse different philosophical approaches but others who agreed ideologically had different interpretations in practice. These differences made participants cautious about accepting advice offered.

One example of conflicting approaches can be found in the ideology of normalization. Recently, the concept of normalization has predominated in the field of developmental disabilities (Culham & Nind, 2003). According to Wolfensberger and Thullman (1982), the principles of normalization mean that human management practices facilitate an environment where people with developmental disabilities are provided opportunities to function in ways that

are consistent with the accepted norms of their society. The underlying school of thought is that people with developmental disabilities should be integrated into normal society with the same rights and privileges as all other people. As a result of accepting normalization as a dominant ideology, people with developmental disabilities have been offered opportunities to learn, share relationships, and participate in society in ways that were never afforded them in the past.

People in society do not always accept people with differences. The stigma attached to difference has served to segregate people with developmental disabilities, even when living outside institutions. As a result, the offshoot of normalization has been an attempt to decrease the difference between this population and the non-disabled group. A distinction between acceptable and unacceptable behaviour has placed strict conditions on how people with developmental disabilities live (Culham & Nind, 2003). In the best interests of the person who is being integrated into normal society, he or she may lose the freedom to roam, the right to engage in a favoured repetitive movement, or to behave in a child-like manner. Although the intention of normalization was the inclusion of people with developmental disabilities in society, the results have taken on a moral dimension about the right and wrong way for people with developmental disabilities to live in their communities. This perspective has located the problem within the person rather than sharing the problem with all members of society (Dudley-Marling, 2004). In other words, the person with the developmental disability is encouraged to change rather than questioning the morality of exclusion itself.

Participants clearly articulated the dichotomy between normalization and their everyday realities. They had learned that professional disagreements on the interpretations of paradigms might result in diverse opinions on what was 'best' for their children. These experiences

reinforced their perceptions that they, as parents, had to make decisions based on their own understanding of the issues rather than relying on the expertise of others.

### Reestablishing Normalcy

While participants experienced many difficulties in raising children with developmental disabilities, they also shared many of the joys that their children had given them. In an interpretive study about the experiences of having children with developmental disabilities, Kearney and Griffen (2001) found that, despite adversity, parents find their children to be a source of love, joy and strength.

Participants' perspectives changed once they became parents of children with disabilities. In this study, assumptions about accomplishments, and how to measure success were challenged through the parents' relationships with their children. Participants found joy in areas that other parents take for granted. Surviving illness or learning a developmental skill took on new meaning as participants experienced life with their children. They shifted their perspectives from one of not meeting expectations to one of nurturing hopes and dreams.

Participants' joy was tempered with a sense of sorrow. Along with celebrating their children's accomplishments, they grieved the loss of expected potential. Participants redefined their sense of what was normal in order to normalize their current realities (Thorne, 1993). Efforts to reestablish normalcy were a complex process that involved, among other things, emphasizing the positive, gaining self reliance, becoming well informed, and regaining control. These responses provided a philosophical perspective that led towards health and well-being. From this new-found position of strength, participants made decisions for their children based on their own understandings of their new reality. They were acutely aware that these decisions might differ from those recommended by other people.

Participants in this study began life with their children from a marginalized vantage point. They gained strength from learning about their children's unique personalities, developing supportive relationships with others and regaining control over their lives. They became effective, well informed advocates and repositioned themselves as politically active representatives for their children. Participants did not view decisions that they made for their children as isolated events. They believed that they made decisions in the context of their lives, their experiences, and their relationship with their children.

While in this study I have focused on the decision makers' perspectives, the results have implications for practice, education and future research. Understanding that decision making for people with developmental disabilities is a contextual, multidimensional phenomena raises questions about how professionals can facilitate the decision making process. In the next section, I discuss how findings from this study might inform knowledge about professionals' participation in decision making.

#### Legitimate Knowledge

When decision makers and professionals encounter situations where decisions have to be made, the question of who possesses enough knowledge to decide what is best is central to the process. Knowledge developed from subjective experiences frequently challenges professionals' beliefs about what constitutes legitimate knowledge. May et al. (2004) found that, when a patient asks a physician for assistance, the physician considers the patient's motive for requesting assistance, the physician's understanding about the legitimacy of presenting symptoms, and the congruence between the patient's and physician's understanding of health and illness. When patients present with subjective accounts of illness that are contrary to the physician's objective observations, the physician may be uncertain as to how to respond. Furthermore, when a patient is

unwilling to accept the physician's recommendations, the physician may question the legitimacy of the patient's motivation for seeking help. In this context, the patient and the physician can enter into the relationship with different ideas about the nature of health and illness.

While participants clearly articulated this impasse in their accounts of their relationships with physicians, they extended their interpretations to include other professionals from whom they sought assistance. They stated that decisions made out of the context of their subjective experiences were not congruent with what was 'best' for their children. As a result, they expressed the belief that they must teach others about their children. They viewed teaching others as a component of advocacy.

In order to facilitate the decision making process, professionals need to understand the subjective experiences of decision makers. Accepting subjective knowledge as credible means that professionals understand that decision makers have a role in teaching them about their relatives with developmental disabilities. Understanding that decision makers are knowledgeable advocates for their relatives ensures that the experiences of the person who lives with the developmental disability is included in the decision making process.

#### Relational Advocacy

Authors in nursing literature suggest that advocacy stems from listening to individuals, continuous evaluation, and respect (Vaartio & Suominen, 2006). Contextual sensitivity to the individual who requires advocacy is an antecedent for meeting the individual's needs rather than the needs as perceived by the advocate. Participants in this study claim that meeting an individual with developmental disabilities for a short period of time does not provide enough information for professionals to be contextually sensitive.

Developmental disabilities frequently affect the individual's communication ability, thus making it difficult for the person to explain him or her self to others. With reduced verbal ability, body language becomes an important augmentation to communication. Facial movements, gaze, touch, gesticulation, interpersonal spacing, posture, odour, and sound are important indices of non-verbal communication (Chambers, 2003). Particular indicators are not easily translated. Non-verbal expressions do not necessarily mean the same thing each time they are observed, even in the same individual. Out of context, non-verbal expressions can be meaningless. In order to create meaning at a non-verbal level, relationships have to evolve over time (Meininger, 2001).

Participants clearly articulated the concept of knowledge over time. They consider their relationships with their children as interdependent where the 'best interests' of their children can only be understood in the context of their shared experiences. Participants believed that they acted in concert with their children when making decisions. In this context, advocacy takes on relational dimensions where the decision maker and the decision recipient are viewed as one. As one mother said, "We are a team - she [her daughter] tells me and I tell them."

In the current health culture, accepting subjective interpersonal knowledge and relational advocacy as a legitimate foundation for professional responsiveness to caring for people with developmental disabilities might be difficult to actualize in practice. My findings, from this study, suggest that future policy development and health care delivery practices should consider including the subjective knowledge of parents and relational advocacy as important considerations when making treatment decisions. In the following section, I consider implications to practice, education and research in light of these findings.

### Implications for Practice

Recently, the lack of clear vision among policy makers has led to confusion about how to best support people with developmental disabilities in the community (Culham & Nind, 2003). Mainstreaming has become synonymous with putting people with disabilities into situations that are not able to support them. Health professionals have also been caught up in this dilemma. Without knowledge of the special needs of this group, they are asked to provide a service with expertise about a non-disabled population. Finding ways to integrate services remains a challenge. As my findings suggest, learning about the health needs of people with developmental disabilities begins with establishing relationships with those who know the person best. Understanding that this population is particularly vulnerable to health challenges and that manifestations of illness are not easily recognized, nurses and other professionals need to acknowledge the expertise of relatives who act as substitute decision makers. Changes in usual behaviour may be linked to underlying pathology (Davidson et al., 2003). Without the assistance of someone who knows the person, prevention and early detection of disease may be compromised (Lewis, Lewis, Leake, King, & Lindemann, 2002). If prevention and early detection of illness occur later in the disease process, making the right treatment decisions may occur at a more acute phase of the illness. As a result, decisions will have higher consequences.

Once diagnosis has occurred, substitute decision makers engage in making treatment decisions. Considering that families who have children with developmental disabilities have been marginalized, professionals must interface with relatives with an understanding of the experiences, consequences, and processes of marginalization (Vasas, 2005). The family decision makers in my study experienced a shift in their thinking about goals, dreams, and ideas about quality of life. As a consequence, they have not always agreed with professionals'

recommendations for interventions. Their experiences of power imbalances and advocacy give them a different perspective about decision making. The processes of hierarchical professional ideology have served to further marginalize them from generic services. Professionals who link decision making and the context under which decision making occurs can reduce power imbalances. Engaging the substitute decision maker through inclusion and participation honours the legitimate knowledge that they possess and increases the potential that decisions made will be 'best' for the individual (Sanders, & Munford, 2007).

Marginalization is a social process that produces power imbalances between professionals and the relatives who make decisions for their family members with developmental disabilities (Vasas, 2005). The experience of having a child with developmental disabilities contributes to the social isolation of the family. The consequences of continued marginalization have direct impact on how families make decisions for their relatives. Families in this study responded to marginalization by developing their skills as advocates for their children. When accessing health care, families may have learned how power imbalances negatively impact the health of their children. Professionals who are contextually sensitive to families who make decisions for their relatives with developmental disabilities reduce the power imbalances that support the families' continued marginalization.

Participants clearly viewed the relational aspects of advocacy as central to their decision making. While advocacy occurred in relation to the individual, participants had experienced advocacy from multiple levels. They engaged with systems and had acted as case managers, mediators, educators, and process facilitators. Professionals, who view advocacy from an individual perspective, may not be cognizant of all the factors that influence decision making. Consideration of the complex and often divergent forces that influence decisions will guide

professional understanding from the decision maker's perspective (Copp, 1986). Thus, facilitating advocacy becomes a process where the professional, the decision maker, and the individual with the developmental disability work together to understand both individual and social dynamics that influence health.

While advocacy is often linked to individual rights, the concept of social advocacy addresses the inconsistencies and inequities that exist at a systems level (Bu & Jezewski, 2007). At the individual level, professionals must recognize the vulnerability to health challenges for people with developmental disabilities. Furthermore, they should consider the decision maker and the individual as interconnected. At the social level, professionals need to advocate for changes to health care systems that continue to marginalize this population. Inadequate educational preparation, stigma, and empirical practices contribute to the continued disparity in health care for this group. Professionals who care for this population must consider processes that safeguard the individual as well as championing equitable health care at a systems level. Deciding what is 'best' for this population is far more complex than previously imagined. In the current health culture, accepting subjective interpersonal knowledge and relational advocacy as a legitimate foundation for professional responsiveness to caring for people with developmental disabilities might be difficult to actualize in practice. My findings suggest that future health care delivery practices and professional education curricula should consider including the subjective knowledge of parents and relational advocacy as important considerations when making treatment decisions.

#### Implications for Education

Health professionals, who may not have education and experience with people with developmental disabilities, will become increasingly exposed to this population as community

integration continues. Without knowledge about the special needs of this population, professionals will have difficulty determining what relevant information to share with relatives who make decisions. This study shows the importance of including education about decision making for people with developmental disabilities in generic curricula. As any policy has the potential to be distorted by the practitioners who interpret and enact its mandate (Culham & Nind, 2003), combining visionary public policy with education about developmental disabilities would increase the probability that current challenges could be resolved. Many medical and nursing schools do not include the specialties associated with developmental disabilities in their generic curricula (Lewis, Lewis, Leake, King, & Lindemann, 2002). Increased professional education about the meaning of marginalization, cultivating social supports, advocacy and reestablishing normalcy for family members who have relatives with developmental disabilities would provide professionals with knowledge that would be invaluable for supporting decision makers. Unfortunately, the educational needs of professionals who treat people with developmental disabilities have not been extensively studied. I have considered some areas that might provide suggestions for future research and knowledge development.

#### Implications for Research

Little is known about the perspectives of health care professionals who participate in decision making for people with developmental disabilities. Without knowledge of their perceived needs, it is difficult to make recommendations about enhancing curricula. As a result, I think that it would be useful to conduct research about health care professionals' current knowledge in the field of developmental disabilities with a view to identifying gaps in current curricula. This research would benefit professionals when they are asked to support family members who are engaged in 'best interests' decision making.

In conjunction with studying professionals' perceptions about knowledge development in the field of developmental disabilities, I would be interested to know about the experiences of people with developmental disabilities when 'best interests' decisions are made for them. Research in this area would illuminate the positive and negative consequences of current practices. In my study, participants described differences in opinion with professionals as to what constitutes 'best.' Participants also pointed out that there was disagreement among the professionals who provide care. These differences increase the challenges associated with 'best interests' decision making. Gaining further understanding of the experiences of people with developmental disabilities for whom decisions are made would provide valuable information that would guide future practice.

Finally, examination of the complex relationships among substitute decision makers, professionals, and people with developmental disabilities would increase understanding of how these dynamics influence decisions. 'Best interests' decisions are facilitated through the interpersonal relationships among those engaged in the process. Yet, little is known about how these relationships affect decisions. I believe that increased knowledge about these interpersonal relationships would provide professionals with information about how to support family members and their relatives with developmental disabilities.

#### Limitations of the Study

Qualitative research occurs in the context of the information shared by the participants who took part in the study and the interpretations of the researcher (Lincoln & Guba, 1985). Therefore, the findings of this study are contextual and cannot be generalized. The theories proposed in this research are bound by the experiences of the 11 participants. I expect that the

findings will expand professional thinking and suggest areas for further research in the field of developmental disabilities and decision making.

Despite the acknowledged limitations of this study, the findings resonate with the research of others. Parents of children with developmental disabilities experience repeated negative responses from professionals (Stoner, et al., 2005). Information is withheld, trust is violated, and parents believe that they have to fight for service. They describe their experiences with advocacy as a struggle (Wang, Mannan, Poston, Turnbull, & Summers, 2004). They perceive this struggle as lifelong and energy draining and they see their role as advocates as essential to responsible parenting (McCabe, 2007). Furthermore, they perceive the effectiveness of therapeutic supports as related to the professionals' technical skills and their ability to work collaboratively with parents (MacKean, Thurston, & Scott, 2005). As the participants clearly expressed, they are the experts about their children and expect professionals to recognize and value their expertise.

### Conclusion

While 'best interests' decision-making appears on the surface to be a fair and equitable standard by which treatment decisions are made, a closer look reveals the complexities that can either positively or negatively influence the perception of what is 'best.' When I began researching the experiences of family members who make decisions for their relatives with developmental disabilities, I knew that family members were experts about their relatives and considered quality of life as a subjective component of decision making. During the study, however, I became cognizant of the fact that the experiences of family decision makers had shifted their perspectives in ways that I had not imagined. The experiences of marginalization invoked a fundamental change in thinking that I had not fully appreciated. This realization has

changed my practice. Instead of trying to understand how family members perceives the concept of 'best interests,' in the future, I will search for the meanings embedded in the experiences of marginalization in order to truly comprehend how to support family members during decision making.

I have also gained knowledge about the processes that continue to marginalize these families. Cultural labels that group family decision makers into categories like 'difficult,' 'nice,' 'involved,' and 'not involved' place families into categories without understanding their experiences. As a professional, I have learned that families experienced diverse reactions to becoming different and isolated. Their sense of self within relationships had changed. They have had to learn to advocate and have redefined their ideas about normalcy. Being aware of these experiences, I believe that I will be more mindful of the power imbalances that exist between the families that I encounter and my presence as a nurse. With this new knowledge, I believe that the relevant information that I provide during decision making will be more contextual and arise from a genuine effort to understand their experiences from a marginalized standpoint.

As community integration practices promote the use of generic health services, information on the health experiences of people with developmental disabilities within this context is essential. Knowledge development of the health issues that face this population along with an understanding of how dominant ideology and public policy affect decision-making will assist professionals to participate in providing reasonable information to make best interests decisions.

Throughout this research, I have demonstrated the need for increased knowledge about how substitute decision makers make decisions for their relatives with developmental disabilities when their wishes are unknown. In choosing to conduct a qualitative study, I assumed that

substitute decision makers construct discourses about the decisions that they have made and that these discourses shape how they navigate their world with their relatives with developmental disabilities. From my vantage point as a nurse, and supervisor within this specialty, and the sister of a man who lives with a developmental disability, I have become aware of discrepancies between the discourses of the professional 'best interests' standard and the way in which families decide. I value the participants' perspectives in shedding light on what these decisions mean to them. Deconstruction of the discourse of family decision making through interpretive description provides professionals with a vantage point from which they may support families in the future when treatment decisions are made.

Health for people with developmental disabilities depends on the establishment of supportive structures at all levels of care giving. Families, professionals, educators, support staff, policy makers and all other participants in the lives of people with developmental disabilities must recognize the unique qualities of this population. Decision making affects the individual and the family and also has social implications for the future. Accessibility to health care means that the social inequities that create marginalization are addressed individually, socially, and politically. The health of people with developmental disabilities depends on it.

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Appendix I

Funding Letter



December 18, 2006

Mrs. Deirdre Gillespie  
c/o Ongwanada  
191 Portsmouth Avenue  
Kingston, Ontario  
K7M 8A6

Dear Deirdre:

I am pleased to inform you that your application for a student research project grant from the Southeastern Ontario Community-University Research Alliance in Intellectual Disabilities (SEO CURA in ID) has been successful. The grant (a value of up to \$2,660.00) is offered to you to support the completion of your project entitled "*How substitute decision makers make decisions for their relatives who have a developmental disability when the wishes of the individual are unknown*" provided you can meet the following terms and conditions:

1. Submit a copy of your final protocol, approved by the University of Victoria, School of Nursing including a timetable for completing the project.
2. Provide a copy of the documents concerning your project submitted and approved by a University Research Ethics Board and a copy of the Ethics Board certificate of approval.
3. Agree to provide a verbal update to the Training and Education Subcommittee of SEO CURA in ID at its Fall 2007 or Spring 2008 meeting (indicate acceptance of award).

You are to submit receipts for expenses to be paid by SEO CURA in ID. Only items allowable as per SSHRC research grant and Queen's University policy will be covered. Please discuss these with Carole Morrison or myself prior to making any purchases/expenditures.

If you agree to these terms and conditions, please complete and return a signed copy of this letter along with the required documents to me as soon as possible.

Caring • Inclusion • Commitment

191 Portsmouth Avenue Kingston, Ontario K7M 8A6  
(613) 548-4417 or toll free 1-866-656-4417 ext. 1115  
Fax: (613)548-8135 Email: [info@seocura.org](mailto:info@seocura.org)  
<http://seocura.org>

Congratulations on your success in this competition. I wish you well in your research and studies.

Sincerely,

Hélène Ouellette-Kuntz  
Director and Steering Committee Co-Chair  
SEO CURA in ID

cc. Stephen Dukoff, Chair (Acting), Training and Education Subcommittee, SEO CURA in ID  
Alan McWhorter Steering Committee Co-Chair, SEO CURA in ID

I, Deirdre Gillespie, accept the research grant from the Southeastern Ontario Community - University Research Alliance in Intellectual Disabilities.

I agree to the terms and conditions outlined in the above letter and have attached all requested documents.

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Deirdre Gillespie

Date

Appendix II

Letter to Representatives of Member Agencies

Dear \_\_\_\_\_,

My name is Deirdre Gillespie. I am a Master's of Nursing student at the University of Victoria. I am currently employed as a Residential Nursing Supervisor at Ongwanada in Kingston, Ontario. As part of my studies, I must complete a thesis research paper. As a representative of a member agency for Southeastern Ontario Community-University Research Alliance in Intellectual Disabilities (SEO CURA in ID), I request your assistance in finding participants for my study.

I am interested in learning about the experiences of people, who are acting for relatives who have developmental disabilities, make decisions for them when their wishes are unknown. The criteria for participation are: to be a relative of a person with a developmental disability; to have acted as a substitute decision-maker in some capacity; to be English speaking and to be willing to discuss this experience with me.

I would like to contact you by telephone to discuss the best way to recruit participants from your agency. For this purpose, I have prepared letters, flyers, and posters for distribution. I am also willing to present my research in person to individuals or groups. I am cognizant of the privacy of the people that you support and would also like to discuss an approach that would maintain confidentiality.

This research has received ethical approval from the University of Victoria and has received funding from SEO CURA in ID.

Thank you for your assistance.

Sincerely,

---

Deirdre Gillespie  
Master's in Nursing Student  
University of Victoria  
(613) 389-6154  
[dgillespie1@cogeco.ca](mailto:dgillespie1@cogeco.ca)

Appendix III

Flyers and Handouts



Looking for...

**FAMILIES** who have made **decisions** for a **relative** with a **developmental disability**, when the **wishes** of the individual were **unknown**.

The **results of this research** will assist nurses in **supporting families** when they have to make decisions for their relatives who live with developmental disabilities. Sometimes these decisions can be very difficult. Knowing the kind of support that a nurse should give would **help families** and **people who live with developmental disabilities** in the future.

### Criteria for this Research Project

- Be over eighteen years of age
- Have a relative who has a developmental disability
- Have acted as a substitute decision maker for your relative
- Be English speaking
- Be willing to share your experiences with me



Contact:

Deirdre Gillespie

(613) 389-6154

[dgillespie1@cogeco.ca](mailto:dgillespie1@cogeco.ca)

This research has received ethical approval from the University of Victoria and funding from Southeastern Ontario Community-University Research Alliance in Intellectual Disabilities (SEO CURA in ID).

Looking for...  
**FAMILIES**  
who have made decisions  
for a relative with a  
**developmental**  
**disability,**  
when the wishes of the individual  
were unknown.



### Criteria

- Be over eighteen years of age
- Have a relative who has a developmental disability
- Have acted as a substitute decision maker for your relative
- Be English speaking
- Be willing to share your experiences with me

The results of this research will assist nurses in supporting families when they have to make decisions for their relatives who live with developmental disabilities. Sometimes those decisions can be very difficult. Knowing the kind of support that a nurse should give would help families and people who live with developmental disabilities in the future.

Thank you \_\_\_\_\_  
for your interest in my research.

My name is **Deirdre Gillespie** and I am a **Masters of Nursing student** at the **University of Victoria**. I also work as a **nurse** with people who live with **developmental disabilities** in **Kingston, Ontario**.

### Contact

Deirdre Gillespie  
(613) 389-6154

[dgillespie1@cogeco.ca](mailto:dgillespie1@cogeco.ca)

All of the information from our meeting will be given a code so that **your name will not be used** on any documents or tapes.

I will offer you **compensation** for your mileage and/or childcare expenses.



This research has received ethical approval from the University of Victoria and funding from Southeastern Ontario Community-University Research Alliance in Intellectual Disabilities (SEO CURA in D).



Appendix IV

Letter to Prospective Participants

Dear \_\_\_\_\_,

Thank you for your interest in my research. My name is Deirdre Gillespie and I am a Master's of Nursing student at the University of Victoria. I also work as a nurse with people with developmental disabilities in Kingston, Ontario. As part of my studies, I must complete a research paper and write a report. By doing this research, I hope to learn more about the experiences of families who make decisions for their relatives with developmental disabilities.

In order to participate, you must meet the following criteria:

- ? Be over eighteen years of age
- ? Have a relative who has a developmental disability
- ? Have acted as a substitute decision maker for your relative
- ? Be English speaking
- ? Be willing to share your experiences with me

I would like to speak with you in person. I am willing to come to your home or meet you at any other location that is convenient. If you travel, I will offer you compensation for your mileage and/or childcare expenses. I would like to audiotape our conversation and take notes. Later, I will transcribe the tapes and notes onto my computer. All of the information from our meeting will be given a code so that your name will not be used on any documents or tapes.

I am asking you to meet with me on two occasions. I have attached a list of questions that I will ask you during the meetings. Each meeting should take about an hour. During the first meeting, I will ask about your experiences. The second meeting is needed so that I can share my findings with you. I would also be very interested in your opinion about how I have used the information that you gave me.

The results of this research will assist nurses in supporting families when they have to make decisions for their relatives with developmental disabilities. Sometimes these decisions can be very difficult. Knowing the kind of support that a nurse should give would help families and people with developmental disabilities in the future.

This research has received ethical approval from the University of Victoria and funding from Southeastern Ontario Community-University Research Alliance in Intellectual Disabilities (SEO CURA in ID).

Thank you again for your interest.

Sincerely,

---

Deirdre Gillespie  
Master's in Nursing Student  
University of Victoria  
(613) 389-6154 dgillespie1@cogeco.ca

Appendix V

Trigger Research Questions for Participants

First Interview

- ? Could you please tell me about your relative who has a developmental disability?
- ? Could you tell me a bit about a decision that you had to make for your relative?
- ? Can you describe the information that you received before you made this decision?
- ? Could you share your reactions to this information?
- ? What did you think about when you made this decision?
- ? What helped or hindered your decision making?
- ? What were your expectations after you made this decision?
- ? Could you share what you think about this decision now?
- ? Is there anything that you would like to add?
- ? I will answer any questions that you might have about the research.

Second Interview

- ? I will tell you about my research findings
- ? I will ask for your opinion of my findings
- ? I will answer any further questions that you might have about the research.

Appendix VI

Participant Consent Form

You are invited to participate in a study entitled “The Experiences of Family Members Who Make decisions for their Relatives with Developmental Disabilities when the Wishes of the Individual are Unknown.”

My name is Deirdre Gillespie. I am a graduate student in the School of Nursing at the University of Victoria. You may contact me at (613) 389-6154. As a graduate student, I am required to conduct research as part of the requirements for a Master’s of Nursing degree. This research is being conducted under the supervision of Dr. Rosalie Starzomski. You may contact my supervisor at (604) 733-4862.

In addition, you may verify the ethical approval of this study, or raise any concerns that you might have by contacting the Human Research Ethics Office at the University of Victoria (250) 472-4545 or email [ethics@uvic.ca](mailto:ethics@uvic.ca).

The purpose of this research project is to gain a better understanding about how people, who are acting for a relative with a developmental disability, make decisions for them when their wishes are unknown. This research looks at how you make decisions as a substitute decision maker by asking about your past experiences with decision making and what you think about this decision now.

The results of this research will increase knowledge about how to support substitute decision makers while they are making decisions for another. Sometimes these decisions can be very difficult. Knowing the kind of support that a professional should give would help substitute decision makers and people with developmental disabilities in the future.

You have been asked to participate in this study because you responded to a letter that I sent to you by mail.

If you agree to voluntarily participate in this research, your participation will include two interviews. Each interview will last from one to two hours. I will audio tape the interviews, take notes, and, later, transcribe the tapes and notes to a computer.

This study may cause some inconvenience as the length of time for the interviews will take you away from your normal activities.

There is a possibility that you may experience fatigue and/or emotional upset during the interviews. In order to prevent or deal with these risks I have provided a list of questions in my introductory letter. I will listen to your story with respect and interest. If you become tired, we could stop the interview and resume at another time. If you become emotional, I am willing to talk to you about how you are feeling or call someone else who would be supportive towards you. I will stay with you until the other person arrives. You may also stop participating in this study at any time.



Appendix VII

Level One Codes

Figuring Out how to Support People with Developmental Disabilities

From birth, participants described a process of learning about their children's way of being in the world. Many turned to their family physicians for advice. Their initial encounters with professionals were described as unsatisfactory. While the two parents of children with Downs syndrome knew immediately about their children's diagnosis, they expressed disappointment in the way that the professionals responded to them. One father stated:

I was in the nursery when he went in after he was, you know, she had just delivered the baby. I said to the nurse, "Ten fingers, ten toes. OK, eh? Everything's great." She looked at me like um... She didn't look at me like I was very bright or something and then she was going to take blood and she more or less she scowled at me. I don't know. I can remember that.

A mother described her reactions when her child was born:

I knew beforehand. I knew there was something wrong. I'm not stupid. They put a baby in there [the NICU]. Well, he told me and [I] already knew anyhow because I went and read the chart without anyone knowing. It was sitting wide open. Being a nurse, so I know.

The other participants described a process of convincing their physicians that something was wrong with their children. They stated that professionals were not always knowledgeable about developmental disabilities. They claimed that this lack of knowledge delayed initial diagnosis and, at times, physicians were dismissive of the parents' concerns. One mother stated,

“I didn’t get any - didn’t get a lot of help from the family physician. He didn’t see a pediatrician and the family physician seemed satisfied that he was developing.” Another mother agreed:

When I went to the family doctor the first time and he said, “Oh nothing’s wrong.”

When I went back the second time I said, “No, something is wrong.’ I wanted a referral to somewhere to get a diagnosis because I did n’t think my family doctor knew much about autism.

A third mother spoke about her physician’s reactions to her concerns, “But I started going to my family physician. And he said, ‘It’s just a stage, nothing to worry about.’”

Once physicians acknowledged that the children were not developing normally, the participants described a series of lengthy investigations that often led to the elimination of another diagnosis rather than providing answers about what was happening to their children. One mother remembered, “Although at one point, I noted that if I jingled my keys behind his head he would not turn and look at them. So we had his hearing tested and it was normal.” A second mother stated, “And actually we had a blood test done to see if he had Fragile X at the same time. We were trying to cover all the bases there.” A third mother described her experience with obtaining a diagnosis, “I would call this diagnosis by the process of elimination.” A father spoke about his experiences:

By the time she was about a month old when babies start tracking and following, she wasn’t doing that. So originally we thought she might be blind because she wasn’t tracking. That didn’t pan out, that wasn’t what was wrong.

When a diagnosis of developmental disability did occur, participants described a process of learning about their children. Participants found that, as their children grew, their behaviour sometimes fell outside of the participants’ expectations of normal development. They stated that

they had to discover new ways of managing ordinary situations. They described a process of trial and error that assisted them in establishing routines, developing new ways of doing things, creating new opportunities, and embracing a different way of understanding. One mother commented, “I hear parents complaining when I’m at work or something about their kid not being toilet trained at 2 years old and I think to myself, ‘Well he wasn’t toilet trained until he was 8.’” Another reflected:

I think that one of the big mistakes that I made in the beginning of this whole thing was sometimes I wait too long before I do give her extra medication because I don’t like, nobody likes their kids drugged. Right?

A third mother spoke about strategies that she had learned:

Do not try to force her because she will not be forced and you know that’s more important than anything else. Because staff will get frustrated, she will get frustrated. No, in the end you can’t make her do it. Doesn’t matter. Just walk away from her. Come back in five minutes and she’ll be fine, usually. Wait that time out. You have to learn these things.

Participants stated that figuring out how to support their children was a part of decision making. They acknowledged that this understanding develops over time. They make their decisions based on what they have learned about their children’s reactions. Their initial perceptions, that the professionals were not supportive of their situations, led participants to rely more extensively on their own understanding of what was happening to their children. When professionals dismissed their concerns, they learned to become more persistent in their quest to find answers. As illustrated by the experiences of those participants who did not have a diagnosis from birth, multiple investigations reaffirmed their concerns that professionals may not have the

information that they needed. As participants began to figure out how to support their children, they developed a reliance on their own perceptions of what decisions were best for their children with developmental disabilities.

### Life's Struggles

While describing how they learned about their children's developmental disabilities, participants spoke of the personal struggles that they experienced along the way. They suggested that life in general has its share of struggling. They found that their own struggles were exacerbated by the personal doubts, trying to maintain a balance, changing relationships and a sense of loss. One mother described her family's struggles, "When he was two years old my husband and I lost our jobs at a manufacturing plant and I went back to school to be a teacher."

Another spoke of struggling this way:

You know. I try really hard to maintain what I've got. I think what's difficult, when I have a really good day, which I have once in a while, when she can do a little bit more, I think wow, maybe I can do this every day. And it doesn't work that way. It's really disappointing because I try so damn hard, I do.

A father spoke of pressures from others:

So I have this pressure from these people telling me what I should do and how it's going to negatively affect [my son] but I go with my gut and I say no, this is what I'm going to do. But it makes you judge. Am I being a bad parent?

In addition to personal struggles, participants described how others reacted to their situations. They acknowledged that extended families were not always supportive and that friends could be judgmental. This added to the participants' sense of uncertainty. One mother commented: "Well even before his diagnosis, my mother-in-law, love her to death, was saying

things I was doing wrong. Like, I wasn't parenting right." Another described the reactions of friends:

Friends of hers that asked her, "Wouldn't you get an amniocentesis?" You know what's behind the question. You know it's kind of your fault because you could have done something about it and prevented having the child.

Participants learned from their difficult times and based new decisions on past experiences. They found that their goals changed. Whether it was a change in career or a shift in perspective, participants realized that they viewed their struggling differently than before they had children with developmental disabilities. They began to understand that others, who may be well-meaning, did not completely appreciate the complexities of their situations. These experiences reinforced the participants' belief that they, not others knew what was best for their children with developmental disabilities. While they considered how their decisions affected their relationships with friends and family, over time, they developed a sense of what would work in their particular circumstances.

#### The Behaviour of People with Developmental Disabilities

Despite personal doubt and the judgment of others, participants indicated that they learned more as their children grew. Over time, they began to associate their children's behaviour as a form of non verbal communication. While individual manifestations of behaviour might not have immediately made sense to participants, they believed that time spent understanding what the individual is communicating was essential to decoding meaning. Participants stated that individual's communication behaviour changed over time with maturation. Therefore, decisions made at one stage of development might be different from those made at another stage. One mother interpreted her child's behaviour this way, "She can't do the

steps. She can't get her body to cooperate with her mind you know. It's not a willful thing."

Another described how her child's behaviour changed over time: "When you have a person that's suddenly coming forward with obvious changes like this right, not only did she needed more, she needed to be supervised after this at all times.

In conjunction with adjusting to changes over time, participants spoke about some of the challenges they faced when their children had difficulties communicating. Participants stated that their children exhibited non-verbal cues that indicated frustration. This frustration could be manifested through behaviour that is commonly referred to as challenging. Challenging behaviours included; running away, smearing feces, throwing objects, yelling, refusing to participate, and hitting themselves. One mother described her child's behaviour, "He ran away regularly, I mean if we took him to the mall he would just take off and showed no interest in where I was or where his father was." Another talked about her child's behaviour after an incident at school, "And so for the following week after he would come home from school, strip naked and he would urinate or do the other on his bedroom floor and was playing with it." A third described how her child expresses frustration, "She bites her arm or she'll pound a wall or a counter or whatever."

Participants expressed that, rather than trying to change their children's behaviour, they tended to modify the environment in order to reduce their child's frustration. They described postponing activities, focusing on a different activity or hiding objects that upset the child as strategies to modify the environment. While the source of their children's frustrations was not always obvious, participants actively engaged in a learning process in order to understand what was happening to their children. As they learned more about their children's communication, they utilized strategies learned in order to reduce frustration and decrease the incidence of

challenging behaviour. One mother described her experience with her child's frustrations, "Her behaviour, you just never know. When she gets frustrated sometimes you know what she is frustrated about and other times you don't have a clue." Another mother discussed strategies that she developed when her child was frustrated, "You have to show patience. If you don't show patience then she really starts to get upset. You have to give her an opportunity to tell you what she is asking for."

Participants stated that not all behaviour is challenging. Each described areas where their child showed interest and managed well. Over time, evaluation of the child's behaviour for strengths and challenges provided the decision maker with clues about how the individual might accept decisions that are made.

The participants stated that they based their decisions on the anticipated reactions of their children. They described their focus as one of changing their approach to make the decision more acceptable to their child. These strategies included offering pleasant activities, establishing routines, and finding an activity that interests the child. A mother talked about how establishing routines as a strategy to assist her child:

Talk to her for a little while, watch a movie with her and by then it is supper time and we basically change her and then our goal is to keep her as calm as possible so she can fall asleep.

A second mother spoke about how she engages her child at busy times, "And I try, even when I'm doing lunch I say, you know, 'I need yogurts. Can you find me yogurts?' These are in flyers or something and that will keep her busy for half an hour looking for it."

Sometimes participants decided not to pursue activities that would be unacceptable to their children. In these instances, they weighed the importance of the activities against the reaction of their children. One mother said:

It's not worth it. If you go down there and make her go for a walk with you, when she comes back she'll be very frustrated. So, on a day like today when she is quite happy and peaceful. It's not worth [it] to be changing that.

Participants acknowledged that decisions may vary according to their children's developmental stage. They described breaking down explanations into steps where the children can respond or changing the level of supervision dependant on how their children manage as examples of how developmental stages influence decision making.

Participants, whose children exhibited challenging behaviour, considered the effect of the decisions on their children's behaviour. They realized that certain decisions might increase their children's frustrations while other decisions would be acceptable to their children. They learned that modifying the environment was a strategy that increased the possibility that their children would react positively to decisions made for them.

Participants became adept at changing the manner in which decisions were offered instead of imposing decisions on their children. Participants also recognized that there were some situations that their children would not accept. Based on their children's anticipated reaction, they weighed the challenges and benefits before deciding to pursue an option.

#### Keeping People with Developmental Disabilities Safe

While participants described strategies that would reduce their children's frustrations and build on strengths, they acknowledged that sometimes, because of the nature of the developmental disability, their children might be exposed to dangers that were less common than

with children who did not have developmental disabilities. They stated that the lack of safety awareness, coupled with their children's unique behaviour, could place them in situations that could be harmful to them. In these instances, participants made decisions that would avoid unsafe situations. One mother said:

This worker would happily take her out for a walk. But, she can take off on you anytime, into any traffic. She may not do it for 10 times. She doesn't have to. She just has to do it once.

Participants' fears about safety were tempered by the awareness that they wanted to encourage their children to be independent as they matured. Participants viewed balancing independence and safety as a lifetime concern. They worried about who would keep their children safe after they died. While participants acknowledged that there were times when they, themselves, could not keep their children safe, they cited safety as a concern that existed twenty-four hours per day and seven days per week. One mother stated:

Yes, my son has just started walking to and from school. I want to encourage that because I want to get him more active but on the other hand, it is a bit scary because he has to cross a major artery.

A second mother spoke of safety this way:

Well, it is big. I mean it's what our parents did in terms of, "Alright I raised you, I'll cover my eyes and you can leave home now," and I just pray "Oh good, she's got a job. Oh good, she's married. Oh good, she can deal with things. Maybe I can relax a bit now." That doesn't happen for parents of children with developmental disabilities.

A third mother reflected:

I work with a girl. Her son is autistic and I don't know what was said but her

response to it was, “Well, that’s OK because I’ll be there to look after him.” I wanted to say, “Maybe not always.” It wasn’t my place to say that. It’s a scary thought when you do come to that realization. Chances are I won’t be there.

As well as their children’s behaviour and lack of safety awareness, participants described their children as vulnerable in society. They expressed concerns that others might not recognize their vulnerability and, as a result, might offer choices that the children were not capable of making. They feared that the misjudgment of others might have devastating, if not fatal consequences. A father summed up his perspective: “And people with developmental disabilities are always vulnerable.” One mother expressed concerns about possible future medical treatment:

Or if he needed something done that was going to be unpleasant, say he needed chemotherapy. And he said, “I don’t want to do it because this hurts, this makes me sick. I don’t like this.” Would they say, “Well okay, we’re not going to treat him. He seems to understand?”

Another mother spoke about her experiences with paramedics during an emergency:

I started to panic because her blood sugars were low and I couldn’t get anything into her. I called the ambulance and the paramedic said, “Well she seems fine to us.” They tried to give her something and she refused to take it. “She seems fine to us and she’s 13 now. We’re not going to do anything.”

In conjunction with the possibility of well meaning others not recognizing unsafe situations, participants expressed concerns about those who might intentionally harm their children. They were aware that their children might not be capable of avoiding situations that could lead to harm. One mother expressed her concerns this way:

And my reasoning was that she would be far too vulnerable because she is not

verbal. There are a lot of good people out in the world, a lot of good people, but there are a lot of bad people, too. And screening doesn't always rule out the bad unfortunately and, I don't care how well they're screened, it's just not a good situation as far as I was concerned.

Another expressed concerns for her son as he aged, "Like my son is getting to an age where he'll have to go to the male washroom by himself, say at Wal-Mart. I've heard at workshops, stories, awful stories. What do you do in that case?"

When making decisions, participants considered safety from the perspective of their own intimate knowledge of their children. They viewed their role as protector as an intricate part of decision making. When making decisions, participants considered the safety of their children in immediate, potential, and future circumstances. They described the constant worry that harm could exist because of the children's lack of understanding or from the actions of others. While they realized that they had to balance overprotection with safety, their decisions reflected their concerns about safety for their children. As one father observed, "He's a free soul now, he's a good boy and I love him with all my heart. I won't let anything happen to him."

#### Successes

While there were difficulties and worries, participants also spoke of their many successes. Participants told me that they had learned to recognize and build on their children's strengths. Establishing routines, discovering talents, and providing opportunities for fun contributed to the joys of everyday life. One mother talked about establishing successful routines, "I do all the personal care for [my daughter]. Like we both do. He [her husband] does his share and I do mine. We have a system."

Another mother also spoke of her daughter's achievements, "She did track and field. She won a swimming trophy." A third mother described her son's talents, "He loves drawing. So he draws what he sees on TV and he has it memorized so he can draw the boy on the moon fishing." A father spoke about his feelings about his son's successes, "The reward seems even sweeter to me, it's like, wow, and you know people won't understand unless they have a child that has a disability."

Participants learned that their children can have fun with others in the community. They supported their children's relationships with others by finding areas that were of interest to the children and structuring activities in order to assist their children to negotiate the world around them. They viewed successful integration into the community as finding areas where their children could succeed. One mother found a gym program for her child:

Then this OT started a program with other OT's called Tumbling Together. So it was all in the summer time and certain kids were selected. Kids with mostly autism that went through this routine and socialization experience. So that was a good decision. Go from the regular to the more structured with a professional who understands their needs.

Another mother described his daughter's activities in the community:

She does volunteer at an elementary school. She goes to the Y. She does cleaning at offices. This is all with a worker. A few evenings a week she goes out with a young girl. They just hang out at the mall, whatever.

Participants based their decisions on their children's previous successes. They indicated that, despite the need for finding specialized supports, they wanted their children to be happy,

integrated members of society. As one father described his daughter, “She’s a happy go lucky kind. It’s just like we would want for any of the family.”

Participants realized that successes did not occur without supports. In making decisions, participants considered how they might modify the environment to ensure success. Tapping into areas of interest, participants chose activities for pleasure as well as utilizing strengths to build success in other areas. The mother whose son loved drawing used this skill to increase his verbal language by asking him to tell her about his pictures. The father whose daughter volunteered in an elementary school described his daughter’s love of children as a basis for choosing how to structure her days. Participants stated that they were guided in making decisions by finding areas where their children could succeed.

#### Politics of Engaging in the Community

While participants tried to build on success, they stated that finding ways to include their children in community life was not always easy. As well as learning about their children, participants also stated that they had to understand the systems that will support them. They became involved in a maze of activities that were designed to assist them. They described the complexity of navigating through these systems in order to determine what was best for their families. One mother observed: “It was a challenge at the very beginning. Just, getting the system to be responsive to his needs.” She also remembered a situation that confused her:

The only way that we could get him into their program and, don’t ask me the administrative issues, but we had to apply to have him admitted and they put him on “permanent discharge.” That’s the way they used to do it.

Another mother described how she saw her role:

You become a case manager. Then you are managing systems on behalf of your

child. You try to understand the system. You try to understand what the funding mechanisms are as much as possible.

Participants described the process of understanding their child, finding out what supports were available, and determining how those supports would meet their child's needs. They suggested that information gathering was a strategic part of decision making. As one mother said, "Every child is different." As a result, each family negotiates supports that will prove beneficial to their particular circumstance.

In order to ensure that existing supports met their children's needs, participants spoke about becoming politically active at many levels. They expressed awareness that, as policies change, these changes had an important impact on their daily lives. Whether they were concerned about the continuation of current programs or school integration, they had to challenge political processes in order to obtain the particular supports that their children required. At times, they made decisions that were contrary to advice they were given, however, they expressed the belief that they were the experts on their own children. One mother observed, "The people who make the decisions don't live our lives." While another stated:

We are at the mercy of the Ministry, unfortunately, but we can only hope that that's what's going to happen is that the group homes will stay because you never know what the Ministry is going to do or say or it seems things go round in circles, you know, after a number of years.

A third mother described her experience at a policy development function, "I was the only parent there. There were trustees, superintendents, school board people, and representatives from agencies. So, if there was some open discussion sometimes, I would say a few things." A fourth

spoke about her experiences at her child's school: "There was a principal who tried to convince us that it was not the best setting for her. I just disagreed with him and said she was happy."

Participants described their political activities at multiple levels. They recognized that their children needed someone to speak for them and viewed themselves as the best advocates for their children's rights. Many expressed their surprise at finding themselves negotiating with bureaucracies. They did not envision themselves as political activists when they first became parents of children with developmental disabilities. One mother said, "Because you've got to be the advocate. You've got to fight, to be there, these guys can't fight for themselves." Another described how she advocated for her child, "We had to write a letter with our lawyer's help, stating that if she was harmed in any way that we would have to take legal action." A third reflected on how her sense of advocacy had changed, "When I started I never saw myself ending up here."

As advocates, participants discovered that the available options might not be best for their children. They learned to navigate the political arenas in order to increase opportunities and meet their children's unique needs. Political processes affected funding in education, medication choice, community supports, residential options, social contacts, and many other areas of life. Participants viewed engaging in a political process as essential in successful advocacy. One mother stated, "Things are going to change. I think parents really must take charge and not be intimidated by them [the Ministry]. If you are not sure, phone another parent up. Then phone the Ministry." Another described her experiences with advocacy, "So I have chosen to become involved in systems that influence the quality of life that he has and it has worked out to his benefit."

A father expressed his concerns about funding, “It was amazing. Even the cost of drugs, just because we have a handicapped child and are not covered.”

While invoking political processes, participants spoke about areas where they required assistance. For example, they found funding applications to be complicated. They stated funding administrators, who were usually government Ministry representatives, were not particularly helpful in completing applications. Participants believed Ministry representatives did not give them all the information that they required to obtain adequate funding. They stated that the Ministry’s objective was to save money and, therefore, their assistance reduced the amount of funding awarded. Participants found that other families were more effective at showing them how to complete the forms and provided direction on how funding could be used. Once approved, these funds were used to obtain home care and respite services that provided the family with support. As one mother observed, “If you do a funding application wrong then you are cut off.” Another suggested:

What I find is that, you mustn’t be intimidated by this form [application for funding]. You have to learn how to do it and be empowered. Because, if you don’t know how to do it; you are not going to get what you want.

A third mother described her experiences, “They are not actually helpful because their goal is to save money. They [funding administrators] are not going to tell you, ‘If you put that in you are going to get more.’” A fourth mother said:

You’re so overwhelmed. You don’t know who to talk to and what to do next. So other families helped to guide me. Things like how to apply for support money and how to spend it once you get it. It is really hard.

Participants indicated that obtaining the right supports in education, work, and housing was often a struggle. Participants found that once they began advocating for their children, they soon discovered that they were fighting for service. Participants stated that decisions made by bureaucrats who were unfamiliar with their individual context were often difficult for their children. They indicated there was a lack of collaboration between services. They viewed their role as a coordinator of those services. Not only did service providers entertain different philosophies on how to support their children, participants felt pressure from service representatives to conform to the proposed, available options. They stressed that they had to “pick your battles” because complaining takes time and energy that was not always available to them. As one mother said: “If I hadn’t come in with that I think they would just have put him in a regular classroom then probably kicked him out for bad behaviour.” Another spoke about the difficulties of coordinating goals for her child:

But even deciding particular goals, his teacher and I had a hard time because we are basing it on this IBI [Intensive Behaviour Intervention] program. We didn’t know exactly what they were working on so it’s like say, this is my goal for him socially and this is my goal for him playing wise and safety wise. And here’s where I think I would like to see him go academically but I couldn’t tell you what IBI he’s working on right now.

A third mother described the pressure that she felt from teachers, “And they warned me that would be the worst decision that I ever made and I kept saying, ‘No, that’s what I want,’ and it ended up being the best decision I ever made.” A fourth mother described how she managed disagreements:

You can’t fight it all. Don’t sweat the small stuff. You’ve got to really figure out,

is it really worth it? You really got to figure that out because you don't want to be a complainer all the time. I have found over the years that there is always a battle.

You have to pick and choose or else you run out of energy.

Participants described how they learned about political processes and developed their roles as advocates. They believed that their role was to question the status quo in order to ensure that the proposed services would meet their children's needs. Building on their beliefs developed through figuring out how to support their children, struggles, their knowledge about their children's behaviour, how to keep their children safe, and how to achieve success, participants' experiences with advocacy reinforced their perceptions that they knew what was 'best' for their children. Participants made decisions based on their new understandings that were gained through their experiences with their children with developmental disabilities.

#### Waiting for Service

Participants stated that even when the right services were available to their children, every service had a waiting list. Their children required assistance from multiple sources and not all of the offered services would be right for their individual child. In order to get services more quickly, participants stated that a family had to be in crisis. They also told me that family crisis did not guarantee services. It just moved the family up the waiting list. In order to support their children, participants engaged in a complex process of finding services, obtaining funding, managing multiple supports, case management, coordinating meetings, and evaluating the effectiveness of service on their children. One mother spoke about the number of services that her child required:

And I know the first type might not be the right one. [The doctor] has said it could take up to six different types. So that's where we are headed now. And again it's

a wait list, waiting to see [the doctor]. We can't really get in with him so we are going to try to squeeze in through the psychologist on the consult.

A second mother spoke about her perceptions of waiting for services:

There's a waiting list everywhere. Always the same thing. Waiting lists. You know there are 225 on the waiting list for Pressures and Priorities [A single point of entry system that evaluates need for service]. Two hundred and twenty-five families on Pressures and Priorities. You know, I would say out of those two hundred and twenty-five, there's probably forty-five of those [that] are desperate cases.

Another mother spoke of her experiences with waiting lists and role as coordinator of services:

My son is discharged from his IBI [Intensive Behaviour Intervention]. We were on a wait list for that for 4 months. So he was in it for almost 4 years. So now I'm on a wait list to see a physiotherapist. We're supposed to have a discharge meeting. I meet with the psychologist next week to go over the assessment. As the case manager, I'm trying to organize all the professionals to meet at the discharge meeting. Then speech and language is supposed to come into the picture but there is probably a waiting list, too.

Participants spoke about the difficulties of accessing services because of long waiting lists. While they were aware that different services existed, they found that not all services provided supports using the same philosophical paradigm. In deciding what was 'best' for their children, they considered not only the appropriateness of service for their children, but also the length of time it would take to access those services. Whether they lobbied for increased funding,

negotiated smooth transitions or coordinated services, participants made their decisions with an overall understanding of the effects of waiting lists on their children's lives.

#### Abandonment

While waiting for services is common, once services are accessed, participants stated that they were aware that supports could be terminated. Reasons for termination included; changes to funding structures, conflict of philosophies between programs, diagnosis that did not fit, aging, changes of status such as entering school or leaving school, wait lists that required termination in order to provide service to other families, their children's behaviour, and professionals' career changes. As participants were aware that services were finite, they suggested that they were concerned about participation in certain programs. They described a feeling of abandonment as the service that they had waited for ceased to be available to them. They worried about what effect the early termination of service might have on their children. One mother said, "I ask myself, is it worthwhile when I know that speech and language will be cut off in six months. We will just get started and then they will abandon us."

Another mother described her experiences of losing services due to changes in service delivery, "They said they took both of my children off the case books and said they were only dealing with children with physical disabilities." A third mother spoke about how wait lists affected her son's services, "He's about to be discontinued at Easter time. I think because the wait lists are so long that they're going to move him out to bring another child in." A fourth mother described how her physician's departure affected her daughter, "Our doctor just had to leave his practice and my daughter and I went to the same doctor. That's a big change for both of us and particularly for her."

While the realization that supports were finite did not deter any of the participants from accepting services, they expressed concern about the effectiveness of the intervention. They also stated short-term supports with different philosophical foundations might be confusing for their children over time. One mother spoke about services being terminated, “I think that I would go ahead and try whatever the service was. I know other families that were terminated and they didn’t agree with the reasons why.” Another described how different philosophical approaches affected services:

So no, school board speech and language would not work with him yet because of the IBI (Intensive Behaviour Intervention). She came in to observe and her philosophy didn’t agree with IBI’s verbal approach. She stated that this difference might confuse my son.

While these participants denied refusing services because of the possibility of early termination, they weighed the effects of termination when making decisions. They were aware that changes were difficult for their children and considered the long-term effects of multiple short-term interventions. The realization, that they could lose services before their children received the full benefit, and that other services might not provide the same philosophical approach, was an important factor in deciding what was ‘best.’ They realized that the combination of waiting for service and the possibility of early termination created situations where services for their children were uncoordinated and, at times, incompatible. They believed that, in their role as advocates, they needed to consider the overall impact of these obstacles when making decisions about how to best meet their children’s needs. As a result of waiting lists and the possibility of abandonment, participants utilized strategies that they had learned through the politics of integration to make decisions for their children.

## Teaching Others

While participants described their engagement with numerous uncoordinated services, they expressed concern that those providing services might not have enough knowledge about their children to be effective. They believed that they had to take responsibility for teaching others about their children. Participants stated that teaching others is a major part of advocacy. They expressed the need to teach teachers, physicians, extended families, social groups, and other members of society who needed information about their children in order to achieve success. One mother described how she approached education assistants, “I used to go in to meet any new EA [Education Assistant]. ‘Hello, and what do you know about autism spectrum disorder?’ The answer was generally, ‘Nothing.’ We go from there.” A father spoke about his seventeen year old son. He was concerned that the teacher encouraged his son to act in a way that could be perceived as socially unacceptable in different circumstances. He described how he taught the teacher about interacting with his son:

There was a teacher that was about 50, and I think that she had good intentions all the way. I walked in and she didn’t see me come in. She’s down like this. “Come on, and give me a big hug.” And I said, “What’s wrong with a handshake?”

A mother spoke about how she educated people who react negatively to her child in public places:

I have business cards. So it’s like a little business card that tells about Autism and what it is, and for more information go to the website. On the back it says, “If you’re puzzled by my child’s behaviour; it is not boldness, nor lack of discipline, my child is autistic.” So instead of saying something, I give this to the person.

Another mother described how she approaches service providers, "I usually begin with, 'What can I do to help you?' And then I say, 'This is what you can do to help us.'"

The assumption that others needed information about their children that they might not be able to find out on their own influenced how much weight participants gave to advice given.

They believed that others, who were knowledgeable about developmental disabilities but did not know their children, might not always know what was 'best' for their children. They also realized that some people had knowledge about the services that they required, but had little knowledge about developmental disabilities. Participants viewed the knowledge that they had gained through their experiences, with figuring out how to support their children, struggling, understanding behaviour, keeping their children safe, successes, the politics of engaging in the community, and the coordination of services, as valuable considerations for decision making. Participants believed that providing people with information that they had gained about their children would enhance the responsiveness of others and inevitably lead to better options for their children.

#### Professional Advice

While participants believed that their role was to teach others, they acknowledged that they also looked to experts for advice. I initially labeled this category as 'expert advice.' During the second interviews, some participants objected to my reference to this label noting that they were the experts about their children. They suggested the term "Professional Advice" when talking about professional assistance. One participant commented, "I'm leery of the word expert. Just use professional. A professional, you hope, might be an expert in their field of study but a parent becomes an expert on the child." As a result of the participants' comments, I will

subsequently use the term 'Professional Advice' rather than 'Expert Advice' when describing this category.

When seeking guidance from professionals, participants expressed awareness that they knew their children better than the professionals who cared for them. They used this knowledge to advocate for their children especially when they disagreed with professional recommendations. They respected professionals who acknowledged their expertise and viewed advice from professionals, who did not consider their particular circumstances, with skepticism. One mother spoke about her experiences with professional advice, "So I found that that experience was kind of the initial set of what was to come with other professionals. Go with my gut; don't go with their bureaucratic philosophies." Another spoke about her experience with a nurse after her son had heart surgery:

He was on the ward and he was cut off the morphine drip which he was on in the ICU and had nothing for pain on the ward for several hours and he was fussing.

And the young nurse said, "Spoiled." So I spoke up and said, "Pardon me?"

A father spoke about how his family doctor dismissed his concerns about his son's symptoms.

He described the difference another physician made when he took his son to the hospital:

He was fevered. And there was a specialist or a grad student doing pediatrics that was coming up the stairs with us towards the elevator. He was very, very wise. He said, "You probably know more about him than I do." But, I was really upset with our family doctor because we were brushed off.

Participants said that professionals are not always knowledgeable about developmental disabilities. Furthermore, participants suggested that they process professional advice by

reconciling professionals' opinions with their everyday realities. They stated that, when a professional provides good advice, it usually confirms what the family already knows.

Participants found that they had to engage professionals in order to support their children. For example, they relied on physicians to provide a diagnosis. Participants stated that, while the accuracy of diagnosis in developmental disabilities did not lead to cure nor did it change the supports that the family required, it was essential to gain entry into the systems that supported their children. A mother described the association between diagnosis and supports, "I would say that an accurate diagnosis is necessary to get appropriate supports." Another agreed: "That's true; an incorrect diagnosis does not give you the right supports." A third mother described how the diagnosis confirmed what she already knew:

We just went through another assessment about a month ago. She [the doctor] hasn't given me the results yet but she did call me and say, "It's discouraging."

But I already know. You know obviously she's not doing what she used to be.

A fourth spoke about the importance of obtaining a diagnosis, "So anyway we got this informal diagnosis. The pediatrician accepted it and we, somewhere along the line there, we got him nineteen weeks of speech and language therapy through child development centre."

Some of the participants stated that their children had more than one diagnoses. Whether other diagnoses were missed initially or developed with aging, participants recognized that they required increased supports to manage the dual diagnosis. One mother explained how a diagnosis changed her son's treatment regime, "He also apparently has attention deficit and at the age of almost seventeen he has been started on medication for attention deficit." Another spoke about the lack of knowledge about developmental disabilities in the medical community:

So yeah, the medical profession needs to understand more about developmental

disabilities and the fact that often times there is a dual diagnosis, so you may have somebody with a psychiatric problem and a developmental problem and sort of dealing with that.

A third mother described her feelings about obtaining a second diagnosis, “She has a dual diagnosis of Downs syndrome. The second diagnosis is Alzheimer’s. Whether that is accurate or not, who knows. She definitely has a second diagnosis.”

As well as relying on physicians for diagnosis, participants talked about other professionals who provided them with advice. While some of their experiences were helpful, there were times when professionals doubted the participants’ decisions. Furthermore, participants expressed disappointment at some of the services that professionals offered. One father spoke about his experiences with teachers who disagreed with his decision to place his daughter in a regular classroom:

This teacher felt that [his daughter] did not belong in a regular classroom.

We were very pleasantly surprised when her grade 10 science teacher in the advanced curriculum spoke up and said, “[Your daughter] can’t follow the curriculum in grade 10 advanced science. However, my feeling is there is a reason why [your daughter] is in my class. It’s not my job to question it. It’s my job to teach her as much as she can learn.” That quieted down the others.

Another father described his experiences with professionals who provide services:

It was not just that, too, people coming in we felt being paid fairly good money to, what’s the word I want to say, assess the situation and assessing stuff, and we just needed help.

We didn’t need an assessment.

One mother stated that the professionals assumed that parents needed to be taught basic skills:

Or coming in and telling you, you know, that you need to, or that you should be throwing the ball back and forth with him and then they showed us how, you know, stuff like that. It was a bit condescending.

A father said: “A lot of people, I don’t think they’re unqualified for what the qualifications ask, but there’s a lot more to the problem than looking at a child that just has a disability.”

Participants knew that some professionals might not have the knowledge about developmental disabilities that was required to care for their children. Many participants described situations where the professional had misjudged the effects of their interventions on the participants’ children. As a result, participants expressed a degree of skepticism about accepting professional advice unconditionally. While they realized that professional advice had an important role in obtaining supports, participants had concerns that this lack of knowledge could have detrimental effects on their children. Incorrect or missed diagnosis could lead to decisions that did not benefit their children.

Participants also had experience with professionals who disagreed with the decisions that they had made. They adamantly defended their positions that they knew what was ‘best’ for their children. As their advocacy roles developed, participants found strategies that assisted them when they disagreed with professionals’ recommendations.

#### Non-Professional Advice

Along with soliciting professional advice, participants relied on non-professionals to assist them. They sought advice from other parents, family members, and friends who had experience with developmental disabilities. Support groups made up of other parents were described as invaluable. Information shared at these meetings provided a reliable source of experience. One mother described how non-professionals guided her towards the diagnosis of

autism, “In that time frame family and friends started saying ‘I think your son may have autism.’ I didn’t even know what it was.” Another mother spoke about the support she received from other parents:

I was very actively involved in a parent support group. We would meet once a week or 2 or 3 times a month. That was sort of sharing of information, talking about some of the stresses, looking at strategies to influence change, those kinds of things.

A father spoke about his reasons for accepting support from other parents: “Just all the trust, because you were with other parents that were in the same situation.”

Other non-professional supports that participants discovered such as Daycare Workers and Education Assistants (EA’s) were highly valued. These groups of people spent time with their children and were able to recognize some of the concerns that parents had brought forward. Non-professionals, who spent time with their children, persevered with their goals, showed parents how to achieve successes and provided guidance to access other supports. One mother described the support that she received from Education Assistants:

And I’ll tell you right now, the EA’s and the people that have helped along the way have been a real stimulant. They have really, really helped the progression. There were a lot of times we were giving up on things, they were still doing it.

Another mother spoke about the support that she received from Day Care workers, “We got him diagnosed and he was at the daycare. The daycare was wonderful. I still didn’t know much about autism, and I didn’t know who to connect with and they led me to all these other

agencies.” A father spoke about the positive influence of an Education Assistant: “Isn’t it nice to meet someone who genuinely enjoys children no matter who your child is?”

While participants understood that professional advice was necessary in order to receive services, they relied on non-professionals to assist them to navigate through those supports. When making decisions, participants sought out advice from non-professionals, believing that people who had experience with developmental disabilities had valuable knowledge about what was ‘best’ for their children.

#### Other Supports

While participants indicated that they looked for advice from professional and non-professional sources, they also relied on other supports aimed at taking care of family stress and alleviating crisis. They valued professionals who had intimate knowledge of their children and were available to the family when they required assistance. They stated that professionals who showed responsiveness to the urgency of family stress usually listened to parents and intervened before crisis occurred. These professionals helped participants and their families to manage the stresses of living with children with developmental disabilities. One mother described how her daughter’s physicians assisted her during times of stress:

I had both their home phone numbers [psychiatrist and family doctor]. I had the psychiatrist’s. He would say to me, “I’m going to go to the cottage for two weeks. If you have a problem you can call.” And I have never called him. But you know, I’ve recited his number in my head many times over, you know, but I’ve never actually called him.

Another mother spoke about the importance of accessing professionals who were familiar with her family, “So it is important that I could get help from somebody that does know us when I

need it. It's very important." A third mother talked about how her family physician provided support before the family experienced crisis:

The week the diagnosis came, the Alzheimer's, my GP immediately made a call, he called me in said, "I just had a report from the doctor," but I already knew because they had called me, and he said, "I'm going to phone homecare right away and make arrangements. You can have some homecare." He said, "Don't overdo it because I don't want you to have any guilt. Just take it one day at a time." So when I got homecare in place and that's a big break, I get three hours from Monday to Friday.

Participants sought out members of their communities to alleviate the stresses of everyday life. They indicated that, when a family has a child who has a developmental disability, their relationships changed. Not all of their friends were able to accept their children into their circle. As a result, participants sought out friends that were accepting of their situation. They stated that communities that accepted their children and welcomed the family enhanced their families' lives. One mother talked about the importance of friendships, "I mean I have friends, I have a good network of friends that I can go out and do things with but I don't have the same freedom that they have." Another described a parent support group, "There was probably about 10 or 12 other mothers, I guess that I socialized with and 4 or 5 that I have maintained relationships with." A third spoke of how her relationships changed, "Having a child with an intellectual disability can be very isolating. Not only in terms of friends because your friends' children, if they are the same age, will quickly be doing different things."

Participants were aware that they needed support for themselves and their families. They knew that the stresses of living with children who have developmental disabilities affected all

members of their families. When making decisions, they considered how their families might react to the decisions. Participants believed that decisions made could either increase or decrease family stress. As a result, they considered the impact of their decisions on their families' lives when deciding what was 'best.'

#### Taking Care of Yourself

In choosing other supports, participants considered their own well-being and that of their families. They looked to their communities to find the acceptance and flexibility needed to facilitate the decisions that they made. They realized that decisions that might increase their isolation from the community would also increase family stress.

While participants acknowledged family stress, they indicated that they needed time to take care of themselves in order to effectively care for their children and their families. They recognized that nurturing their own interests, maintaining a healthy lifestyle, and cultivating social relationships were ways of replenishing their resources. One mother found that writing about her experiences helped her decrease stress: 'I'm starting to keep a journal for myself when I was having that rough go with the school board but I haven't kept it up. But I thought some day in the future I could go back.' Another began exercising as a form of stress reduction, 'The last 5 years were just thrown out the window, pleasing others and not feeling satisfied. Now that I go to the gym, I try to go at least 5 times a week.' A third mother ensured that she maintained contact with her friends to reduce stress:

I have friends. To me it is like a mini escape. It makes me feel that I am still a person. It's sort of an escape from being the parent of a handicapped kid. I am a person like anybody else that has needs.

Another way in which participants took care of themselves was to establish clear expectations of support workers. They cited the difficulties of having support workers come into their homes every day when the families' needs were not being met. Support workers may or may not blend with family routines. Participants stated that decisions made about how to utilize the assistance of support workers were aimed at reducing personal and family stress. Funding did not cover all of the supports that they needed. Therefore, they chose supports that were more important in maintaining personal balance. One mother set clear expectations about routines: "But personal care you can call me and I'll take care of it. That's been my expectation and I make it clear." Another stated that the support worker's relationship with her daughter was more important than setting clear expectations about tidiness in her home:

You have to weigh the pros and cons. So I make the bed and I pick up the towels, you know it's all crunched up over there and I'll pick it up. Because as far as the support for my daughter goes, she's the best that I've ever had.

A third describes how she decided to use support money: "This was a decision made because I had to cover my time at work. We both work full time. I struggled with that decision." A fourth said:

I have that support money. I use it before and after school. But my husband and I never go out together. We never get a support worker just so we could go to a movie or anything. You don't want to use up the money either.

Decisions about how participants took care of themselves personally were varied. Participants agreed that it was difficult to take personal time. As one father observed, "I don't think enough people do that. It is an area that people think that they really don't have time for."

While some participants acknowledged that they do not take as much time as they need to care for themselves, they agreed that taking time was an important consideration. They suggested that, when making decisions, they focused more on their children than themselves. Participants believed that reducing their own stress assisted them to make better decisions for their children.

#### The Future

While speaking about past experiences, participants also discussed the future. They had hopes and dreams about the future but worried about how their children would manage.

Participants, whose children remained at home, were concerned that the options of housing and work were limited. Furthermore, they stated that the choices offered were not desirable. One mother said: "My dream for him is at least a semi-independent living situation. I don't want to see him in a group home." Another expressed her concerns about the future, "What happens to the child or young person after the parents are gone? In terms of things like, who is willing to supervise them? If an institution takes over, what are the decisions that the institution might make?" A third mother considered the options that were available to her daughter and spoke about her vision, "I have a very different plan for my daughter down the road." A fourth expressed her uncertainty about the future,

That's uh very foggy for me. I'd like to say that I see something clear in a vision, but I don't. I'm concerned. Will he ever be independent? I'm getting older. I'm not going to be around forever. Nobody's going to care for him the same way I do, or we do, I should say, we do.

Participants whose children were in care expressed more optimism about the future. They were also concerned about how agencies might meet their children's needs as they aged. One mother expressed concern about her son's future:

At what point does some agency sort of take over and decide they're going to put him in a nursing home or something? Because apparently there is a tendency now to take people with intellectual disabilities and put them in long-term care facilities.

Another spoke of her worries about her daughter's future, "I kind of worry. I've got things hopefully in place for when I die but there's still a worry." A third added, "Keeping him safe insures access to programs and supports that he needs and quality of life. I don't want him to just lie in the bed or sit in the chair, look out through the window without any stimulation."

Participants clearly viewed decision making as a complex multidimensional endeavor. Their decisions were informed by past experiences, present circumstances, and future possibilities.