ABSTRACT

The focus of this thesis is stress in rehabilitation professionals. There are three terms used to define stress: burnout, compassion fatigue and moral stress. Within this thesis, burnout encompasses compassion fatigue and moral stress. Therefore, burnout is the emotional and ethical fatigue which is produced through organizational and clinical expectations present when working with individuals who live with disabilities. This thesis argues that current rehabilitation service delivery models exacerbate burnout through their neglect of emotional and ethical needs in professionals.

The goal of this thesis is to develop an alternative model of service delivery which addresses burnout in rehabilitation professionals. The thesis answers the following question. How does Jean Vanier’s thinking about relationships between individuals, living with and without disabilities, contribute to the field of rehabilitation therapy and, more specifically, to reducing stress currently experienced by rehabilitation professionals? To answer this question and to meet the thesis goal, the research is situated within a constructivist paradigm and uses a single, interpretive case study design.

This research has produced the transformational rehabilitation model of service delivery. This model states rehabilitation is a transformational process. Whereas traditional rehabilitation views the client as the focus of the change process, the transformational model states both the client and professional benefit from their participation in a transformational change process. The change process is directed at the personal identity of client and professional and is characterized by increased awareness and acceptance of key aspects within self and other. Whereas in more traditional rehabilitation models, creating the relational conditions necessary for change is the
professional’s responsibility, within the transformational rehabilitation model, both client and professional contribute to the relationship which is characterized by commitment, cooperation and compassion. In addition, client and professional experience the outcome of transformation, maturity. A mature person is defined by his/her capacity for agency and authenticity.

This thesis argues that Jean Vanier is relevant to rehabilitation professionals. The articulation of an alternative model of service delivery, based on Vanier’s thinking about relationships between individuals living with and without disabilities, makes a significant contribution to reducing stress in rehabilitation professionals.
Acknowledgments

There are many people who have contributed to the successful completion of this thesis. I would like to thank the following people.

My thesis supervisor, Dr. Mary Ann McColl, for her strategic reminders of the important contribution this thesis makes to the field of rehabilitation therapy and for her constructive input into the thesis over the past four years.

Dr. Margo Paterson and Hélène Ouellette-Kuntz, as members of my thesis committee, for their intellectual interest in and support of the work I have been doing.

Jean Vanier, for the interview I conducted with him and also, the hospitality shown to my husband and I when we traveled to the community of l’Arche Trosly-Breuil in France.

Key informants who provided me with thoughtful interpretations regarding Jean Vanier’s ideas and their application within l’Arche group homes.

My family and also, friends, for the emotional support they provided over the past four years.

My niece, Sarah, for her technical expertise with the model development.

Finally, my husband, Joe Fardella, for his continued interest in and support of this project during the past four years and for his timely suggestions to take much needed breaks along the way.
Table of Contents

ABSTRACT ......................................................................................................................... i

ACKNOWLEDGEMENTS ...................................................................................................... iii

CHAPTER ONE: GENERAL INTRODUCTION

1.1 Stress in Rehabilitation Professionals .............................................................. 1
1.2 Organizational Strategies Designed to Reduce Stress .................................. 9
1.3 Parameters and Scope of the Problem ......................................................... 13
1.4 Rehabilitation Models of Service Delivery ....................................................... 15
1.5 Jean Vanier ........................................................................................................... 26
1.6 Orientation to Thesis: A Personal Perspective ................................................. 30

CHAPTER TWO: METHODS

2.1 Research Goal, Question and Objectives ....................................................... 34
2.2 Study Design
   Constructivist Paradigm ......................................................................................... 35
   Single, Interpretive Case Study .............................................................................. 35
   Addressing the Limitations of Case Study Design ................................................. 37
2.3 Data Sources .......................................................................................................... 40
2.4 Data Collection ...................................................................................................... 45
2.5 Data Analysis ......................................................................................................... 47
2.6 Theoretical Approach .......................................................................................... 51

CHAPTER THREE: CASE CONTEXT

3.1 Historical Context ................................................................................................. 52
3.2 Significant Influences .......................................................................................... 54
3.3 Current Context ..................................................................................................... 56
CHAPTER FOUR: MAIN FINDINGS

4.1 Definition of the Problem
   Personal Identity.................................................................59

4.2 The Transformational Relationship ...........................................60
   Commitment ...........................................................................61
   Co-operation ........................................................................65
   Compassion ..........................................................................69

4.3 The Transformational Process of Change .....................................75
   Awareness of self ..............................................................76
   Acceptance of self .............................................................82

4.4 The Transformational Outcome-Maturity .....................................86
   Agency .................................................................................87
   Authenticity .........................................................................91

4.5 Theoretical Principles .............................................................99

CHAPTER FIVE: DISCUSSION

5.1 Comparison of Transformational Rehabilitation to Service Delivery Models.
   Biomedical Model ...............................................................102
   Independent Living ............................................................104
   Client-Centred Model ........................................................105
   Community Based Rehabilitation ..........................................107

5.2 Comparison to Transformational Learning Theory .........................108

5.3 Relevance to Stress in Rehabilitation Professionals .......................112

5.4 Theoretical Implications ........................................................117

5.5 Organizational Implications .....................................................120

5.6 Clinical Implications ............................................................121

5.7 Research Implications ........................................................124

5.8 Study Limitations ..............................................................126

5.9 Personal Statement Regarding Research ....................................128

References .............................................................................130
APPENDICES

Appendix 1- List of Books: Year and Purpose........................................142
Appendix 2- Key Informants.................................................................143
Appendix 3-Letter to Jean Vanier.......................................................144
Appendix 4-Key Informant Interview Guide......................................145
Appendix 5- Vanier Interview Guide..................................................146
Appendix 6- Sample of Reflective Journal Entries.............................148
Appendix 7- Coding Diagram ..............................................................150
Appendix 8- Glossary of Terms..........................................................151
LIST OF TABLES AND FIGURES

TABLES

Table 1- Transformational Relationships ..............................................................74
Table 2- Transformational Process of Change ......................................................84
Table 3- Maturity as Agency and Authenticity ....................................................96
Table 4- Transformational Model of Rehabilitation .............................................98
Table 5- Theoretical Principles of the Transformational Model of Rehabilitation ....100

FIGURES

Figure 1- Coding Strategy ..................................................................................51
Figure 2- Transformational Relationships ..........................................................75
Figure 3- The Transformational Process of Change ............................................85
Figure 4- Maturity- The Transformational Outcome ...........................................97
Figure 5- Transformational Model of Rehabilitation .........................................99
CHAPTER 1: GENERAL INTRODUCTION

This chapter is focused on the stress which is currently experienced by rehabilitation professionals. It begins by outlining three main types of stress currently experienced by rehabilitation professionals. It defines and discusses burnout, compassion fatigue and moral stress. It also identifies organizational solutions typically used to address these stresses and finally, describes the consequences associated with ongoing and unresolved stress in rehabilitation professionals. In addition, the chapter also outlines the four models of service delivery which inform the work currently done by rehabilitation professionals. Through my discussion of these models, I make the argument that stress in rehabilitation professionals is associated with specific characteristics found in all four models of service delivery. The chapter also looks more specifically at Jean Vanier and his relevance to stress in rehabilitation professionals. This discussion orients the reader to the work Vanier has done in establishing group homes for individuals living with intellectual disabilities. It also gives the reader an early indication of how Vanier’s approach to professional-client relationships provides the foundation for an alternative model of service delivery, one which addresses the burnout, compassion fatigue and moral stress in rehabilitation professionals. This chapter concludes with a personal statement of interest in this thesis topic.

1.1 Stress in Rehabilitation Professionals

Within the rehabilitation literature, there are three terms used to describe stress in rehabilitation professionals: burnout, moral stress and compassion fatigue. While these three types of stress can be distinguished according to their cause, they are connected through the emotional and ethical consequences they have for rehabilitation
professionals. Recent formulations of burnout demonstrate that this concept is an umbrella concept which captures elements of both moral stress and compassion fatigue. For the purpose of this thesis, burnout is defined as the experience of emotional and ethical fatigue in rehabilitation professionals. Compassion fatigue and moral stress are terms which provide insight into specific causes of burnout in professionals.

**Burnout**

Burnout is an emotional process which takes place over time and in response to organizational demands including the pace of, control over and satisfaction derived from work. Early in her research regarding human service workers and burnout, Maslach made the link between emotions and stress at work (Maslach et al, 2001). This led to the identification of three specific but related processes responsible for the experience of burnout. As Maslach established, emotional exhaustion is considered the core or first step in the experience of burnout. This leads to the second phase of burnout, cynicism or depersonalization. Occurring as a direct response to the experience of emotional exhaustion, depersonalization is the worker’s attempt to distance self from clients through detaching and/or viewing them as objects and not as unique human beings. Together, emotional exhaustion and depersonalization contribute to a sense of reduced professional efficacy. Therefore, when a professional feels tired because of ongoing emotional demands or when he/she continues to remain distant from clients, there is a tendency to experience reduced effectiveness in his/her occupational performance. Maslach has studied professionals who work in a variety of employment settings, including health care, education and social services. Through this research, she and her colleagues have
demonstrated that lengthy exposure to significant emotional and interpersonal demands at work will lead to burnout in professionals.

According to Brotheridge and Grandey (2002), the burnout literature mistakenly assumes that it is the duration or frequency of interactions which causes burnout in workers. While the frequency of interactions is a contributing factor, the key variable in burnout is the need to regulate emotions while interacting with clients (Brotheridge & Grandey, 2002; Zapf, 2002). More specifically, Zapf (2002) argues emotional skills are used when emotions are displayed in such a way as to influence the affect, behaviours or attitudes of another person and when the display of emotions follows particular rules. These rules include repressing the negative expression of emotion and also, expressing positive emotion that is not genuinely felt. The extended use of these rules creates emotional dissonance and eventually, emotional exhaustion and depersonalization. It is this emotional dissonance which is the key emotional process for burnout at work (Zapf, 2002). Therefore, burnout is caused by emotional dissonance and expressed through emotional exhaustion and depersonalization (Brotheridge & Grandey, 2002; Zapf, 2002).

Rose et al (2004) explored the connections between negative emotions and burnout. More specifically, Rose et al (2004) studied negative emotional reactions in staff working with clients who have intellectual disabilities and challenging behaviours. Through their research they were able to establish that there is a positive correlation between negative emotions and key variables of job burnout. In other words, the experience of negative emotions was related to emotional exhaustion and depersonalization but not with a sense of personal accomplishment (Rose et al, 2004). While the authors of this study
recognized that negative reactions accumulate, they did not make any clear links between regulation of emotions and emotional exhaustion.

In the past three or four years, Maslach and other researchers have concluded that the concept of burnout is weakened by its one-sided and negative measure of job experiences. Research regarding a more balanced measure of work experience has led to the concept of job engagement (Maslach, 2003; Maslach et al, 2001). If work experience is measured on a continuum, job engagement and burnout are at opposite ends of the scale, with job engagement measuring a more positive set of dimensions regarding work experience (Maslach, 2003). With the introduction of job engagement, Maslach et al (2001) have identified six specific domains of work life which contribute to the fit between the professional and his/her organizational environment (Maslach et al, 2001). The six domains are workload, control, reward, community, fairness and values. A good fit between the individual and these domains leads to job engagement. However, it is the lack of fit which leads to burnout. An individual who is occupationally engaged has energy and a sense of involvement with and efficacy at work (Maslach et al, 2001). While all six domains are important, one of the key domains is values.

According to Maslach et al (2001), values contribute to job engagement in several ways. An individual who perceives the workplace as just and fair is more likely to be engaged in a positive way with the organizational environment. In addition, the presence of conflicts between personal and organizational values reduces job engagement and increases the likelihood of burnout. Maslach argues that values may also have a role in how the other five domains are experienced within the workplace. Therefore, a professional who views the workplace as both fair and just and as having a good fit with
personal values is more likely to view this workplace as one which rewards employees’ efforts, gives control over workload demands and builds a sense of community. Through introducing the concept of job engagement to discussions regarding burnout, Maslach and colleagues have established that there is an important link between personal and organizational values.

In addition to the work that Maslach and her colleagues have done with regard to concepts of job engagement and burnout, authors such as Saks (2006) argue that the term job engagement needs to be properly defined and understood. According to Saks, an employee who lacks engagement with his/her workplace is burned out while an engaged employee is involved with and attentive to their work. Through his research on these concepts, Saks demonstrated that job engagement is increased in workplaces which are perceived as supportive and more importantly, in those which are viewed as just and fair in their approach to employee issues. The work done by Saks provides support to the arguments made by Maslach (2003) and Maslach et al (2001) regarding job engagement.

Research currently being done contributes to our knowledge of both burnout and job engagement. Burnout and job engagement are influenced by workplace demands and also, through the employee’s experience of justice, values and ethics within the workplace. In addition, the need to regulate emotions and control expression of emotions contributes to the emotional exhaustion which is considered the first step in the burnout process.
Moral Stress

Maslach and others have demonstrated that ethical and emotional conflicts influence burnout in rehabilitation professionals. The concept of moral stress gives further insight into the specific ways that ethical conflicts contribute to the experience of stress.

Professionals use ethics as part of daily working life. For example, most professionals need to prioritize between various potential agenda items and will make use of values in order to set their agenda. Generally speaking, the resolution of ethical dilemmas requires that the provider identify and list possible choices of action in any given situation, use ethical codes of conduct to recognize the most appropriate course of action and then, follow through with this action. Gibson (2003) argues that ethical conflicts are complicated because they involve competing demands between the individual, his/her employer and professional ethics. However, through the consideration of ethical and organizational codes, the professional eventually arrives at what would be described as either the least harmful or the right course of action.

While ethical conflicts can be resolved through the application of ethical codes of conduct, moral stress is a response within the professional to a unique type of ethical conflict. More specifically, moral stress is caused when the professional is exposed to conflicts between equally compelling or competing sets of values. These conflicts are distinct forms of ethical conflicts because they occur in situations where one value does not override or take priority over another. Audi (2001) defines moral dilemmas as situations in which a professional is required to choose between two sets of behaviours and neither of these can be overridden. Raines (cited in Kälvemark et al., 2004) uses the term moral stress to describe situations in which the professional knows the right thing to
do but is prevented, for various reasons, from engaging in what he/she has defined as the right course of action. As such, moral dilemmas are recognizable because they are experienced by the professional as ‘no-win’ situations. Moral stress is created in professionals when they are exposed to these ‘no-win’ situations.

In addition to stress which occurs when faced with dilemmas that cannot easily be resolved, Tessman (2005) argues that professionals who work with marginalized populations are particularly vulnerable to moral stress. As their clients are often socially and economically disadvantaged and oppressed due to race, social class or disability, these professionals often experience an overabundance of anger. This is particularly so when professionals struggle with, and on behalf of, clients to bring about more just social conditions. Therefore, Tessman (2005) argues that moral stress is also caused by the accumulation of negative emotions in professionals who regularly work with social systems in order to advocate on behalf of marginalized populations.

Compassion Fatigue

Within the stress literature, compassion fatigue and burnout are connected through the emotional fatigue they produce in professionals. The main difference between these concepts is the identified cause of this emotional fatigue. While burnout is a response to organizational and workload demands, compassion fatigue occurs in response to the clinical content of client’s lives. As the literature on compassion fatigue reveals, there are two main schools of thought about compassion fatigue. It is described as either secondary trauma or as empathy fatigue.

Siebert (2004) argues that compassion fatigue is a term that describes secondary trauma experienced in the professional. As such, compassion fatigue is a counter-
transference reaction to client material. According to Siebert (2004), providers who are vulnerable to this type of compassion fatigue are those who have unresolved childhood traumas. These traumas are activated during the clinical encounter and are the foundation for the fatigue that is experienced within the service provider. As secondary trauma, compassion fatigue is an acute response that happens suddenly and without the gradual accumulation of emotions typically associated with the experience of burnout (Siebert, 2004). While agreeing that compassion fatigue is similar to secondary trauma, both Stebnicki (2000) and Bell et al (2003) believe that compassion fatigue is more correctly described as empathy fatigue.

Stebnicki argues that empathy fatigue is a more credible description of the emotional process underlying compassion fatigue. As such, empathy fatigue is the acute experience of emotional or mental exhaustion which is induced through the act of providing empathy to a client. More specifically, through providing empathy, the professional identifies with and makes an effort to understand the difficulties experienced by clients. The act of entering and identifying with a client’s world is considered to have emotional consequences for the professional (Bell et al. 2003). Understanding the important role that empathy has in contributing to compassion fatigue reduces the concern for unresolved childhood issues. However, Stebnicki (2000) and Bell et al (2003) maintain that organizations need to provide professionals time and space to deal with empathy fatigue.

As demonstrated through this discussion regarding stress in rehabilitation professionals, burnout is the experience of emotional and ethical fatigue in rehabilitation professionals. It is caused by ethical and emotional conflicts which exist between a
professional and his/her clinical and organizational responsibilities. In other words, it is the ongoing management of emotional and ethical conflicts which leads to burnout in rehabilitation professionals.

1.2 Organizational Strategies Designed to Reduce Stress

Currently, a variety of strategies are employed to address the emotional and organizational demands which lead to burnout. Organizational strategies tend to be focused on the individual employee and the reduction of his/her stress level within the workplace. Therefore, strategies range from staff education about symptoms of, and solutions to, high stress levels; flexible work schedules to reduce family and work scheduling conflicts; and finally, encouraging the practice of guided imagery, meditation and relaxation (Korman & Petronko, 2004; Sherman, 2004; Lowe, 2002; Nolan, 1995). As well, increasing the clinician’s awareness of his/her own thoughts and feelings during clinical work is perceived to increase job satisfaction and offers a buffer from the consequences of unresolved stress (Gerits et al, 2004; Epstein, 2003; Stange et al, 2003; Williamson, 2003; Kleinman, 1988). Finally, in their meta-analysis of the literature regarding workplace strategies directed at employees, van der Klink and colleagues (2001) found a small but significant effect for strategies directed at the individual employee. Both cognitive behavioral and relaxation strategies reduced stress-related complaints while improving the perceived quality of work life and also, psychological resources and responses (van der Klink et al, 2001).

As job engagement has gained recognition within the stress literature, several studies have been published which address the promotion of job engagement in the workplace. As Saks (2006) states, in order to reduce burnout and therefore, encourage job
engagement, organizations must integrate strategies across multiple levels within the workplace. Employee engagement takes time and is supported through multiple interactions within a workplace that encourages interdependence as part of the organizational culture (Saks, 2006). Management practices which promote job engagement include increased respect for and rewarding of the work done by employees. In addition, as Wittig et al (2003) state, job satisfaction is increased when workers feel cohesion with peers, when they are given increased autonomy and authority to make decisions and finally, when they feel that they are recognized and valued for the work they do within an organization. Although job engagement is a relatively new concept, studies are slowly emerging which provide needed insight into how job engagement can be promoted in the workplace.

While organizations have initiated strategies which address the emotional and organizational challenges which contribute to burnout, there are few strategies which have been identified to deal with moral stress, and little evidence that these strategies have been implemented. Studying ethical conflicts in hospital employees, Kirschner and colleagues (2001) concluded that ethical training of professionals is an insufficient workplace strategy to deal with these conflicts as the content of ethical dilemmas will change over the career of any professional. Alternatively, Gibson (2003) proposes that moral awareness be encouraged in all professionals. According to Gibson, conflict is a part of life and therefore professionals require the ability to make choices in difficult situations. Through promoting moral awareness and also, autonomy in thinking and decision making, professionals are better able to discern which dilemmas are resolvable through application of codes of ethics and which require more independent thinking and
problem solving (Gibson, 2003). In addition, Taylor and Bentley (2005), agreeing with Gibson that ethical conflicts are an unavoidable part of professional life, suggest that professionals recognize that the need to make difficult decisions will sometimes produce guilt and anxiety. Using the work of existentialist Rollo May, Taylor and Bentley (2005) suggest that one of the ways professionals deal with this anxiety and guilt is to recognize that life is complicated. In addition, living life authentically means accepting the reality that when dealing with ongoing ethical conflicts, one sometimes engages in what is described as ‘good enough practice’. The professional who understands and accepts that she/he has done the best possible job is better able to move on to other work and also, less likely to suffer from burnout. As both Gibson (2003) and Taylor and Bentley (2005) indicate, value conflicts are part of professional life and should not always be viewed in a negative light.

Building on the strategies promoted by both Gibson (2003) and by Taylor and Bentley (2005), Tessman (2005) argues that professionals and social activists who work on behalf of marginalized populations can buffer themselves from moral stress through recognizing that sadness and suffering can co-exist with more positive emotions like joy and happiness. Emotional experience is complex and therefore, the experience of tragedy or suffering does not, nor should it, eliminate the possibility of joy or happiness in life (Tessman, 2005). According to Tessman, the professional who can maintain this emotional equilibrium can reduce the impact of moral stress.

In addition to strategies directed at stress in individual employees, there is a recent trend in the management literature toward applying humanistic and faith-based concepts across various levels within organizations (Kennedy, 2003; Lowe, 2002; Alford &
Naughton, 2001). For example, faith-based organizations are recognized for their support of spiritual dialogue and expression in the workplace and also, creating workplace cultures which value the whole person and the contributions he/she makes to the organizational community (Veninga, 2003; Graber et al, 2001). Examples of faith-based companies include Johnson and Johnson and Cadbury (Alford & Naughton, 2001).

Humanistic organizations are different from those described as faith-based because they place greater emphasis on particular values like democratic participation of staff members. More specifically, they emphasize the need for increased input from staff in decision making, a flatter organizational structure and a greater recognition of the role that ethics and morality place in the workplace (Lowe, 2002; Alford & Naughton, 2001). Current examples of organizations integrating humanistic approaches are found in the National Institute for Occupational Health and Safety in the United States and in Tom’s of Maine, a well-known maker of toothpaste and other personal products (Lowe, 2002; Nohre, 2001). While faith-based and humanistic concepts are integrated into government and business environments, there is no evidence in the literature that rehabilitation professionals have been exposed to or benefited from these changes.

Despite efforts to apply solutions to stress within the workplace, organizations have failed to reduce the experience of burnout in rehabilitation professionals. High absenteeism rates, combined with both retention and recruitment problems indicate that rehabilitation professionals and their health and human service colleagues continue to experience stress in the workplace.
1.3 Parameters and Scope of Stress in Rehabilitation Professionals

More than 1.4 million Canadians were employed in health and human services during the year 2001 (Canadian Institute for Health Information, 2005; Roeher Institute, 2002). This number includes those working within both institutional and community settings. While it is difficult to accurately measure the stress associated with providing service to someone living with a disability, absenteeism rates are used as the main indicator of this stress. In 2004, health care workers missed 12.8 days of work due to illness, with rates varying from 8.4 in Alberta to 16.5 in Quebec (CIHI, 2005). While most industries have experienced reductions in compensation and disability claims over the past ten years, rates in health care workers have declined at a slower rate and in fact, increased slightly since the late 1990’s (CIHI, 2005). According to the Canadian Institute for Health Information (2001), recent restructuring within the health care system has led to increased workload demands and less perceived control over workload and even, concerns about the quality of care provided to clients. These work related experiences have resulted in emotional consequences for health care workers including burnout, depression and anxiety (CIHI, 2001). As both the Roeher Institute and CIHI data indicate, health care and human service workers are experiencing high levels of emotional stress, tiredness and burnout (CIHI, 2001, Roeher Institute, 2002). Finally, CIHI estimates that the cost of lost days due to illness or disability in these workers is made concrete when it is estimated that days lost due to illness represent the equivalent of 13,700 full time jobs within the health and human services labour force (CIHI, 2001). As indicated, the burden of unresolved stress in healthcare is associated statistically with both absenteeism and disability related claims for health and human service workers.
In addition to statistical information provided by agencies like the Canadian Institute for Health Information, the research literature provides further descriptions of the impact that stress has on rehabilitation professionals. For the individual, the lack of resolution to workplace stress leads to emotional stress and in some workers, the ongoing experience of emotional stress leads to alcoholism, depression and suicidal ideation (Hewitt et al 2004; Sherman, 2004; Stebnicki, 2000; Barrett et al 1997). Some workers respond to stress through seeking employment in other sectors and this leads to issues of both recruitment and retention in the workplace. Organizations must face the cost of employee turnover rates, difficulty delivering continuous services and finally, low staff morale in the face of high turnover rates (Lowe, 2002; Barrett et al, 1997). Finally, and most importantly, clients must also deal with gaps in services, lack of consistency in staff providing services and perhaps, compromised care as a result of poor staff morale (Gerits et al, 2004; Korman & Petronko, 2004; Sherman, 2004; Stange, 2003). The costs to the individual, his/her clients and organizations remain high, yet the issues faced by these professionals remain unresolved.

The preceding discussion regarding burnout, compassion fatigue and moral stress indicates that these types of stress have significant and ongoing consequences for both the rehabilitation professional and the organization within which he/she is employed. The discussion suggests that it is emotional and ethical fatigue which leads to burnout in rehabilitation professionals. Despite organizational efforts to reduce burnout, it continues to have consequences for both the individual experiencing the stress and the organization within which he/she is employed.
1.4 Rehabilitation Models of Service Delivery

Currently, there are four models which inform the delivery of rehabilitation services: the biomedical, the independent living, the community-based rehabilitation and the client-centred models (McColl et al 1997). A review of the literature regarding these four models reveals that each model has a particular perspective regarding the nature of the problem or issue which needs to be resolved through rehabilitation, the type of relationship needed to work on this problem, an understanding of the change process required to resolve the problem, and finally, goals or outcomes which are associated with this change process (Sumison & Law, 2006; Finkelstein, 2004; Goble, 2004; Restall et al 2003; Kendall et al 2000).

Biomedical

The biomedical model addresses problems which are associated with the bodily functions and structures of particular individuals. Due to the presence of either an impairment or deficit, the bodily structures and functions of these individuals deviate from what are considered normal or standard for human beings (Goble, 2004; Dunn, 1999). According to DePoy and French-Gilson (2004), all individuals who live with a specific impairment or deficit experience the problem in the same way. These individuals live with impairments which share a similar set of characteristics and which demonstrate a similar course over time. Therefore, the biomedical model facilitates the assessment and diagnosis of these impairments.

Given the presence of an identified impairment or deficit, the goal of the biomedical model is to assist the patient in obtaining the highest possible level of functioning (McColl et al. 1997). Professional services are designed to restore the individual to what
are considered normal levels of personal and functional independence (Goble, 2004). For many individuals living with disabilities, the goal is to maximize their ability to engage in activities of daily living.

The biomedical model is focused on the individual patient who is living with an identified impairment or deficit. The goal of the work is to maximize the patient’s ability to live a normal and independent life. The relationship which facilitates the work between professional and patient is characterized by an unequal distribution of power. As such, power and authority reside within the professional who is considered to have the expertise and knowledge needed to return the patient to normal levels of functioning. There is a one-way transfer of information and knowledge from the professional to the patient. Decisions about treatment are made by the professional and his/her team and communicated to the patient. As Goble (2004) describes this relationship, the patient is expected to be a passive participant in the relationship and therefore, accept the expertise and input of professionals. According to Dunn (1999), the patient complies with the advice of the professional and in so doing, is assisted in his/her adjustment to the impairment or deficit.

Within the biomedical model, the change process is initiated by the professional who, through the use of specialized tools, techniques and technologies, classifies the nature of the impairment, assesses the extent of functional loss and finally, identifies limits and restrictions in activities which are experienced as a result of the impairment (Young, 2004). As DePoy and French-Gilson (2004) describe this process, the professional collects the observables and reportables and then, designs a rehabilitation plan to address these concerns.
As the professional determines the extent of the limits or restrictions in capacities or abilities, he/she develops rehabilitation strategies which will assist the patient in regaining or maintaining his/her highest level of functional ability. These strategies can include the introduction of adaptive technologies into the home or personal routines of a patient. They also include exercises or techniques which strengthen remaining abilities. Change occurs as the patient integrates, uses and practices techniques, skills and technologies supplied by the professional. Through this process, the patient adjusts to the disability and in addition, is expected to become as independent as possible in his/her functioning.

**Independent Living**

The independent living (IL) model shares its heritage with the American civil rights struggles of the 1960’s, consumer movements and finally, trends to deinstitutionalize individuals living with mental health and intellectual disabilities (DeJong, 1983). Advocates of the IL model take issue with the biomedical model and its emphasis on normality and independence. Proponents of this model argue that the biomedical model perpetuates the belief that disability is an abnormal state of affairs for human beings. The IL model also takes issue with social attitudes and social processes which are disabling when they act as barriers to work, recreation and normal activities of daily life. Consequently, the IL model addresses problems which are considered to be social in origin.

In addition to its perspective on the nature of the problem which is being addressed, the IL model has clearly identified goals for the work being done with a disabled individual. As the IL model has developed in response to barriers which limit the social
participation of individuals with disabilities, one of its goals is that the individual living with a disability should achieve his/her highest level of personal and social development (Young, 2004). A second goal of this model is to increase the power and control that individuals with disabilities have over decisions made about their care (Morris, 2004; Dunn, 1999).

The goals of the work which is being done within an IL model include personal and social development and also, increased power in decision making. Individuals living with disabilities argue that disability is not a life long medical issue. However, it is considered a personal issue which affects an individual’s entire life course. Consequently, the IL model challenges the view that individuals living with disabilities need long term involvement with and support from professionals (Hasler, 2004). Within the IL model, the relationship between client and professional is structured so that the person with the disability maintains maximum control over decisions made about his/her care. In this way, the client decides on and/or defines his/her needs and then, purchases services which he/she believes will meet these needs. The IL model provides a critique of the biomedical model and in so doing, insists on a different kind of relationship between professional and client.

In addition to its reshaping of the relationship between clients and professionals, the IL model emphasizes the importance of other types of relationships. For example, relationships with peers take on a more prominent role in this model. The IL model encourages peer support as provided through friendship centers (Dunn, 1999). The emphasis on peer support acts as a further counter-balance to this model’s concerns about the dominant influence of professionals on the rehabilitation process.
The IL model advocates for a particular kind of relationship between the individual living with a disability and those who provide services to this person. The relationship is structured in such a way that the individual with a disability maintains maximum control. This concern over control is a response to the influence exerted by professionals. However, it is also informed by a concern about how vulnerable individuals are perceived within society. More specifically, individuals who are considered to be vulnerable are less likely to be given control over their lives and more importantly, perceptions of vulnerability prevent individuals with disabilities from taking the risks needed to live an independent life (Hasler, 2004; Morris, 2004). A vulnerable person is not someone who can control his/her own fate and therefore, vulnerability is a threat to independence (Hasler, 2004). The IL model is concerned about the impression of vulnerability and the impact this has on the ability to act as an independent and autonomous person.

Within the IL model, change occurs at both the individual and the social level. Empowerment of the individual living with a disability is achieved in several different ways. First, assessments are based on the needs of the client rather than eligibility criteria. In addition, empowerment is promoted through giving the client increased control, choice and flexibility with regard to how health and social needs are met. This process is meant to give clients the opportunity to increase their skills and confidence in problem solving and independent living. It is achieved through the sharing of information relevant to decisions being made and through planning with, rather than for, the service user. At the social level, change occurs through the removal of financial and social barriers to housing, transportation, work and participation in civic life. As social barriers are removed, the individual with a disability increases his/her ability to function...
independently. In addition, the individual is able to access human and civil rights granted all citizens.

**Community-based Rehabilitation**

According to Kendall and colleagues (2000), community-based rehabilitation (CBR) is a response to “the prescriptive, paternalistic and institutionalized approaches that have dominated service delivery in the past” (p. 436). CBR is a low cost, community-driven response to the rehabilitation needs of individuals living in developing countries (Kendall, 2000; McColl et al, 1997). As a model with its origins in developing nations, CBR views disability as an outcome of social attitudes, structures and processes (McColl et al, 1997). Therefore, the problems which this model is concerned with are external to the individual living with a disability and are considered to be social and political in origin.

The goal of CBR is to increase the participation of the person living with a disability in his/her community. This includes increasing both the job skills and employability of the individual living with a disability. In addition, the model strives to equalize opportunities for social integration of individuals living with disabilities (Kendall et al 2000). An additional goal for CBR is that the community will assume ownership of services provided to individuals living with disabilities.

According to Mitchell (1999), CBR relies on the involvement of the person living with a disability who is expected to be a motivated, active and responsible member of his/her family and larger community. As Kuipers et al (2003) state, the working relationship is established between a client and a professional, both of whom are expected to actively shape goal setting and decision making. As this model is considered a community
development strategy, the client is defined broadly and includes the individual living with a disability, his/her family and the local community. Therefore, the professional develops working relationships with a range of local and community stakeholders.

Within the CBR model, change occurs through the use of community development strategies. This includes developing, mobilizing and maintaining local and natural support systems and resources. While the professional may introduce training and development strategies, change occurs when the individual and his/her family begin to use and integrate the suggested strategies. The change process is consolidated when the individual, his/her family and/or local community take ownership of and/or a leadership role in services provided.

**Client-centred**

With a client-centred model of service delivery, the problem or issue which needs to be addressed is defined by the individual living with a disability. A professional working within this model would not presume to define the problem for the client, but would support the client’s right to determine the nature of the issues which require the input of a professional.

As the client-centred model is designed, the client defines the nature of the problem. This model recognizes that individuals living with disabilities experience a range of issues as they adjust to living with a disability and therefore, they will bring a range of problems to rehabilitation professionals. With specific regard to the goals for the work which is to occur between client and professional, this model emphasizes the role of the client in deciding what goals should look like. As Cott (2004) discovered through her research with Acquired Brain Injury clients, individuals with disabilities want
individualized care plans which reflect their own specific needs. In addition, goals should be based on outcomes which are meaningful to the client.

In order to facilitate client involvement in identifying problems and goal setting, the client-centred model relies on a particular kind of relationship between a professional and an individual living with a disability. Within this relationship, the professional must make efforts to ensure that power is distributed in a fair way, demonstrate active listening and finally, integrate the perspectives and needs of the client into all aspects of clinical decision making (Sumison & Law, 2006). More specifically, power is directly addressed through the development of a collaborative partnership between client and professional (Sumison & Law, 2006; Cott, 2004; Restall et al 2003). This means that professional dominance and control is discouraged (McColl et al, 1997). The relationship is non-directive, supportive and allows each client maximum freedom to make his/her own decisions (Kensit, 2000). Therefore, the role of the professional is to assist the client as he/she decides on appropriate goals and courses of action (Sumison and Law, 1996).

As suggested by McColl et al (1997), the client-centred model has been influenced by the counseling approach developed by Carl Rogers. Rogers emphasized the importance of the relationship to his approach with clients. Rogers believed that individuals possess an innate ability to understand themselves and, given the right circumstances, to make the right choice about their situations (Rogers, 1980). According to Rogers, there are three qualities of relationships which provide the necessary and sufficient conditions for change. These are the provision of unconditional positive regard or acceptance, an empathetic attitude towards the client’s world view and finally, congruence or attentiveness during clinical interactions (Josefowitz & Myran, 2005). The emphasis on
respecting client self-determination that is considered so fundamental to a client-centred model of service delivery can be traced to Carl Rogers and his belief in the therapeutic qualities of relationships.

Within the client-centred model, change occurs as individuals define their needs, develop plans to have these needs met and then, successfully meet these needs. Within this model, the change process is described as self-actualization. This process happens as clients define their interests and goals and then, make these happen. Furthermore, as Duggan (2005) indicates, the change process is facilitated in the client who gains experience of his/her own personal power and is able to move from passive to active involvement in meeting his/her own needs and those of others. Within the client-centred model, change is viewed as an internal process that is described as self-actualization.

Critique of the Models

As indicated through the preceding discussion regarding models of service delivery, each model has a particular perspective on the nature of the service issue or problem needing to be addressed, the structure of the relationship best suited to resolving the issue, the process of change required to deal with the identified issue and finally, goals or outcomes which are associated with the change process. Each model has a unique role to play in the diagnosis, treatment and rehabilitation which occurs in relation to a particular individual who lives with a disability (McColl et al 1997).

Despite their distinct approaches to service delivery, all four models recognize that professionals apply ethical codes of conduct and also, govern emotions within the clinical relationship. Within all four models of service delivery, the professional is encouraged to maintain a neutral and objective stance in relation to the client or patient. This means the
professional does not engage in the exchange of emotions or feelings. In addition, all models are based on an ethical stance which views the relationship between client and professional as a contract between two people who are essentially strangers to each other (Reinders, 2000). It is the objective and non-personal nature of the relationship which has been criticized by some philosophers who have expertise in the areas of ethics and disability issues.

With regard to ethics and the nature of the contract between professional and client, philosophers like Hans Reinders (2000) suggest that both modern society and modern medicine are preoccupied with curtailing the influence of professionals within the decision making process. This has led to an increased emphasis on patient rights, autonomy and self-determination and to a focus on procedures, duties and obligations within the relationship. When relationships become focused on duties and obligations, they are described as contractual in nature. According to Reinders, the contract is understood as one which is focused on the benefits accrued to the patient or client and provides no recognition of benefits to the professional.

Reinders argues that current approaches to relationships in health care are defined by their contractual nature. In order to meet the requirements of this contract, the professional is expected to maintain an impersonal relationship with the client or patient. The impersonal nature of the relationship means procedures, duties and obligations are met and delivered in an objective and impartial fashion. The maintenance of distance within the relationship between client and professional ensures that subjectivity and partiality do not interfere with the standardized application of professional services.
Reinders (2000) believes the approach to relationships taken by professionals today over-emphasizes duties and obligations. Donnelly and Long (2003) suggest that the relationship is also problematic because of the imbalance it maintains between rationality and emotionality. The history of Western culture demonstrates that rationality has been considered ‘the ultimate good’ and therefore, reason is considered a more reliable influence than emotion over most aspects of decision making and behaviour (Cottingham, 1998). This bias against emotions is based on the belief that feelings or passions exist outside the realm of conscious thought and therefore, cannot be controlled. Consequently, due to their unstable nature, emotions are considered to act as a potential source of interference in the objectivity needed to do most healthcare work (Nussbaum, 2001).

However, Nussbaum criticizes what she considers to be an inaccurate view of emotions. As Nussbaum (2001) argues, the rationality versus emotionality debate incorrectly places these two human experiences on opposite ends of the cognitive spectrum. Nussbaum recognizes that emotions can be intense and that, at times, they can move individuals to act or react quickly and urgently. However, the intensity with which emotions are felt is more correctly interpreted as a statement about importance and value. Nussbaum states that emotional reactions provide information about the importance or meaning of particular people or events in someone’s life. In this way, emotions represent cognitive evaluations or appraisals regarding issues that matter to someone. Nussbaum’s approach to emotions leads us to realize that emotions are rational and therefore, open to debate and also, control. Her work challenges the detached use of rationality which is found in current models of service delivery.
In summary, the four current service delivery models are critiqued for the way that professionals manage emotions and ethics within the clinical relationship. The literature on stress reveals that professionals may respond to prolonged emotional and ethical conflicts through the experience of burnout. In addition, the over-emphasis on objectivity and contractual relationships within the four models of service delivery contributes to burnout in rehabilitation professionals. Because the four models currently available to rehabilitation professionals are unable to effectively address burnout in professionals, there is a need to develop alternative models which deal more specifically with these ongoing and unresolved issues. This thesis proposes that Jean Vanier’s approach to relationships between individuals living with and without disabilities could provide the foundation for an alternative model of service delivery.

1.5 Jean Vanier

Jean Vanier is the founder of l’Arche International, a series of group homes for individuals living with intellectual disabilities. The first l’Arche home was established in Trosly-Breuil, France over forty years ago. Since that time, Vanier has been instrumental in the development of l’Arche communities around the world. Within these particular communities, individuals with intellectual disabilities live in small family-like homes with individuals who do not have disabilities. These homes form a network of communities which are referred to as l’Arche International.

Through his years working and living with individuals who have intellectual disabilities, Vanier has developed expertise and knowledge about a complex impairment which influences cognitive and also, social functioning. More specifically, as discussed by Rapley (2004), the American Association of Mental Retardation defines intellectual
disability as a condition in which the individual, prior to the age of 18, demonstrates significant limitations in intellectual functioning which coexist with impairments in the ability to accomplish activities of daily living.

The language used to describe Vanier’s particular area of expertise has changed in response to more contemporary thinking about cognitive impairments. At present, this area is referred to as the field of developmental disabilities or intellectual disabilities (Stainton & McDonagh, 2001). Recent organizational and journal name changes demonstrate the significant shifts in language which are used to describe this area of work and research. More specifically, the Journal Mental Retardation recently changed its title to Intellectual and Developmental Disabilities (Schalock et al., 2007). In addition, in early 2007, after a great deal of discussion and debate, the American Association of Mental Retardation changed its name to the American Association of Intellectual and Developmental Disabilities (Schalock et al., 2007; Turnbull et al. 2002). Reflecting current use of language and constructs, Vanier is someone who has extensive familiarity with and expertise in the field of intellectual and developmental disabilities.

Vanier has written many books about his work with individuals who have intellectual disabilities. Throughout his books, Vanier emphasizes the growth and development of both individuals living with and without disabilities. According to Vanier, relationships provide a unique environment within which individuals with disabilities can grow and change. In order to support these kinds of relationships, individuals who provide care to an individual living with a disability must engage in their own growth process (Vanier, 1998a; Vanier, 1997). Through this process, an individual gains insight into emotional, intellectual or spiritual parts of self which may influence the quality of relationships
developed with individuals living with disabilities. Vanier indicates in several books that his primary concern is with growth that takes place in the individual living with a disability. However, he is also concerned about the well-being of the person who provides care to that individual living with a disability (Vanier, 1998a; Vanier, 1997).

Recently, researchers in the field of intellectual disabilities have concluded that the approach taken to relationships, within l’Arche communities, merits closer examination and study. Mutuality and friendship are two important concepts which have received particular attention. Pottie and Sumarah (2004), Cushing (2003) and also, Cushing and Lewis (2002) believe that mutuality and friendship play valuable roles in the relationship between professionals and individuals living with disabilities. More specifically, Pottie and Sumarah (2004) argue that the interpersonal connections encouraged within l’Arche group homes play an important role in the emotional and physical well-being of the client, but also recognize that the person without an identified disability gains from the relationship. Pottie and Sumarah (2004) argue that both clinicians and individuals with disabilities can successfully negotiate differences in abilities and also, reciprocity in the relationship. Reciprocity is valued because it benefits the person providing and also, receiving care (Pottie & Sumarah, 2004). In addition to the arguments presented by Pottie and Sumarah (2004), Cushing (2003) and also, Cushing and Lewis (2002) suggest both care providers and individuals with disabilities benefit when power and influence are recognized and shared within the relationship. Using concepts which have been influenced by the thinking of Jean Vanier and given expression within the l’Arche model, Cushing (2003) argues that relationships between individuals living with and without disabilities demonstrate qualities of mutuality when both participants gain from the
relationship. In addition, when Cushing and Lewis (2002) examined relationships between a small sample of women with intellectual disabilities and their care providers, they concluded care providers who recognized and negotiated power differences were able to promote a sense of personal agency in women living with this particular type of disability. Pottie and Sumarah (2004), Cushing (2003) and also, Cushing and Lewis (2002) provide insight into the potential linkages between Vanier’s ideas and emotional well being in professionals and clients.

While Cushing and Lewis and also, Pottie and Sumarah are examples of researchers who have examined Vanier’s work for its significance to clinical relationships, there has been no systematic effort to understand whether Vanier might offer solutions to the stresses experienced by rehabilitation professionals. Given that Vanier pays specific attention to the well-being of the person providing care to an individual living with disabilities, there are good reasons to look more closely at his work in order to determine what he might offer discussions regarding models and stresses in the field of rehabilitation therapy.

Before completing this initial discussion regarding Vanier, it is important to clarify the language which is used within this thesis. Vanier is recognized internationally for his work with individuals who have intellectual disabilities. Vanier is also known for his use of the term ‘assistant’ to describe the person providing care to an individual living with a disability. However, it is important to recognize that Vanier does not limit his concern to ‘assistants’. Vanier does make reference to professionals like psychiatrists, social workers and teachers and he does recognize their work with individuals who have disabilities. Furthermore, the relevance of his work extends beyond individuals living
with intellectual disabilities and therefore, has significance to individuals living with a variety of impairments. Maintaining a respect for the concerns of Vanier while also meeting the identified goal of developing an alternative service delivery model, the thesis makes use of the terms professional, client and also, individual living with a disability.

1.6 Orientation to Thesis - A Personal Perspective

The motivation to do this thesis has come from a variety of sources. Prior to starting the PhD program, I worked as a social worker for over twenty years. My professional work included employment in child welfare settings and also, clinical support to individuals living with a variety of disabilities and chronic illnesses including intellectual disabilities, seizure disorders and cancer. As I prepared to start the PhD, I was aware that I was experiencing some type of professional fatigue. I was not able to put a label on the experience. However, in the year before starting the thesis, I realized I was not listening as attentively to clients. I was concerned about this process as I noticed myself anticipating answers before clients had even begun to tell their stories. The original motivation for the thesis therefore came from my own personal experience. I was motivated by a need to understand more about the professional self I experienced as I finished my clinical work and prepared to enter the PhD program.

As I became aware of my own shifting responses to clinical work, I noticed my colleagues were also experiencing a number of stressors, many of which were a direct response to changes in the delivery of health services. As healthcare in Ontario has been continuously restructured over the past ten years, many of my colleagues have been faced with a variety of organizational and clinical challenges. I watched as colleagues, who were nurses, occupational therapists and social workers employed in community home
care services, adjusted to the clinical consequences associated with competitive bidding for contracts within this sector. These consequences included tighter restrictions on time per visit with client and increased numbers of client contacts per week. For some of my colleagues, the consequences of new competitive structures within homecare services included being transferred between several employers. Consequently, these colleagues had to come to terms with a variety of emotional, clinical and organizational stresses while continuing to provide services to individuals who needed their services in the community. As indicated, the newly restructured face of healthcare has caused a variety of stresses in my professional colleagues. This thesis has been motivated by a need to understand the impact of these stresses on my colleagues and friends who continue to be employed in a variety of community and hospital settings.

While this thesis has been informed by a need to learn more about professional stress and burnout, my belief that Vanier has something to offer rehabilitation professionals is based on several distinct experiences I have had with Vanier over the years. In my late teens and early twenties, I worked for several summers and also, part-time during the school year, at a community agency which provided a variety of services to individuals living with intellectual and other disabilities. This community agency was started by an Anglican couple who, for over a year, had lived and worked at l’Arche Trosley-Breuil, France. The couple used Vanier’s philosophy and approach to inform the organizational structure of the agency. This meant that relationships between clients and staff and also, staff and supervisors were modeled on the approach used by Vanier in his l’Arche homes. The experiences I had working in this agency exposed me to an organizational model that supported growth in both clients and professionals. This meant that I was mentored by
other staff and encouraged to be a reflective professional. In addition, my colleagues and supervisors engaged in regular discussions about relationships with clients. We were also encouraged to establish personal relationships and to view the relationship as one in which there was some give and take between client and professional. Since that time, I have worked in a variety of community and hospital settings. I do not believe I have ever experienced such a unique combination of client and collegial relationships in any other setting.

After finishing undergraduate degrees in psychology and social work, I moved on to employment in child welfare and eventually, to health service work. Since my early exposure to Vanier, I have had no direct contact with his approach to individuals living with disabilities. However, I have read about Vanier, read books by him and also, heard him speak on several occasions. A few years ago, I read an older book which was written by Jim Clarke. In his *l’Arche Journal* (1973), Clarke chronicles the year he and his family spent living and working at l’Arche Trosly-Breuil. In the book, Clarke is candid about the emotional roller coaster he experienced while living and working at Trosly-Breuil. Although he was not trained as a counselor, it was Clarke’s ability to describe and reflect upon a range of emotions, including laughter, celebration and anger, which stayed with me after finishing the book.

While living in Lethbridge, Alberta from 1995 to 1998, I had the chance to attend an evening lecture Vanier gave at a small United Church. What struck me as surprising about the lecture was Vanier’s ability to openly reflect on the range of emotions he felt while providing direct care to a man with severe physical and intellectual disabilities. His ability to speak directly to the challenges and rewards in relating to an individual with
disabilities made me realize that there was an incredible depth to him. I left that evening with a greater appreciation for his capacity to reflect honestly on himself and his ability to share this reflection in an authentic way with others.
CHAPTER TWO: METHODS

2.1 Research Goal, Question, and Objectives

This thesis is concerned with stress in rehabilitation professionals. There is one main goal for this thesis. The goal is to develop an alternative model of service delivery which reduces burnout in rehabilitation professionals. This model includes theoretical principles which illustrate and define relationships between concepts.

The research uses the work of Jean Vanier to enhance the understanding of solutions to stress currently faced by rehabilitation professionals. It answers the following question. How does Jean Vanier’s thinking about relationships between individuals living with and without disabilities contribute to the field of rehabilitation therapy and more specifically, to reducing the stress currently faced by rehabilitation professionals?

In order to meet the thesis goal and answer the thesis question, a series of objectives have been created. These have been framed as the following questions.

- What is the issue or problem that Vanier is concerned about?
- What does Vanier say about the nature of the relationship between individuals living with and without disabilities?
- What is the process of change associated with this relationship?
- What are the outcomes associated with this process?

2.2 Study Design

Two key features inform the design of this study. The first is that this study makes use of a constructivist paradigm. The second is that it makes use of a single, interpretive case study design.
**Constructivist Paradigm**

According to Guba and Lincoln (2004) there are four possible paradigms that any researcher can choose from. These are the positivist, post-positivist, critical and constructivist paradigms. Guba and Lincoln state that the choice of paradigm is more important than choice of method as the paradigm choice reflects the researcher’s belief system or world view. The constructivist paradigm gives priority to understanding and to reconstructing worldviews in order to obtain a consensus view of the subject matter (Guba & Lincoln, 2004). Because this research is motivated to understand the worldview of Jean Vanier as represented by Vanier, key informants and key text passages, the constructivist paradigm provided an approach to the research which closely matched the goal and objectives of this study.

**Single, Interpretive Case Study Design**

There are many different research designs a researcher can choose from; the two most relevant to decision making regarding this thesis are the biography and the case study design (Creswell, 1998). A biography is concerned with the life history and context of one particular individual, while case study represents an in-depth examination of a particular case and makes use of contextual material in order to understand the case (Creswell, 1998). Both case study and biographical research collect data from similar sources including oral interviews and archival material (Creswell, 1998). However, the case study is different from biography because it makes use of historical documents and context in order to understand current or contemporary concerns and issues. Therefore, the case study is distinguished from historical approaches through its emphasis on the here and now (Yin, 2003). This research uses the thinking and writing of Vanier and
relates these to a particular and current set of problems in rehabilitation professionals. Therefore, it makes use of a case study design.

Having decided to use a case study, further decisions were required regarding the use of evaluative, interpretive or descriptive designs and finally, whether to use a single or multiple case design. Merriam (1998) distinguishes between evaluative, descriptive and interpretive case studies. These distinctions reflect differences in the overall goal of the study. Evaluative case studies are designed to examine a program or organization with the intent to evaluate or judge. Descriptive case studies are interested in providing detailed information about a particular phenomenon or person; they are not generally concerned with generating theoretical propositions about the matter under study. Interpretive case studies are designed to develop conceptual categories, to illustrate, as well as to challenge theoretical assumptions and, if necessary, to develop interpretations, analysis and hypotheses about the phenomenon under study. Because Vanier’s work is being examined for its conceptual development and interpretations about the nature of the relationship between the rehabilitation professional and his/her client, the interpretive case study design is used in this research (Merriam, 1998).

In addition to clarifying the intent of this case study and therefore, choosing an interpretive case study, a decision has been made between single and multiple case design. This decision has been guided by the study question. Multiple case studies allow the researcher to compare and contrast across cases and therefore, provide greater opportunity for generalization of results. According to Yin (2003), the multiple case study design provides a more robust study design than the single case study. However, a single case study is the best strategy when the case is expected to reveal unique
information. Because Jean Vanier is considered to be a unique person who has specific insights to offer the field of rehabilitation therapy, a single case study design represents the most appropriate research design for this research.

According to Merriam (1998), case studies are designed to provide a comprehensive description and analysis of a person, program or event. An important feature of a case study is the definition of a clear boundary around the object of study (Merriam, 1998). In addition, the boundary acts as a limit on the amount of data which needs to be collected in a case study (Merriam, 1998). In order to manage the data collection and analysis, the boundary for this case study is drawn around Jean Vanier and his thinking about relationships between individuals living with and without disabilities. The drawing of this boundary means that the study does not give extensive consideration to l’Arche International or the literature written about l’Arche. While it is recognized that these decisions limit the scope of the project, they have ensured that the study is manageable and realistic in its objectives.

Addressing the Limitations of Case Study Design

A case study design is chosen with its strengths and weaknesses in mind. The strength of the case study is its ability to deal with multiple sources of information, as well as a variety of types of evidence, including documents, artifacts, interviews and observations (Yin, 2003). A case study provides the structure needed to examine contemporary, complex social phenomena where the boundaries between the phenomena and their environmental context are not clearly evident (Yin, 2003; Merriam, 1998). Although it is difficult to generalize from a case study, the researcher can expect to refine understanding and modify larger generalizations. Case studies are criticized, however, for a possible
lack of rigour and objectivity. They are considered to be vulnerable to the influence of the researcher’s own bias (Yin, 2003; Merriam, 1998). Consequently, they are heavily reliant on the sensitivity and integrity of the researcher (Merriam, 1998).

According to Stake (1995), the case study researcher wants to demonstrate that she ‘has it right’ and that she has provided a comprehensive description and accurate interpretation of the phenomenon under study. Within case studies, the researcher increases her chances of ‘getting it right’ through strategies such as triangulation, the use of member checking and thick description of data. Each of these strategies increases trustworthiness and credibility within a case study (Yin, 2003, Creswell, 1998; Stake, 1995).

As indicated in Creswell (1998) and Stake (1995), triangulation is achieved in several different ways. Triangulation of data sources is done through bringing together and also, comparing multiple sources of information. The use of multiple information sources ensures that interpretations offered are correct because they are confirmed or challenged by more than one data source. Triangulation is also achieved through having other researchers participate in the coding process in order to ensure that data is accurately interpreted and coded. According to Cutcliffe and McKenna (1999) having other researchers review and give input into coding procedures provides a much needed challenge to the developing and emerging themes and categories.

This thesis makes use of several triangulation strategies. First, data has come from three different sources. Using text passages, key informant interviews and the interview with Vanier provides multiple perspectives and insights on the issues which are being studied. During data analysis, two other triangulation strategies have been used. After the
data was categorized according to self, relationship and transformation, it was
triangulated according to data source. Therefore, the three categories were analyzed
according to text passages, key informant interviews and the interview with Vanier. This
provided insight into how the concepts remained stable or changed according to data
source. A final triangulation strategy which has been integrated is having the coding
checked by one other person. Once categories were identified and confirmed, my thesis
supervisor provided an important second perspective on the coding process and ensured
that the data has been accurately interpreted and coded.

In addition to triangulation strategies, the researcher gains feedback about the
accuracy of interpretations through the use of member checking (Creswell, 1998; Stake,
1995). According to Stake (1995), case studies involve ‘actors’ and member checking is
the process in which the ‘actor’ is asked to review material for accuracy and palatability
(p.115). As recommended by Stake, member checking occurs after the collection of data
is considered complete. Member checking involves sharing emerging interpretations and
through this process, the researcher receives both confirmation and clarification of
interpretations (Cutcliffe & McKenna, 1999).

Within this thesis project, member checking occurred with both key informants and
also, Jean Vanier. Toward the end of data analysis, key informants and Vanier were
provided with an executive summary of the research results. In addition, as Vanier
requested, he was provided with a list of all quotes from the interview in France which
were used in the thesis. I provided this list to him at the same time I sent the executive
summary.
In addition to triangulation and member checking, thick description is also an important tool in case study research. As Stake indicates, thick description includes “providing readers with good raw material for their own generalizing” (p. 102). This means that the researcher provides a fair amount of narrative text. Thick description of the data is important as it provides the reader with a chance to learn, to gain experiential understanding of the material and to gain access to multiple realities (Stake, 1995, p. 43).

Within this thesis, thick description was integrated into the findings section. Therefore, through the use of both long and short quotes, the reader is given the opportunity to engage with the material and increase his/her familiarity with the data. In addition, the findings section consistently makes use of data from all three sources.

As indicated, a number of strategies have been integrated into this research project. These include triangulation, member checking and also, thick description. Each of these strategies is used in an effort to establish credibility and trustworthiness of interpretations which have been developed.

2.3 Data Sources

There were three sources of data for this thesis. These included books, interviews with key informants and finally, an interview with Vanier himself. Each source of data contributed to the development of concepts and theoretical principles.

Books

Eight books were chosen to inform the thesis because they represent both an official statement and a permanent, accessible record of Vanier’s thinking. See Appendix 1 for a list of the books used. The books were chosen according to the following criteria. 1. The books were authored by Vanier. 2. The books were written in English. 3. With regard to
content, books were included if they had significant disability and rehabilitation themes.  
4. Books which were explicitly religious in content were excluded from the initial sample.  
5. With regard to date of publication, the initial sample included books authored by Vanier during and after the 1990’s.  

The rationale for choosing more recent books included the recognition that Vanier has been writing for over 30 years. Therefore, more recent books were examined initially as it was expected that they would reflect issues of current concern to rehabilitation professionals.  

I made the decision early in the process to exclude explicitly religious books in order to ensure that the books reflected a range of rehabilitation themes and also, ideas about relationships with individuals who have disabilities. More specifically, within the past three years, Vanier has written at least two books which explore particular parts of the old and new testaments (Vanier, 2005; 2004). These books were clearly meditative and religious in focus and therefore, they were excluded from the sample.  

As indicated, this case study is concerned with Vanier’s thinking about disability issues, therefore books used for the purposes of data collection needed to be authored by Jean Vanier. There is a large body of work written about both Vanier and l’Arche and this was not used as a source of data.  

After collecting data from six books, it appeared that there was a saturation of concepts as no new issues were emerging. A choice was made at this point to begin preparing for interviews with key informants. Through the completion of key informant interviews, two further books were identified which needed to be read. These two books were not included in the original sample because they did not meet the criteria for book
selection. One book was an older book and the other had an explicitly religious theme.

Through the key informant interviews, it became clear that these two books needed to be included in the sample as they contained ideas which were identified as significant by the key informants. These books are identified in Appendix 1 through the use of an asterisk. This brought the total number of books in the sample to eight.

**Interviews**

Nine key informants were interviewed. These nine informants were chosen on the basis of their experience with Vanier’s ideas. The informants were interviewed for information about the development of the conceptual model and theoretical principles. See Appendix 2 for more information about key informants.

Informants were included or excluded according to the following criteria. 1. All key informants needed to be familiar with Vanier’s thinking about relationships with individuals who have disabilities. 2. Key informants needed to be in a position of responsibility in order to be interviewed. This criterion was used because it was important to speak with people who had extensive experience and familiarity with Vanier’s thinking. In addition, it was important to speak with administrators and managers who influenced the work of others and therefore, the manner in which Vanier’s ideas were interpreted and applied. Consequently, both front line employees and individuals with intellectual disabilities were excluded from the sample because they were not considered to be in a position of influence within the organization nor were they expected to provide the broader perspective which would come from someone in a senior position. 3. Key informants included those both currently employed and also, those who had been employed at l’Arche. Previous employees or affiliates were included if they met the
primary criteria of extensive familiarity with and also, the ability to influence the practice of others in relation to Vanier’s ideas.

With regard to internal key informants, I provided the criteria for familiarity with Vanier’s work to the internal gatekeeper at l’Arche Canada and this person made a decision about which administrative staff met the criteria. With regard to key informants who were not currently employed by l’Arche, it was my own personal judgment which led me to conclude that they had the breadth of familiarity with Vanier that was needed to assist me in this project.

Key informants were located through several strategies. As this thesis is primarily concerned about the Canadian context for rehabilitation professionals, the initial sample for interviews came from l’Arche Canada Head Office in Toronto. The choice to use l’Arche Canada staff in Toronto for the initial sample was made for several reasons. Although I have studied French and German, my second language skills are limited and therefore, these interviews needed to be done in English. Therefore, there was an intentional choice to interview English speaking staff.

Initial contact was made with a senior staff person at l’Arche Canada. This person agreed to be the organizational contact and arranged for a series of interviews to take place at the Toronto Office of l’Arche Canada. Two days of face to face interviews were arranged for April 2005. Six people were interviewed in total.

While Vanier was in Kingston giving the retreat at Queen’s University, he located and introduced a seventh individual, who also lived in Kingston and agreed to be interviewed. This particular individual had worked with Vanier and l’Arche many years ago and although no long working at l’Arche, maintains regular contact with the organization and
with Vanier. Finally, two other individuals who are familiar with Vanier, and also, l’Arche, were located and agreed to be interviewed. These individuals were located through l’Arche Canada and were invited to participate in this thesis because of the particular clinical expertise and skills they have. One of these individuals had worked for many years as a consultant to l’Arche and currently, has less frequent contact. The other is someone who has worked on film projects with Vanier and is now on the Board of Directors with a small l’Arche community in Northern Ontario. Due to location, these two individuals were interviewed by telephone.

**Interview with Vanier**

The final data source was the interview with Vanier himself. The interview provided Vanier with the opportunity to comment on the emerging conceptual model and the chance to confirm or challenge interpretations of his work.

The interview process was initiated through a letter which was mailed directly to Vanier’s home in France. See Appendix 3 for a copy of this letter. Vanier initially declined due to his busy schedule. However, during the fall of 2004, Vanier was in Kingston and gave a one day retreat to Queen’s University students. During the retreat, I introduced myself to Vanier. My participation in the retreat, and the opportunity to make a personal connection, appeared to influence Vanier’s decision to meet for the interview. Shortly after this retreat, a meeting time was confirmed. Vanier consented to an interview in his home at Trosly-Breuil, France during the summer of 2005. The interview was booked and this researcher traveled to France to meet with Vanier. The interview took place on July 1, 2005 and lasted approximately two hours.
2.4 Data collection

Books

Data collected from books consisted of verbatim quotes that were taken from each of the texts. Passages were selected because they made specific statements about principles which informed the relationship and/or care provided to individuals living with disabilities. Principles were defined as ideas fundamental to Vanier; they represented fundamental truths which form the basis of reasoning and as general laws which guide action (Sykes, 1986). These principles included specific statements about behaviour or attitudes, between individuals with and without disabilities. Behaviour was defined as the manner or way in which a person acted and attitude was defined as the dispositional posture of a person (Sykes, 1986). The selected passages were typed, entered into a computer file and catalogued according to book. Reflective notes and emerging insights about themes were maintained in a separate file.

Interviews

Interviews were semi-structured in order to provide maximum opportunity for those interviewed to reflect on themes and issues under consideration. On average, they lasted 90 minutes. See Appendix 4 for interview questions. Questions were asked in an open-ended manner and some questions were edited when it became clear that interviewees required further elaboration of the intent behind the question. All interviews were audio taped and reflective notes were made following each interview. Two interviews were done by telephone due to time constraints and also, the location of the interviewee. These interviews were also audio taped. Several interviewees asked to review their transcripts. Edits to the interviews were completed as requested.
After all the audiotapes had been transcribed verbatim, they were saved as electronic files according to a numbered system, with the first interview referred to as Interview #1 and the last interview as Interview #9. The data from interviews was in the form of questions and answers. As there was some confusion about one question early in the interviews, this question was altered to ensure its intent was clear. In general, this researcher made an attempt to keep fairly closely to the interview questions and therefore, the data accurately reflects the questions asked. However, as the interviews were meant to be semi-structured, there were many instances where there was more interaction and discussion.

**Interview with Vanier**

The interview with Vanier was based on a draft model and related questions which had been emailed to him in advance and which he had reviewed. See Appendix 5 for a copy of the draft model and interview questions.

The data collection strategy included a semi-structured interview format in which I asked Vanier questions about the model and obtained his reaction to the concepts, principles and emerging relationships. The interview with Vanier was audio-taped and transcribed upon return to Canada. Vanier was mailed a copy of the interview transcript. However, no edits were requested by Vanier. The transcript was entered into the electronic filing system as Interview #10.

The data from this interview was in the form of questions and answers. It was different from the book and key informant data as Vanier spent the first 10 minutes of the interview giving a general response to the model and concepts. As the interview unfolded in a more conversational and therefore, less structured way, the questions were
answered in a slightly different order than originally intended

2.5 Data analysis

Data preparation and Preliminary Analysis

All the electronic data files were entered into NVIVO Software.

As part of the preliminary analysis which occurs as data is collected, case study methodology requires that two steps be taken. First, all documents must be described and authenticated. Therefore, in this case study, all books were reviewed and described according to date and purpose of book. This was done in order to authenticate and confirm that Vanier had written the books and to identify where third parties were involved in either translating or editing of books. Appendix 1 includes a description of each book and its purpose.

In addition to authenticating data sources, case studies require a review of the case and its historical or biographical context (Creswell, 1998). In order to meet this requirement, four books were used to gain biographical and contextual information about Vanier. These books included Vanier’s own story of his father’s life, In Weakness, Strength (1971), Kathryn Spink’s 1990 biography of Vanier entitled Jean Vanier & l’Arche: A Communion of Love and also, the 2006 version of Vanier’s biography, also written by Spink, titled The Miracle, The Message, The Story: Jean Vanier and l’Arche. Finally, a book by Father Thomas Phillipe, You are Precious in My Eyes (2002) was used to gain insight into the case context.

Data Reduction and Data Analysis

The first step in data analysis included a return to the research question and the objectives for the research study. In addition, there was a review of all printed materials
including text passages from books, key informant interviews and the interview with Vanier.

Journaling was done throughout data analysis. It included notes taken immediately after the retreat led by Vanier at Queen’s University in the fall of 2004, as well as, journal entries made during and after the visits to l’Arche Canada in Toronto and also, l’Arche Trosly-Breuil in France. Journaling was used as a reflective strategy and in an effort to consolidate thinking about various concepts and their relationships. Sample journal entries can be found in Appendix 6.

As the goal of this thesis is the development of a conceptual model of service delivery with theoretical principles, grounded theory was chosen as the analytic strategy. As an approach to data analysis, grounded theory gives a researcher the ability to identify key concepts and generate hypotheses about relationships between these key concepts (Browne, 2004).

The ability to generate propositions about relationships between concepts begins with open coding of data sources. This represents the detailed search for themes and categories which are within the data itself. Open coding produces categories which form the basis for further data analysis. Categories are also identified through terms or concepts which are derived from the literature about a particular topic (Strauss & Corbin, 1998). Categories should be at a similar level of abstraction and are meant to represent distinct, robust concepts (Merriam, 1998). The rightness or wrongness of a category is determined by its effectiveness at describing the data.

After identification of core categories and sifting of data according to these categories, the researcher proceeds to axial coding. When the researcher moves to axial coding,
he/she is looking more closely at each category in order to identify its properties and dimensions (Strauss & Corbin, 1998; Strauss, 1996). As the researcher completes the description of categories according to their properties and dimensions, he/she is also looking for a central concept or category. The last stage in data analysis is the identification of this central concept or category.

According to Strauss and Corbin (1998), this category is considered essential to the model and therefore, provides the link between categories and concepts. Through establishing a central category, the researcher is able to identify how concepts relate to each other (Strauss & Corbin, 1998). Relationships between concepts emerge through the identification of strategies, actors, consequences and conditions (Strauss, 1996). Therefore, relationships between concepts are found through answering the following series of questions. Who is doing what? Under which conditions are they doing this? What are the consequences? Through answering these questions, grounded theory gives the researcher the ability to describe a conceptual structure or model and also, more importantly, the processes which inform this structure (Strauss & Corbin, 1998).

As the data analysis progressed within this particular research project, open coding produced over 200 concepts. Through a return to the research objectives, framed as questions, these concepts were organized into three main categories which were labeled self, relationship and transformation. The labels given to these three categories reflected terms used by both Vanier and key informants. Data which was assigned to the category self included concepts about the essential qualities of human beings. The category relationship included all concepts which pertained to the nature or quality of interactions between two or more individuals. Finally, the category transformation included all data
which referred to the process of change.

After identifying the three category labels, the data was manually coded and then, with the use of NVIVO software, this coding system was used to produce three data files which were labeled self, relationship and transformation. These three data files were printed. The data from self, relationship and transformation was analyzed according to properties and dimensions (Strauss & Corbin, 1998; Strauss, 1996). Within the category self, three properties were identified as spirit, affect and intellect. Within the category relationship, the three properties were identified as commitment, compassion and co-operation. Within transformation, these were labeled causes, processes and consequences. In addition, the data within self, relationship and transformation was further analyzed according to professional and individual living with a disability. After these steps, a written descriptive analysis of each category was completed. Through this process, the central category was identified as transformation. Figure 1 provides a visual representation of the coding strategy used.
As Creswell (1998) states, once the central category has been identified, a coding diagram is developed in order to depict relationships between categories. The coding diagram describes the central category as a social process, including its conditions, strategies, actors and consequences. See Appendix 7 for the coding diagram.

2.6 Theoretical Approach

As outlined by Creswell (1998), case studies can and do use theory at several different stages in the research process. As this thesis was primarily interested in generating or developing a conceptual model of service delivery, the use of theory has been limited. Therefore, the thesis used what Creswell refers to as a ‘theory after’ approach. In this way, theoretical perspectives are integrated into the discussion and provide the foundation for a meaningful discussion regarding the model developed (Creswell, 1998).
CHAPTER 3: CASE CONTEXT

3.1- Historical Context

Vanier was born into and grew up within a family which was both educated and religious. He was born September 10, 1928 in Geneva, Switzerland. He is the fourth of five children born to Georges and Pauline Vanier. At the time of Jean’s birth, Georges Vanier was working as a military advisor to the League of Nations, however, Georges Vanier is perhaps best known for the work he did late in his career, when he was Governor General of Canada from 1959-1967. During his childhood, Vanier was educated at a private school in Britain and spent summer holidays with his parents in Northern France. During World War Two, Vanier’s father was posted to military service in Quebec. At this time, Jean Vanier came to Canada with his family. In 1942, shortly after coming to Canada and just 13 years old, Jean Vanier left Canada and returned to England. He intended to train as a military officer at the British Naval College. Jean Vanier finished his training after the end of World War Two and therefore, did not see active military service. After a short tour of duty, he left the Navy in 1946.

Throughout the late 1940’s, 1950’s and 1960’s, Vanier was exposed to a variety of experiences and challenges. Shortly after he left the Navy, Vanier’s mother introduced him to Father Thomas Philippe. In Father Thomas, Vanier met a spiritual teacher and lifelong friend. Father Thomas, who was a Dominican priest and theologian, acted as a spiritual advisor to Vanier’s mother. Vanier developed a deep and enduring friendship with Father Thomas. Through this friendship, Vanier joined Eau Vive in the 1950’s. Eau Vive was an alternative student community run by Father Thomas in Paris, France.
Eventually, Father Thomas returned to Rome and consequently, Vanier led this student community for a short period of time.

During his years in Paris, Vanier studied theology and philosophy at the University of Paris and completed a doctoral thesis on Aristotle. After successfully defending his doctoral thesis in 1962, Vanier returned to Canada and taught philosophy for one year at the University of Toronto. Throughout his studies and year of teaching, Vanier maintained contact with Father Thomas.

While on a return visit to France during the summer of 1963, Father Thomas invited Vanier to live there permanently. At that time, Father Thomas and two colleagues were considering the possibility of establishing a community for individuals with intellectual disabilities. They hoped that Vanier would agree to be a part of this process. In the summer of 1964, Vanier returned to France and by the fall of that year, he had moved into a home with three men who had intellectual disabilities. This home was located in Trosly-Breuil, France. With the support of Father Thomas and his two colleagues, Vanier established the first l’Arche home. Since the first home was established in 1964, l’Arche has evolved into an international movement with similar homes situated in communities around the world.

Vanier remained as director of l’Arche throughout its early years of growth in France and internationally in countries like India, England and Canada. During this time, Vanier lectured at many conferences and retreats throughout the world. Vanier stepped down as Director of l’Arche in 1980. Since that time, Vanier has written and published a number of books. Through his writing, Vanier has reflected on many aspects of his life with
individuals who have intellectual disabilities, revisited his doctoral work and also, post-
September 11, 2001, written on the need for peace in current times.

3.2 Significant Influences

Despite the advantages which came from his family background, Vanier was exposed
early in life to vulnerability and suffering. During his military service in World War
One, Vanier’s father had a leg amputated. According to Jean Vanier, his father had a
great sense of humour. Although his leg caused him discomfort and pain, Vanier writes
about how his father used his artificial leg as a source of comedy with his children and
others. Vanier’s biography reveals that Father Thomas had a significant hearing
impairment which presented many challenges to him throughout his lifetime. In addition,
Vanier has lived for most of his adult life with individuals who have intellectual
disabilities. He has been in close contact with pain and suffering in many people. He has
watched and learned as these people have, in a variety of ways, come to terms with
disability.

A second external influence on Vanier is the Roman Catholic Church. Vanier was
raised a Roman Catholic by parents who were deeply committed to their faith and to the
church. At one time, Vanier considered a vocation to the priesthood but eventually
concluded his life’s work was in community as a layperson. Vanier was influenced by the
faith of his parents. His father was deeply attracted to the mystics, specifically, St. John
of the Cross. Vanier’s father went to Lourdes many times throughout his life as he
experienced a strong feeling of well being when he was there. The faith of Vanier’s
parents appears to have had a significant influence on Jean Vanier’s own beliefs and faith
experiences.
In addition to the commitment to Catholicism witnessed in his parents, Vanier was exposed to a second and important influence through his friendship with Father Thomas. As a Dominican priest and scholar, Vanier saw in Father Thomas a man of deep faith life who was committed to a simple and humble lifestyle. Through Father Thomas, Vanier also learned about the importance of love and hospitality toward the poor. In addition, Father Thomas was a priest who believed that God was present in all religious traditions and participated in the faith practices of Buddhists and also, Hindus. This was also an attitude that Vanier had witnessed in his own father and was something that he, Vanier, would continue to demonstrate throughout his life.

While the Catholic Church represented a significant influence in Vanier’s life, it is important to remember that Vanier has traveled extensively throughout the world and been exposed to many different ways of living and being in the world. In this way, Vanier has been influenced by the spirituality and thinking of many people including Catherine Doherty, Martin Luther King, Ghandi, and Mother Teresa. In addition, through the 1940’s, 1950’s and 1960’s, as alternative religious and student communities developed around the world, Vanier had the opportunity to live in such a community at Eau Vive, Paris, France. He also visited several others during and after his studies. More specifically, Vanier visited Friendship House in New York City and was familiar with Tony Walsh’s Benedict Labre House in Montreal. Each of these communities provided welcome and housing to the poor and marginalized in those cities. As indicated, through his travels and life experiences, Vanier had contact with several alternative communities that were developed in the United States, Canada and France.
Vanier has also been shaped by the international movement to de-institutionalize individuals with intellectual and other disabilities. As did contemporaries like Wolf Wolfensberger, Vanier committed himself to lifelong involvement in the community living movement. His exposure to a number of alternative communities, along with the encouragement of Father Thomas and others, led Vanier to establish the first l’Arche home in Trosly-Breuil, France.

3.3 Current Context

Since the establishment of the first community in Trosly-Breuil, l’Arche has grown and there are over 100 communities currently in existence across the world. As indicated previously, Vanier stepped down from his formal involvement with l’Arche in 1980. Today, Vanier lives in a small, beautiful, stone cottage. The cottage is located within the l’Arche community of Trosly-Breuil. Vanier travels extensively and leads retreats around the world. He was 78 years old in September, 2006. Vanier continues to lecture, write and publish on a number of topics including philosophy, faith and disability issues.

In July, 2005, I met with Vanier at his home in Trosly-Breuil. Although Vanier lives alone, his home is nestled into the larger community and therefore, surrounded by workshops, homes and also, beautiful gardens. Walking through a series of winding paths, I made my way to Vanier’s cottage with the assistance of Vanier’s personal secretary of many years, Barbara Swanekamp. On our way to the interview, Barbara gave me a tour of the home where Vanier first brought Philippe, Raphael and Dany to live with him. As we walked further up the pathway, I had a physical sense of connection to a past that I had only previously accessed through books or the stories of other people. I was deeply impressed by the sense of history at l’Arche. While I confess to feeling
intimidated by my surroundings, Vanier met me at the doorway of his home with a great smile and a warm, welcoming hug.

I spent the next two hours asking questions, but most importantly, listening to Vanier as he reflected on the material I had sent him in advance of the meeting. While I was making every effort to be serious and attentive, it was impossible not to relax in his presence. My memories of his front room are of papers on most flat surfaces, of his very large eyeglasses perched on his nose, birds chirping outside the window and of a man who gave me his full attention during the time we were together. Vanier responded to and challenged my interpretations of his work and gave me much to think about in the months ahead.

After the interview with Vanier, I attended a mass in the chapel at Trosly. The chapel is simple but accessible in its layout and design. At the chapel, I participated in a service that included a variety of people, who represented a mixed background of ages, cultures, and abilities. This service left me with the understanding that l’Arche today is a place which welcomes difference, whatever its name.
CHAPTER 4: MAIN FINDINGS

It has taken a long time to discover, to put words on things. The most amazing discovery we have made is that people tell us that living in l’Arche has transformed them. Everybody who spends even a little time here says that they have been transformed. So this is something we need to look at more closely. The big question is: What is this transformation? What are people telling us? (Vanier Interview, 2005)

Transformational Rehabilitation

The goal of this thesis has been to develop an alternative model of service delivery which addresses burnout in rehabilitation professionals and which is based on Jean Vanier’s thinking about relationships between individuals living with and without disabilities. Through analysis of text passages, key informant interviews and the interview with Vanier, I have developed a model which I have titled the Transformational Model of Rehabilitation. This model has four main elements. 1. Definition of the Problem. 2. The transformational relationship between client and professional. 3. The transformational change process. 4. The outcome of transformational processes.

This model views rehabilitation as a transformational process. The term transformation means to make a change in the form, outward appearance, character or disposition of something (Sykes, 1986). As Soanes (2001) defines the word, transformation refers specifically to changes which are marked or significant in nature. Within this model, transformation is the key concept which influences all four elements. Therefore, the nature of the problem under consideration, the way relationships are
structured, the change process and its outcomes are each impacted by the core concept, transformation.

4.1 Definition of the Problem

Personal Identity

The focus of concern in transformational rehabilitation is personal identity. An individual’s identity is reflected in his/her thoughts, feelings and belief systems. It is also reflected in his/her choice of work, friends and recreational activities. Over the course of an individual’s lifetime, his/her identity will be shaped by relationships with family, friends and co-workers. This model is particularly concerned about individuals who do not receive affirmation of their own unique identity as human beings and therefore, may not appreciate their own thoughts, feelings, and/or beliefs. According to this model, when individuals lack experience of their own value as persons, they may lose their self-esteem and consequently, they are more vulnerable to external sources of authority.

*When we are made to feel inferior through a lack of respect for our deepest needs, we often begin to accept the vision of the powerful and to believe that we are inferior, that we should do what we are told...we submit to those who have power, lose our self-esteem and enter into a form of depression.* (Finding Peace, 2003, p. 20)

Both individuals living with and without disabilities can experience difficulties with identity and therefore, both are capable of conformity to sources of authority outside the self. With regard to individuals living with disabilities, this model is aware that identity is influenced by the experience of disability. Consequently, identity is defined in relation to disability. In addition, as the following quote from a key informant states, individuals living with disabilities feel the need to be recognized and to belong and they may respond to these needs in a variety of ways, including conformity or rebellion.
Even the most profoundly disabled people, they may not be full of metaphor and abstract thought, but what they understood was that they didn’t fit in and they didn’t belong. They concluded that they must be a disappointment and therefore, they would get into some very unhealthy patterns with caregivers from a very early age of needing to be completely compliant or needing to rebel in order to gain attention, to earn a place, to be recognized and to be noticed. (Key Informant #1)

While this model is primarily concerned with the personal identity of the individual living with a disability, it maintains that professionals also have problems with personal identity and more importantly, that these issues can have a bearing on the work which is taking place with an individual who has a disability.

This is a model which believes that each person is a unique combination of thoughts, feelings and beliefs about self and others. Within the transformational model of rehabilitation, both clients and professionals may experience a lack of appreciation for their own identity. These concerns about personal identity in both client and professional define the nature of the problem within this model. As Vanier stated in *Our Journey Home* (1997), “… in order to live fully as human beings we need to have a definite identity” (p. 27). During the interview in France, he emphasized that the real challenge for all humans lies not in being the most successful person, but rather in having an identity and being able to express this identity.

*In both the Christian vision, and also in larger society, the quest is not just a quest of being the best or not the best. It’s quest of being who I am. So, it comes back to identity.*

(Vanier Interview, 2005)

### 4.2 The Transformational Relationship

Within the transformational model of rehabilitation, the relationship is considered the therapeutic strategy or tool which the professional uses to effect change. It is the particular qualities of this relationship which facilitate the change process. The
therapeutic quality of relationships is evident when Vanier states, “I believe anyone can change if he/she enters into a true relationship with someone” (Finding Peace, 2001, p. 35). Key informants emphasized this point as well. “It’s in relationship. Healing doesn’t happen and growth doesn’t happen in solitude” (Key Informant #7). The following quote gives further insight into the importance of relationships.

*Well, the one that immediately hits me is based on relationship. The principle is that people discover their value, their worth, their sense of fruitfulness, their giftedness, their shadows or weaknesses.* (Key Informant #3)

For Vanier and key informants, transformational relationships exist alongside other relationships and are situated within larger communities, including l’Arche group homes. Therefore, transformational relationships have the potential to form from within a wide range of relationships, including those with friends, peers and mentors. Consequently, while this model is primarily concerned with the relationship between a client and rehabilitation professional, other relationships can, and do, influence and provide support to the transformational process. Throughout text passages, key informant interviews and the interview with Vanier, transformational relationships are distinguished by three properties. These three properties are described as commitment, co-operation and compassion.

**Commitment**

The dictionary defines commitment as ‘binding, pledging or involving self’ (Sykes, 1986). In this model, commitments are made to particular types of relationships and to a particular level of involvement with others. Consequently, an individual commits to personal engagement and to covenant relationships.
Commitment as personal engagement

Both client and professional commit to a particular level of involvement with each other. This level of involvement is referred to as personal engagement. This was a significant theme found across all data sources. Key informants noted that there is a ‘difference in the degree’ of involvement. Key informants stated that they are involved and ‘engaged with their whole life’. Commitment means that ‘some of the barriers are broken down’ and ‘clients are engaged with’. There was a feeling that this was not just a ‘working relationship’ but also a ‘friendship’. When engaging in a personal way with clients, the person providing help is known as a person and closeness is encouraged. As key informants described this, it means an end to the view that professionals are different than the clients they work with. In other words, an end to

... the concept that your life is different and separate from them, you stop your work, you go home to your own life and it’s to something that is ‘my’ life. (Key Informant #4)

Vanier also acknowledges the importance of being known as a person. He extends this to the way we think about the individual with a disability. To view an individual with a disability as a person means we recognize that he/she has unique qualities and capacities. In the following quote, he argues that

... it is because we see them as brothers and sisters in humanity that we learn not only to accept them as they are with different gifts and capacities, but to see each one as a person with a vulnerable heart. (Becoming Human, 1998, p. 59)

When involved in a relationship in which he/she is known as a person, the professional is given the opportunity to express him/herself as a unique individual and this level of involvement in the work gives it more meaning. As the following quote from a key
informant states, function and status are not as important as having a name which is known and which says something about who you are as a person.

*But it is meaningful because I’m known as ***. I’m known as a person, not the role I have, the position I have.* (Key Informant # 6)

Being engaged in a personal way with clients gives meaning to the work but it also buffers the professional from burnout. As the following quote indicates, engagement with clients fosters engagement with one’s work.

*If I am going to stay in my field, I have to break down some of the barriers. I can’t be an automaton, treating people like robots. I have to be engaged with my people. I think that’s the core.* (Key Informant #1)

As indicated, professionals and clients commit to what is referred to as a more personal level of involvement. Because this type of involvement is pursued in a way that is beneficial to all members of the relationship, it is also monitored and observed.

*We take into account how close we are to people. So that if part of the behaviour plan includes working around relational boundaries, we might have to hire someone outside the home or go to their circle of contacts outside the home, so that we don’t blur the boundary in an unhealthy way.* (Key Informant #1)

Within this model, there is a commitment to being engaged in a personal way with others. Therefore, individuals are known as persons and not just for the roles or functions they perform.

**Commitment as covenant**

While commitment is made to personal engagement with clients, it is also made to covenant relationships. The dictionary defines covenant as contracts and bargains (Sykes, 1986). In this model, covenant is a contract made with the poor. The word ‘poor’ is used metaphorically; it refers to the many different ways that people can be lacking at the
personal level. Therefore, it refers to those who lack in personal skills or abilities and even, relationships. As a faithful commitment to the poor, covenant is defined by its welcoming and hospitable attitude toward others. Therefore, as Vanier refers specifically to the spirituality of l’Arche communities, he writes

\[\text{I’Arche’s spirituality is not chiefly about doing things for the poor. But about listening to them, welcoming them and living with them a covenant- a relationship of fidelity rooted in Jesus’ fidelity to the poor. (Heart of l’Arche, 1995, p. 50)}\]

Both key informants and Vanier believed that covenant was informed by a Christian faith tradition. However, they emphasized that covenant was also informed by a social justice perspective. Integrating principles of social justice means that the needs of the weakest members are taken into consideration and addressed. The following quote provides an insightful description of the way that social justice is enacted within covenant relationships.

\[\text{So the values are valuing weakness over power, valuing the community over individual strength, valuing the little person in the group, at the meal or in the shopping expedition, you want to make sure that the slowest person or the person who doesn’t have any clothes, gets clothes, not that you get the best t-shirt. The person who is hurting is supported as opposed to left behind, which wouldn’t happen in the culture of the West today. (Key Informant #7)}\]

Key informants also defined covenant as a steadfast commitment to long term relationships. In the following quote, a key informant describes the importance of this quality of covenant relationships.

\[\text{I think the other thing he has to offer is this idea that people benefit from long term consistent relationships. That it’s not that many other organizations don’t do good work with people but so often their relationships are fractured again and again … and Vanier is saying that these}\]
handicapped or disabled people have suffered a lot of loss already and if one can provide them with something more consistent, then you stem the flow of loss. You’ve given them hope, consistency and security. (Key Informant #9)

As discussed, within this model, commitments are made to personal engagement and also, to covenant relationships.

Co-operation

Co-operation is the second property of relationships. As the dictionary defines this term, co-operation is the act of ‘working with’ others toward a similar purpose or to produce a particular effect (Sykes, 1986). Within this model, the primary purpose or end which is worked toward is transformation in the personal identity of an individual living with a disability. In addition, co-operation is an attitude which is distinguished by ‘being with’ the person with a disability rather than ‘doing for’ them. More importantly, to ‘be with’ another person means that differences are acknowledged and accommodated. Consequently, within this model, co-operation is the inter-dependence which is achieved through acknowledging and accommodating differences.

Acknowledging and Accommodating Difference

Within this model of relationships, co-operation rests on the assumption that differences are acknowledged and accommodated. Differences are handled in a transparent and realistic way. They are ‘named’ and ‘negotiated wisely, very wisely’. In Our Journey Home (1997), we learn that “the important thing is to signify difference while respecting the person” (p. xvii). This acknowledgement of difference recognizes the unique capacities and challenges that each person brings to the relationship.

Therefore, there is a recognition that

no person with a disability is the same as any other person.
There is great difference within that community, within that
segment of the population, like any others, gays or women or immigrants or Canadians or any other group. There is a great variety of people, personalities, life history which affects them. (Key Informant #1)

It means that the relationship is founded on a realistic appraisal and acknowledgement of differences between its members.

The most important difference which needs to be recognized is that which relates to ability. In the quote below, a key informant describes relating to a person who has a disability and indicates that the recognition of difference does not interfere with the development of a relationship between them.

*It is mutuality over difference. It is a bridge between she and I that doesn’t negate the difference between us, but acknowledges it continuously and also gets beyond it. It doesn’t allow the difference between us to be a barrier from being companions on life’s journey together.* (Key Informant #1)

As the following quote indicates, differences in authority are identified and also, when appropriate, discussed.

*Sometimes, I’m in conversation with someone and they know that I’m meeting with them as community leader. I have to bring in a different level of authority, but that’s always named and it’s up front about which ‘hat’ is on right now.* (Key Informant #5)

When differences are acknowledged, they need to be accommodated. Recognizing different capacities can mean that there are different expectations and responsibilities within the relationship. As this key informant goes on to clarify, “equality does not mean sameness or exposure to all the same stresses and challenges and meetings” (Key Informant #3). As indicated in the following quote, adaptation is an important feature of relationships.

*Most people with mental handicaps are not sick and do not need constant medical treatment, they need to live in*
surroundings adapted to their needs, in which they can grow, develop and find meaning in their lives. (Heart of l’Arche, 1995, p.30)

Key informants described how differences are accommodated. This accommodation is often around communication. In the words of one key informant, there are “different ways of communicating, so we signed over to her” (Key Informant #4). In the following quote, a key informant describes the way external therapists have modified the counseling process to account for limited verbal skills.

_In that case, we have been creative, some people do that kind of therapy, but the therapist will modify it as well as they can, using pictures more than just words to help people express what they are feeling, very powerful, very successful._ (Key Informant #1)

Consequently, the act of accommodating differences promotes and maintains active participation in the relationship. As the following quote indicates, accommodation also means skills and capacities are appropriately and effectively used.

_We had a community council and we found that it stressed the core members as it was too abstract for them and moved too fast, so we divided up the work and have three councils now, core, assistant and community council._ (Key Informant #3)

And, as this key informant indicates, through accommodating difference, this model is able to encourage and support different kinds of participation.

_People are encouraged, either through mime, pictures or different ways. They’re given that opportunity and they become people that lead._ (Key Informant #5)

As differences are accommodated, communication and participation are maintained and even, increased.

**Inter-dependence**

As differences are acknowledged and accommodated within the relationship, inter-dependence is created. Inter-dependence is accomplished when all members contribute to
the relationship and when the relationship successfully compensates for differences between members. As key informants consistently stated, inter-dependence happens when we recognize that we need the help of others.

_We promote that there is a real sacredness of weakness, or of not having it all together. This really invites other people in and so this interdependence becomes more livable and happening in our society. When we do that kind of thing and when we can admit where we don’t have it all together or where we could stand some support or somebody else’s help._ (Key Informant #2)

In order for inter-dependence to happen, professionals need to ‘learn to be able and willing to follow’. All members of the relationship are given the opportunity to ‘lead us in some way’. When talking about Vanier, one key informant stated,

_he flipped it around, that the strong need the weak, that weakness isn’t a defect. We learn from the poor, the weakest, those with intellectual disabilities, they become our teachers._ (Key Informant #8)

As this same key informant continued, inter-dependence means expertise is shared.

_I have walked with them in a way that I never would have walked with them before. Some of the work doesn’t change. If I’m doing a token economy system, that doesn’t change, but my way of looking at the fundamental nature of my being there and my interactions has switched. I no longer see myself as having to come from the total position of being the expert. There is a dialogue with people. I will listen to people in a way that I wouldn’t have listened to them before._ (Key Informant #8)

Vanier also described this inter-dependence during the interview.

_Tomorrow, I am leaving for Jordan and I will be working with young delinquents off the streets. I will also try to pass the message on to their educators that what meets the needs of these young people is that someone believes in them, that they are okay, that they are not the scum of society. But it’s not just that they are okay, it is that they have something to give me. That they can give me something…it’s the same thing with teachers when teachers believe that children can teach them. We are changing the_
direction of authority in the relationship. Before it went from top down, now it is something which is coming from bottom up. (Vanier Interview, 2005)

While inter-dependence means that the professional needs the help of the person living with a disability, it also means that the individual with a disability needs the help of others, including professionals. The need for assistance is integrated into the relationship. As the following quote from a key informant indicates, assistance can be provided without disrupting the balance of power and therefore, the essential attitude of ‘being with’ the other person is maintained.

*When I am with *** and *** and the others, we are just with one another. That is sort of a vague, almost existential comment, but I am not thinking of any power imbalance when I am with them. I am not. There is prayer time, there is just being with one another, there is celebrating over the meal. It’s expected that I can do certain things like guide *** downtown safely to the coffee shop because he does have some limitations physically and needs some assistance in walking from time to time. (Key Informant #8)*

**Compassion**

Compassion is the third and final property of transformational relationships. Within this model, compassion is defined as the provision of unconditional regard to another person and also, the sharing of emotions within the relationship.

**Unconditional regard**

Within this model, compassion involves providing unconditional regard to another person. In the following quote, a key informant describes how the unconditional nature of compassion is expressed in relationships.

*It’s very easy to see, when I am welcomed unconditionally and loved unconditionally and when I am forgiven for being a jerk as quickly as I am. (Key Informant #2)*
As another key informant stated, this is an expression of unconditional acceptance; the other person receives this recognition regardless of who they are.

*The thing that is foundational to the therapy of l’Arche is for someone to get that mirroring that they are beautiful, that they are valued and that they have something to contribute, even as they are. They don’t have to do anything to earn those things.* (Key Informant #1)

This unconditional regard is demonstrated through receptivity to and acceptance of the other person’s perspective. As Vanier argues in the following quote, this unconditional aspect of compassion requires that the listener let go of theoretical perspectives. In other words, normative judgments are temporarily suspended in order to gain an accurate understanding of the client’s internal frames of reference.

*Listening to the words or body language of another implies a kind of dying to myself, it implies an openness to receive what he or she wants to give, sometimes darkness and rebellion, but also inner beauty...As I learn to listen, I learn not to judge people according to rules or to what is ‘normal’.* (Heart of l’Arche, 1995, p. 36-37)

In this way, unconditional regard is a form of empathy as the listener opens him/herself to the worldview of the client. The intent of the listening is to learn more about the unique world of the client.

*I think Vanier is right; we have to be able to talk to each other. You have to be able to hear each other’s story and know what is important or of value.* (Key Informant #4)

**Exchange of Emotions**

Compassion is unconditional regard provided to another person. Yet, compassion is also the exchange of emotions. Thus, there is a ‘real reciprocity’ or ‘real mutuality of receiving and giving’. As one key informant clarified, this reciprocity is emotional in nature.
It has to do with mutual relationships. That is at the heart of l’Arche. Once we enter into relationship with people with disabilities, we very quickly realize that they have a great deal to give us. Mostly, that has to do with the realm of the heart. (Key Informant #2)

This same key informant goes on to describe how individuals with disabilities contribute to this emotional exchange.

When my mother died she [a woman with a disability] was equally supportive and understanding and comforting to me as I was to her. There are many things in life where it just doesn’t matter our color, race or intellectual capacities. What really comes through is this compassion. This is where we can be equal in so many ways. We can be equal in our care for one another. (Key Informant #2)

Individuals with disabilities are also considered to be particularly skilled at understanding suffering in another person.

I spoke a little bit about this type of empathy that the person with a development disability might have for someone else who has suffering, who has skills but is less than perfect. (Key Informant #1)

According to key informants, the exchange of emotion is a key part of compassion.

However, there are some emotions which are more important than others in this model. One of these emotions is forgiveness. Several key informants made this link between compassion and forgiveness. Key informants indicated that working in close relation to others means there will be times when mistakes are made and feelings are hurt. Therefore, ‘a lot of it just comes down to forgiveness’ (Key Informant #5). While many key informants talked about forgiveness and acceptance, the following key informant provided important insights into how these concepts are linked together.

We give ourselves permission, perhaps more so than the average work place, to be broken, to accept that and forgive each other. It doesn’t matter who we are, priest, assistant or ordinary person on the street, we are all human and we go through that same journey and I think
Therefore, being human means that we will make mistakes and that we will need the forgiveness of others.

During the interview with Vanier, he talked about cultural and economic differences which can act as a source of misunderstanding and also, hostility. This discussion is relevant to relationships where there are other types of difference present, including those which relate to ability or disability. In the quote below, Vanier describes misunderstandings which occur between people and which lead to what he refers to as ‘walls of hostility’. Vanier suggests that compassion reduces misunderstanding and furthermore, that forgiveness reduces hostility.

*Compassion will lessen misunderstanding and forgiveness will bring down the wall of hostility, so the great road ahead is compassion and forgiveness ... but, actually, forgiveness goes further, because acceptance is a good beginning, but it is not yet entering into a relationship where I accept the gift you have to give me in your difference.* (Vanier Interview, 2005)

Compassion includes forgiveness and it also includes the provision of love. While the word love is not usually a word associated with clinical relationships, the love which is being described here is not romanticized love. It is also not a love that is defined by a sentimental or possessive nature. This love is a love which is based in concern for the other person and his/her capacity to grow and develop. As this key informant emphasizes, love is an important aspect of the compassionate experience. *“The core of therapy of l’Arche is this accepting and loving people as they are”* (Key Informant #1). In the following quote, Vanier discusses how this love is provided to an individual living with a disability.
To love is not just to do something for them but to reveal to them their own uniqueness, to tell them that they are special and worthy of attention. We can express this revelation through our open and gentle presence, in the way we look at and listen to a person, the way we speak and care for someone. (Becoming Human, 1998, p.22)

As Vanier and key informants repeatedly emphasized, to love someone is to put their interests above your own and to provide them a sense of their own ‘beauty’ and ‘value’.

As one key informant indicated, this love is expressed in a multitude of ways.

Yes, standing beside people, the tenderness of touch, the tenderness of a regard, a glance or speaking with someone, or perhaps, it means not speaking. I tend to speak a lot and so, I might be inclined to be quiet and let someone else speak. I might be gifted by the presence of the person who doesn’t speak at all and so I have to stop talking in order to communicate with them and in order to receive the gift of their presence. (Key Informant #7)

While love is often associated with sentimentality and possessiveness, in this model it is used to affirm the presence and value of the other person in the relationship.

In text passages, Vanier repeatedly emphasizes the importance of this emotional reciprocity. Emotional reciprocity creates vulnerability in the relationship. During the interview with Vanier, he described this vulnerability.

When you enter into communion of hearts you become vulnerable one to another. So what does ‘being with’ imply? I would push you to go further. It is moving from generosity to communion of hearts and communion of hearts is to be vulnerable. It’s never easy to be vulnerable. Because I could be wounded and then, I will be hurt or feel that you don’t want me or you don’t love me. (Vanier Interview, 2005)

As the following quote from a key informant indicates, when a professional demonstrates emotional vulnerability, it is easier for a client to do so.

Particularly in psychotherapy, where you are invited into a very intimate place in someone’s life and where they are very vulnerable. In fact, to be there you have to be
vulnerable yourself, because if you are powerful in your affect the client won’t feel safe enough to be vulnerable.
(Key Informant #7)

As indicated, compassion is the provision of unconditional regard and the sharing of emotions. More specifically, it is the sharing of particular emotions including love and forgiveness. Compassion is demonstrated by both client and professional.

As indicated through this discussion, transformational relationships are defined by commitment, co-operation and compassion. These three concepts are essential because they create the relational environment needed to promote transformation in another person. In other words, transformational relationships are relationships in which each participant is recognized by the other as a person and this experience of self promotes and facilitates the transformational process within each participant.

Table 1 provides a summary of these concepts and their characteristics.

<table>
<thead>
<tr>
<th>Concept</th>
<th>Characteristic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Commitment</td>
<td>Personal engagement</td>
</tr>
<tr>
<td></td>
<td>Covenant</td>
</tr>
<tr>
<td>Co-operation</td>
<td>Acknowledgement and accommodation of difference</td>
</tr>
<tr>
<td></td>
<td>Inter-dependence</td>
</tr>
<tr>
<td>Compassion</td>
<td>Unconditional regard</td>
</tr>
<tr>
<td></td>
<td>Exchange of Emotions</td>
</tr>
</tbody>
</table>

Table 1- Transformational Relationships

As demonstrated through discussions regarding each concept, both the professional and the client contribute to and experience these three elements of transformational relationships. Figure 2 provides a visual depiction of transformational relationships. Both client and professional contribute to the relationship and therefore, both sit within the relational circle. Both client and professional experience and contribute to the commitment, co-operation and compassion which define the transformational relationship.
4.3 The Transformational Process of Change

Relationships provide the context within which transformation occurs. More specifically, when participants experience commitment, co-operation and compassion, as intentionally structured within this model, they are provided the opportunity to experience their own unique transformational process. This model places significant emphasis on the opportunity for transformation in both professional and client. More importantly, it assumes that when a professional has had some prior experience with the transformational process, he/she has dealt with some of his/her own personal issues and is, therefore, more capable of assisting clients with theirs. In the following quote, Vanier
discusses this issue as it relates to Nadia, a woman who is providing services to Claudia, a woman living with a disability.

Claudia’s growth was then subject to Nadine’s growth. How could Nadine accept Claudia in all her chaos or madness if Nadine refused to accept the chaotic aspects and shadow areas in her own life? (Becoming Human, 1998, p. 31)

The transformational process hinges on two sub-processes which are awareness and acceptance of self. The change process begins through exposure to a unique experience which can be either positive or negative. Through this experience, the individual becomes aware of defense mechanisms and other tensions within the self. Transformation is the process in which an individual gains increased awareness of these aspects within self, accepts that he/she has both strengths and weaknesses and finally, comes to terms with any historical issues that may have contributed to these tensions within self.

**Awareness of self**

Awareness of self initiates the transformational process. Awareness is an internal process in which the individual looks at key aspects of self. Repeatedly and consistently, throughout text passages and interviews, the transformational process was described as awareness which was directed inward, toward self. As one key informant stated, “they have helped me understand me, understand what is going on” (Key Informant #1). In the following quote, Vanier states that “as we begin to understand ourselves, we begin to understand others” (Becoming Human, 1998, p.25).

**Awareness of need for change in self**

The process is concerned with self and starts when an individual becomes aware of self and more specifically, the need for change in self. The process can be initiated in a variety of ways. It can be initiated through exposure to failure in self. “That passage
happens through hitting bottom. It happens from not succeeding, from being tired or unable to cope” (Key Informant #7). As Vanier indicated during the interview, it is provoked through exposure to suffering, in self or other. “And what will help people to move from the collective self or social self to the true self? It will likely be suffering” (Vanier Interview, 2005). As Vanier went on to describe during the interview, the process can also be initiated through exposure to different perspectives on life and relationships.

Relationship of another vision, another vision of life.
Because they meet someone who is different. Perhaps, they haven’t been a success in school and then, they meet an Indian guru, and this suddenly seems to reveal something to them. It is frequently unexpected. It could even be an inner revelation of sudden beauty. They look into a picture or watch a movie. Something new is revealed to them and yet, somehow the barriers seem to have fallen. It could be music, it could be something else is revealed, which tells them about who their real self is, but they can’t verbalize it. It’s a feeling. (Vanier Interview, 2005)

The following quote from a key informant confirms that positive experiences can initiate transformation.

To have a room full of 15 people tell you how wonderful you are. It’s sometimes overwhelming. To look at someone and they just say “thank you”. But it does move your soul. (Key Informant #1)

As was consistently emphasized throughout text passages, and the key informant interviews, something happens which unsettles the self. Therefore, the individual realizes that something needs to change. As one key informant indicated, this may mean realizing that he/she is not coping well with stress.

So again it goes back to that growth experience, in that the experiencing of stress indicates that something is not working well or right and so it’s that invitation to look at what needs to change, what needs to be different, how do I need to change? How do I need to be different? (Key Informant #5)
As Vanier indicated during the interview, this includes feelings of being ill at ease within oneself.

*I’ll give you an example of an assistant who told me that because her parents were always fighting, she had decided not to go into any relationships. She concluded that relationships were dangerous, so she put all her energy into school and then work. She was a great success. Then, at the age of 30 she began feeling a sort of dis-ease, because she discovered she had always been running away from relationships.* (Vanier Interview, 2005)

The transformational process starts when something is exposed or revealed. It is this exposure to some aspect of self or other which provokes awareness that something needs to change in self.

**Awareness of strengths and weaknesses in self**

Once the individual realizes that something needs to change, he/she must look more closely at key aspects of self. Individuals look at both challenges and strengths in self. The most important aspect of self which needs to be addressed is defense mechanisms. As one key informant described them, these are “buttons which are being pushed in somebody” (Key Informant #5). These defense mechanisms are also called ‘walls’ or ‘barriers’. During the interview with Vanier, he confirmed that the reflection process includes looking at how these emotional defense mechanisms can be problematic.

*You need to look at the different processes of transformation. It isn’t like this (snaps fingers twice). It is a consciousness of self. Why am I getting angry in front of this thing? Why am I frightened? What am I frightened of?* (Vanier Interview, 2005)

Building on this idea of emotional reactions, key informants stated that these defense mechanisms included counter-transference reactions within the professional which interfered with the relationship and therefore, needed to be addressed.
One of the things for the assistant we often found is, of course, often the assistants had trouble with their own anger, and then, sometimes, their own unspoken anger was getting into the interchange and helping to escalate things. (Key Informant #9)

As another key informant confirmed, “we become aware of our own pain as we help people in pain” (Key Informant #8). During the interview with Vanier, he also talked about these defense mechanisms.

True, because I touch my anger, I touch my defense mechanisms. I see that I am more defensive than I thought I was. So, there is something happening. (Vanier Interview, 2005)

In addition to emotional defenses, there is a need to be aware of how beliefs and values can also be a weakness. Vanier discusses the need to shake “our hierarchy of values and prejudices” (Our Journey Home, 1997, p. 228). Vanier also states,

...the role of therapy is to help people discover the ideology that governs them so that they can choose freely and not be governed by fear and guilt. (Made for Happiness, 2001, p.9)

While Vanier emphasized that beliefs and values could act as a weakness, this was not a significant theme in key informant interviews. When reference was made to these kinds of issues, it was with regard to intellect. Consequently, one key informant talked about the need to ‘hang up your intellect and coping patterns’. And another key informant alluded to intellect as a potentially harmful part of self.

No. I feel good. The bottom line for me is that I speak out of my intellect, which I have been blessed with. But, I also know that my intellect is where I have some things about myself that were very harmful. (Key Informant #1)

In several places Vanier indicates a concern with religious beliefs. He believes that religious beliefs ‘can seal us off from others’ (Finding Peace, 2003, p. 22). Vanier argues that religious beliefs are problematic when they lead to the exercise of spiritual power
over others. Therefore, Vanier states that “above all, we are called to let go of our compulsions and be purified of our thirst of power, for admiration and for righteousness” (Finding Peace, 2003, p. 58).

In addition to recognizing the role of defense mechanisms, beliefs and value systems, there is a need to be aware of strengths or, as they are referred to by Vanier and key informants, gifts in self. The concept of gift was emphasized across text passages, key informant interviews and also, the interview with Vanier. The concept of gift refers to unique skills that each individual has. Both individuals living with and without disabilities have gifts. Key informants described a number of skills or gifts that they had including ‘being a good dresser’, ‘computer skills’ and also, ‘expertise in providing emotional support to others’. However, individuals with disabilities also need to gain some understanding of what their gifts are. These gifts or strengths include planning, making and cleaning up after a meal for others, welcoming guests into their home or even, physical characteristics like having a ‘fabulous smile’. Individuals with disabilities were often described as having relational skills or gifts. These particular skills included the provision of ‘empathy’ or ‘acceptance’ or a ‘gentle presence’. Therefore, as these concepts are articulated within this model, both client and professional are expected to have some understanding of their unique gifts and strengths.

Becoming aware of one’s gifts can be difficult or uncomfortable for some people. As this key informant states,

*It was much easier for me to say “I will work really hard for you” then for me to hear that I was beautiful and gifted and had something to offer, that people really knew me. They knew me with all my warts. But, what they really valued were my gifts, not my disabilities. And that is the same for the person with a disability.* (Key Informant #1)
Gifts are sometimes discovered by others, who see some potential for growth.

So, with regard to computer skills, I am technically inept, but it can be celebrated as a gift, someone sees some potential there. In community, there is always the need to use all of those different skills and so, you are celebrated and encouraged to do it. (Key Informant #5)

Transformation begins when the person becomes aware of the need to change. The professional is expected to enter the transformational process in advance of supporting this process in a client. However, this model recognizes that he/she will continue to experience emotional reactions and therefore, have an ongoing need to examine feelings and beliefs. In order to ensure the focus remains on the client and his/her transformational process, the professional seeks out relationships which provide him/her with the opportunity to reflect on and deal with key emotional experiences. Consequently, the professional is encouraged to discuss these responses with colleagues or, what Vanier and key informants refer to as, mentors.

So we ask them to kind of walk with an elder for a while and as they do that very quickly there is a lot of stuff that starts to just come up for them, that may be they wouldn’t have stopped to look at in themselves before. They could very easily distract themselves and go and do this or that, and they are invited not to do that, to just look at these questions, look at feelings that are arising in them from their relationships with core members. Sometimes, they are in front of some pretty hard stuff, like somebody who could be violent or self abusive and these can be triggers for some people, like amazing, so we encourage people to just talk through those kinds of things. (Key Informant #3)

Through making use of colleagues and mentors, the professional avoids burdening the client with these issues. In addition, as they assist with processing of emotional reactions, mentors also provide ‘wisdom’, ‘role modeling’ and ‘empathy’.

As discussed, the transformational process increases awareness into key aspects of self. Through exposure to experiences in self or other, the individual gains awareness that
there are parts of the self which are problematic and which need to change. In addition, the individual recognizes that he/she has gifts and strengths. Awareness of self occurs in both client and professional. Finally, both the client and professional may access other supports to assist with the process. These external supports include peers, mentors and other professionals.

**Acceptance of self**

Awareness is necessary to transformation. However, it is not enough to promote change. When in relationship with another person, change occurs when an individual becomes aware of particular aspects of self and more importantly, accepts these as parts of self. The following quote from a key informant describes this process of acceptance.

*The acceptance is from being naked, vulnerable, frightened and having that exposed, feeling that it’s offered in the relationship or it’s evident in the relationship or it’s allowed in the relationship and you’re still acceptable, it’s that, it’s having the naked places seen and held.* (Key Informant #7)

Acceptance is an important aspect of transformational processes. It includes acceptance of both strengths and weaknesses and also, of personal and family history.

**Acceptance of strengths and weaknesses**

As Vanier indicates in many text passages, the professional must accept that he/she has weaknesses and flaws.

*In order to accept other people’s disabilities and to help them to grow, it was fundamental for me to accept my own. I have after all, learned something of my own character.* (Becoming Human, 1998, p.101)

Acceptance means we are realistic about our weaknesses and that we acknowledge our capacity for errors.

*The more we accept the truth in ourselves, the more we find the courage to acknowledge our mistakes and our*
responsibilities and to go forward peacefully toward the future, seeking out truth in everything, the truth which makes us free. (Seeing Beyond Depression, 2001, p. 71)

As key informants talked about this process of acceptance, they understood that this was a process that individuals with disabilities also needed to go through.

_The person with a disability does have to accept that they have certain lacks and certain things that they are not going to be able to do. It’s not helpful to them to indulge in the fantasy that one day I’m going to drive a car, if it’s clear that they are never going to drive a car._ (Key Informant # 9)

Again as another key informant indicates, for some individuals with disabilities, growth includes knowing when to ask for help.

_The biggest success I have ever been involved with was with a woman who had the diagnosis of borderline personality, as well as an intellectual disability. She also has Down’s syndrome. The growth she has made in her life, which I think mirrored my own growth in my life in many ways, although I don’t have those labels, or those illnesses, has been because she, and where she has helped me in my growth is she is able to say “I need help. Every single day, I need people around me to help me negotiate my life. I need them”. She does a check in every day, when she comes home from work, about how the day went, what her feelings are about it, what she might have been doing there that was not going to get her what she really wants in her life._ (Key Informant #1)

**Acceptance of personal and family history**

In addition to understanding and accepting gifts and limits, an individual may need to take a further step which involves accepting the influence of personal and family history.

In key texts and in the interview itself, Vanier emphasized that there may be a need to examine personal and family history. In *Our Journey Home* (1997), we learn that

_the first choice at the root of all human growth is the choice to accept ourselves, to accept ourselves as we are, with our gifts and abilities, but also our shortcomings, inner_
wounds, darkness, faults, morality, to accept our past and family and environment. (p. 149)

This also means “finding the inner strength to live and accept our past just as it is... with its wounds, without escaping into a world of illusions and dreams” (Seeing Beyond Depression, 2001, p. 30). Further on in this same text, the importance of insight into family history is emphasized.

When we discover that if during our childhood, our parents have hurt us, it was because they themselves had been hurt during their childhood, or were in some way in difficulty or pain, then we begin to understand them better. We can then begin to forgive them. The past no longer has power over us. (Seeing Beyond Depression, 2001, p.71)

As indicated through this discussion, the transformational process begins when, through some unsettling experience, an individual recognizes that there is a need for change in key aspects of self. This recognition initiates the transformational process. As awareness of self increases, it leads to acceptance of self. Table 2 provides a summary of the transformational process, along with its concepts and characteristics.

<table>
<thead>
<tr>
<th>Concept</th>
<th>Characteristic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Awareness</td>
<td>Awareness of need for change in self.</td>
</tr>
<tr>
<td></td>
<td>Awareness of strengths and weaknesses</td>
</tr>
<tr>
<td>Acceptance</td>
<td>Acceptance of strengths and weaknesses.</td>
</tr>
<tr>
<td></td>
<td>Acceptance of personal and family history.</td>
</tr>
</tbody>
</table>

Table 2 –The Transformational Process of Change

In Figure 3, we see that the change process occurs when the individual gains awareness of and then, accepts the presence of both strengths and weaknesses in self.
Finally, both client and professional engage in this process through their relationship.

![Figure 3- Transformational Process of Change](image)

As both Vanier and key informants indicated, the transformational process is an internal process of change which reduces the need for protective or defensive mechanisms within self. The transformational process releases new or different parts of self. During the interview, Vanier described this process.

*So, this transformation, which people can’t immediately put words on, except that they feel liberated, they feel more peaceful, they feel transformed, occurs when the walls that they had put around them to protect their vulnerability, have started to fall down and then, something new has arisen.* (Vanier Interview, 2005)

This new identity is defined by its maturity. A mature person is recognized by his/her sense of agency and authenticity.


4.4 The Transformational Outcome - Maturity

Vanier stated during the interview that ‘something new’ arises as a result of the transformational process. This ‘something new’ is the expected outcome of the process. One key informant referred to the development of ‘full human beings’ or ‘full citizens’, of adults developing ‘in the fullest sense’. When referring directly to a woman living with an intellectual disability, this same key informant described her as reaching a state of ‘wellness and wellness is not the absence of suffering and pain, but to be able to find a safe self image, a safe healthy level of intimacy with others’ (Key Informant #1). Another key informant talked about self-actualization and highlighted that both clients and professionals should experience this outcome.

"Maslow doesn’t talk in any of his writings about listening to the most disabled. His model is set up for university people, the most gifted of the lot to reach their full potential and Vanier spent his life letting people realize that the lowest of the low have every right to be given the same opportunity and in fact, that if we go on this journey to do this, we will end up self-actualizing in our own way. (Key Informant #8)"

In text passages, Vanier clearly and repeatedly stated that individuals were expected to mature and that maturity means becoming ‘as perfectly accomplished as possible’ (Made for Happiness, xiv). As Vanier indicates in the following quote, maturity is a unique outcome for each person.

"An assistant’s role is like that of a midwife: to bring forth and help foster life, to let it develop and grow according to its own natural rhythm. Assistants in l’Arche are not there to make people with disabilities somehow ‘normal’ but to help them grow towards maturity. For each person in l’Arche this growth toward maturity will be different. (Becoming Human, 1998, p. 27)"

The preceding quote also gives the reader an indication of Vanier’s thinking about theoretical approaches. From this quote and the emphasis it places on the word ‘normal’,
it appears that Vanier does not fully support the use of theories which impose or guide the professional toward definitions of what ‘normal’ looks like in a disabled person. He indicates that growth toward maturity is different and therefore, unique for each person. While key informants did not use the word maturity, in their descriptions of what ‘full’ or ‘self-actualized’ adults look like, they used concepts which were similar to maturity as described by Vanier. Although neither key informants nor Vanier used the words ‘agency’ or ‘authenticity’ to describe maturity, these two words accurately capture maturity as the outcome of the transformational process.

**Agency**

Throughout text passages and interviews, the concept of agency was frequently linked with maturity. Although the word ‘agency’ was not used by Vanier or key informants, this concept is defined as power, choice and responsibility.

*Agency is Power*

Agency means having a sense of power. As one particular key informant described this concept in relation to individuals living with disabilities, it means that ‘we use our power to help them claim their own power’ (Key Informant #1). In other words, the professional ‘helps her gain more personal authority’ (Key Informant #1). “So there can be a transfer of more power to them” (Key Informant #6).

Agency also means trusting in self and in one’s capacities.

*Most of the time in l’Arche, we need to call others to life, to help them stand up on their own feet, to help them trust in themselves and their own inner capacity for love.* (Scandal of Service, 1998, p. 47)
As the following quote describes, power happens when relating to others. More specifically, power is realized when a need is expressed and as importantly, that need is met.

*There would be a group of people who are sitting together, assistants and core members, planning where they would like to go. I think that instills a sense of power in people, that they can go places, that they have desires. That they know where it is they would like to go. As well, when people articulate through some path or process what some of their dreams are and those dreams happen.* (Key Informant #5)

**Agency is choice**

In the following quote, a key informant gives further insight into how agency is respected within this model. The key informant makes the link between agency as power and agency as choice. This key informant also reveals that when confronted with agency in someone living with a disability, it is perceived as a positive expression of self.

*I find the people I have personally felt the most satisfaction working with are always people who have told me off and always pushed back and said “I want to be my own adult” and once they have done that and I have been able to say “yes, you are right” then, they can also say, “here is where I need your help”. I think it is very, very hard work for us, even when we are aware of this, to try to help people cultivate their own choice.* (Key Informant #1)

As the above quote indicates, agency is something which is seen as a positive development in individuals with disabilities. This message came out in many different ways. A second key informant described a situation with a client who wanted to participate in a particular kind of religious ceremony and when “he advocated for himself” this was responded to and he was supported in making the activity happen. It was clear that key informants respected agency in clients and supported its expression.

*So there was always I think that balance of not taking over, letting the person with a disability move at their level and*
do what they could and make their choices. (Key Informant # 9)

Agency is making choices and then, acting on these choices. As this key informant indicates, agency means deciding what you want, rather than what others want, for you.

It's about always trying to promote their life. Just because somebody says they love to eat hamburgers doesn't mean they really love to eat hamburgers. It's always about how you put things out there so people have more choice. Because some people can’t read, it may be a visual thing that people need in order to better articulate what it is that they want. People are still oppressed to just follow along with whatever the caregiver puts out for people. So, how do you promote that for people? And then, how do you listen? (Key Informant #5)

As the preceding quote indicates, the professional supports agency through listening and through promoting choice.

Both Vanier and key informants stated that the capacity to make choices that are free from external pressures and then, act on these is an important part of agency. The following quote from a key informant gives further insight into this idea.

If people feel that we are really listening to their heart’s desire, trying to help them name that and then trying to help them succeed in attaining it, then their confidence grows, because what they desire is more important than what I desire for them. (Key Informant #1)

Other key informants commented on this idea that individuals with disabilities need to develop the capacity to make free choices, based on their own likes and dislikes. In text passages, freedom to choose and to act is also linked with agency. As Vanier states, as a quality of agency, free choice should be encouraged in everyone. More specifically, Vanier argues that “to attain real human happiness, we need to be responsible for our own lives and to act from free choice in every circumstance” (Made for Happiness, 2001, p. 151).
During the interview in France, Vanier talked about the consequences of transformation. As he did so, he briefly commented on his own family background as one which discouraged personal freedom or choice. Vanier stated that he did not grow up in a “culture of personal conscience, but rather obedience” (Vanier Interview, 2005).

However, Vanier went on to say that the transformational process is one which encourages the freedom to act according to one’s conscience. In other words, “we can relate to each other without fear, we can relate to each other and not be controlled or possessed” (Vanier Interview, 2005). Consequently, as the following quote indicates, agency is the ability to act and choose freely, according to one’s conscience.

They begin to realize that to become fully human is not a question of following what everyone else does, of conforming to social norms, or of being admired and honored in a hierarchical society, it is to become free to be more fully oneself, to follow one’s deepest conscience, to seek truth and to love people as they are. (Becoming Human, 1998, p. 95)

As individuals develop their own sense of agency, they make choices and more importantly, they make free choices and then, base their actions on these choices.

**Agency is Responsibility**

While agency means developing the ability to make individual and free choices, it includes being responsible for these decisions. It also means being responsible for others. As Vanier indicates, this is connected to maturity and therefore, expected of everyone.

Human beings need to be encouraged to make choices and to become responsible for their own lives and the lives of others. We need to be encouraged to evolve in order to become mature and to break out of the shell of self-centredness and out of our defense mechanisms. (Becoming Human, 1998, p.15)

As responsibility, agency is expected of individuals with disabilities.
Many people with disabilities live with the burden of never being asked to contribute and because of this, they are not full citizens. They can’t become full human beings without being asked to care for another or just even listen to another’s heart. (Key Informant #1)

Finally, in the following quote, another key informant provides an insightful description of responsibility as it occurs in relationships between individuals living with disabilities.

I can give you an example. I remember I held a house meeting with myself and the house members around one of the core members who had been hitting people and people had started to get frightened of him and were kind of dodging out of his way and cringing and avoiding him and so, we had a meeting to try and talk about it. We encouraged the people in the house to say what it was they were feeling toward this person...And so a number of people said “I am afraid of you”, “I think you are going to hit me”, “I’m upset that you hit so and so the other day” and this young man looked at them and there were tears in his eyes. He said “I wouldn’t hurt you. I’m not somebody who would hurt you”. And they talked to him again and said “but you did hurt so and so”. And, so he said, “Yes I did and I am really sorry”....I think, in that group, those handicapped people were learning from each other and were learning, some of them, learning how to express what they felt. Because one of the others was able to do this and then, they could copy. (Key Informant #9)

Authenticity

The transformational process was consistently described as a process which increases self awareness and self acceptance. To live life authentically means to live it with awareness and acceptance of strengths and weaknesses, personal and family history. Therefore, the self knowledge which is produced as a result of the transformational process is integrated into identity and influences interactions with others. An authentic person is defined as someone who demonstrates integrity and honesty within self and when relating to others.
**Authenticity is integrity**

The authentic self is an integrated self. As the following quote from a key informant indicates, an authentic person lives with full awareness of his/her strengths and weaknesses. This means that self is not defined by either strengths or weaknesses, but an integration of both into self identity.

> Knowing your gifts and your strengths, and not just focusing on your weakness, but holding together that we are humane beings, are infinitely broken and infinitely gifted, not one after the other, but intertwined and we all live with loss, with suffering, with our own disability forever. (Key Informant #1)

This key informant goes on to describe this integration as wholeness and as something that is found in both individuals with disabilities and without.

> People with developmental disabilities are never cured. Their mental illness might be cured somewhat, or more likely as for most of us, we find ways to live more fully with appreciation of our whole self, which includes some parts that might be quite broken. (Key Informant #1)

Key informants discussed the integration of affect, intellect and spirit and also, suggested that these aspects of self existed in balance with each other. “Where the vitality of someone’s spirituality is so important, the synthesis of heart and mind is so vital” (Key Informant #8). When talking about the balance between work and faith, one key informant described this feeling of being integrated.

> You don’t have to compartmentalize your life...wherever you are at, it’s a part of who you are and there is a space to say that or to experience that or share that. (Key Informant #4)

In the following quote Vanier describes this integration as unity and more importantly, indicates that physical and spiritual parts of self are connected.

> Through relationship with the poor or weak person or with the child, the heart, compassion and goodness are
awakened and a new inner unity is established between body and soul. (Scandal of Service, 1998, p. 188)

In the following quote, Vanier links unity with acceptance of weaknesses in self and others.

*It takes a long time to discover unity in ourselves so that we can be a source of unity for others, to welcome our wounds so that we can welcome those of others...it takes a long time to drop our masks and accept ourselves as we are with all our limitations, so that we can accept others.* (Heart of l’Arche, 1995, p. 90)

During the interview with Vanier, while discussing the importance of coming to terms with physical limits in clients, Vanier suggested that living authentically includes integrating an awareness of death and mortality. In the following quote, Vanier reveals this more existentialist aspect to authenticity.

*I see this with the young people who come here. It’s not evident what is going to help them to touch their irremediable limits and their own concerns about death. It is interesting. A young woman recently wrote a note to me saying, “I was always scared of dying but I am not frightened anymore of dying. Today is my last day at the foyer and inside my heart I feel only peace and contentment. This year has changed me, never has one year had so much intrinsic meaning. I am more a lover of silence now. The thought of dying which once overwhelmed and scared me is now something that makes me feel more alive”. Phenomenal. I find that amazing.* (Vanier Interview, 2005)

As the preceding quote indicates, to have integrity means to live one’s life in full awareness of limits to one’s own existence, including illness, disability, life and death. As the following key informant indicates, it also means paying attention to the whole context, both the good and the bad and in this way, “*taking the time to be attentive to the world I am in and the gift and beauty of the world, not just its pain*” (Key Informant #1).
Finally, there was a strong indication from all data sources that having integrity means that a person shares a common humanity with others and therefore, is part of something larger than self. This was communicated by key informants when they talked about the consequences of transformation.

For the vast majority of assistants, when they leave, they have found friendship, relationship with a person that, beforehand they may have walked on the other side of the street to avoid and as they leave they realize that they are far more alike, than different, far more alike. So, there is a learning there about humanity which these assistants will take away with them. (Key Informant # 3)

For Vanier, it is important for individuals to understand that they are unique but that they are part of the unfolding story of the universe; they are part of something that is bigger than self. Each person is connected to the larger, social good or whole.

But things are not isolated. There is an order in the universe that holds everything together. In the end, the flower returns to the earth, because everything is in a state of movement and that is another good. To learn to contemplate is thus also to get used to seeing things as part of a whole, to see that all things tend towards their good, but also, co-operate ultimately in one final good. (Made For Happiness, 2001, p. 96)

As discussed, an authentic person has integrity. This integrity occurs at several different levels. It means that a person lives with a sense of his/her strengths and weaknesses. It means that life is viewed as a complex interaction of both beautiful and painful experiences. An authentic person lives with a sense of how he/she is part of something larger and that she shares a common humanity with others.

**Authenticity is honesty**

While an authentic person has integrity, he/she is also honest. An honest person recognizes that he/she is a unique entity in the world. An honest person does not feel the need to wear masks when interacting with others. There is no pretense when relating to
others. Key informants described this lack of pretense as it is noticed in individuals with disabilities.

_The thing with people with disabilities, is that they’re not always able to have these masks and pretense and appearance and appear to be something different, other than they are. They just really are who they are._ (Key Informant #6)

Another key informant describes her own experience of authenticity as honesty in presentation of self. “I remember being struck by, oh, I really like this, I don’t have to wear a mask, I don’t have to pretend” (Key Informant #2). As another key informant stated, “this means getting past the striving to appear all together, then we can really be ourselves and we can be known and valued” (Key Informant #1). In the following quote, Vanier gives further credibility to this idea of being oneself. “He did not have to wear a mask, or to pretend to be other than he was...he could be himself (Our Journey Home, 1997, p. 222).

Authenticity means being true to self when interacting with others, it also means expressing self in an emotionally honest way. As the following quote from a key informant indicates, this means that an individual is open to an exchange of emotions when in relationship with others.

_I am passionate about l’Arche because I have received therapy myself, where my heart has been liberated and my thinking is now servant to my compassion for myself and other people and 20 years into it, I am finding it is breaking me open more. I am not wiser. I am more open and more confident and this is due to my whole journey._ (Key Informant #1)

Vanier describes this emotional expressiveness as an opening up.

_To have an open heart that lets the waters of compassion, of understanding, and of forgiveness flow forth is a sign of a mature person._ (Becoming Human, 1998, p.102)
And, in another text passage, Vanier states that when the barriers are removed within self, we are better able to express ourselves emotionally.

*It means allowing the barriers with which we protect ourselves to fall so that we can allow that which is most fundamental in us to emerge: the vulnerability of our hearts and our ability to live in communion.* (Heart of l’Arche, 1995, p.71)

As presented, an authentic person experiences and expresses self in an integrated and honest way. To live with a sense of integrity means that the individual includes multiple levels of awareness into his/her interactions with others. It means awareness of self along with awareness of one’s connectedness to a whole that is larger than self. To be honest means to present self without pretense, to be genuine in emotional expression and to be true to one’s unique sense of self.

As this discussion has demonstrated, the transformational process leads to maturity. A mature person is someone who has a sense of agency and is authentic when relating to others. Table 3 provides a summary of maturity, with its concepts and characteristics.

<table>
<thead>
<tr>
<th>Concept</th>
<th>Characteristic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agency</td>
<td>Power</td>
</tr>
<tr>
<td></td>
<td>Choice</td>
</tr>
<tr>
<td></td>
<td>Responsibility</td>
</tr>
<tr>
<td>Authenticity</td>
<td>Integrity</td>
</tr>
<tr>
<td></td>
<td>Honesty</td>
</tr>
</tbody>
</table>

*Table 3- Maturity as Agency and Authenticity*

An important and defining feature of the transformational outcome is that it is not an isolated experience of self and therefore, it is expected to be transferred to and expressed within other relationships. Consequently, transformation is both ongoing and cyclical in nature. This theme was consistently expressed across data sources. However, perhaps, Vanier said it best during the interview.
So we are concerned with how we can help people open up and trust in themselves. And, then, how to help people move from fear to trust in themselves and, then, trust in others. And it’s only when one has trust in one’s self, and therefore, trust in others, that our lives can become fruitful, that we can give life to others. (Vanier Interview, 2005)

As indicated through this section, the outcome associated with the transformational process is maturity. Figure 4 provides a visual representation of maturity as it relates to the transformational relationship and also, the process of change.

Figure 4- Maturity-The transformational outcome
Table 4 provides a summary of the key concepts and characteristics which define the transformational model of rehabilitation.

<table>
<thead>
<tr>
<th>Transformational Elements</th>
<th>Concepts</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Definition of Problem</strong></td>
<td>Personal identity</td>
<td>Thoughts, feelings and beliefs</td>
</tr>
<tr>
<td><strong>Transformational Relationship</strong></td>
<td>Commitment</td>
<td>Personal engagement</td>
</tr>
<tr>
<td></td>
<td>Co-operation</td>
<td>Covenant</td>
</tr>
<tr>
<td></td>
<td>Compassion</td>
<td>Acknowledge &amp; Accommodate Difference</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Inter-dependence</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unconditional Regard</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Exchange of emotions</td>
</tr>
<tr>
<td><strong>Transformational Process of Change</strong></td>
<td>Awareness</td>
<td>Awareness of need for change</td>
</tr>
<tr>
<td></td>
<td>Acceptance</td>
<td>Awareness of strengths and weaknesses</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Acceptance of strengths and weaknesses</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Acceptance of personal and family history</td>
</tr>
<tr>
<td><strong>Transformational Outcome-Maturity</strong></td>
<td>Agency</td>
<td>Power</td>
</tr>
<tr>
<td></td>
<td>Authenticity</td>
<td>Choice</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Responsibility</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Integrity</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Honesty</td>
</tr>
</tbody>
</table>

Table 4 - The Transformational Model of Rehabilitation

Figure 5 provides a visual summary of the key concepts found within the transformational model of rehabilitation. As mentioned previously, a key feature of the model is the ongoing and cyclical nature of transformational relationships and processes. In Figure 5, the arrow which comes out of the transformational relationship is meant to depict the ongoing and cyclical nature of transformation. Therefore, transformational relationships produce adults who are able to provide this opportunity to others.
4.5 Theoretical Principles of the Transformational Model of Rehabilitation

Table 5 provides the theoretical principles which inform the transformational model of rehabilitation. These principles emerge from this model’s understanding about the nature of the problem, the nature of the relationship between clients and professionals, the process of change and finally, the outcomes associated with this change. They provide insight into the relationships between concepts and in this way, reflect the primary concern of this model which is the transformational process as it occurs in both client and professional. They also provide a conceptual link between this model and the problem of burnout in rehabilitation professionals.
Table 5- Theoretical Principles of the Transformational Model of Rehabilitation

There are seven theoretical principles which inform the transformational model of rehabilitation. Within this model, the relationship is structured so that it creates the conditions within which an individual can enter and move through the transformational process. The relationship promotes transformation in personal identity when it leads to increased awareness and acceptance of self. Awareness and acceptance of key aspects within self lead to maturity in personal identity. A mature person demonstrates the capacity for agency and authenticity and furthermore, is motivated to provide the transformational experience to another person. Therefore, a mature person contributes to the conditions needed for transformation in another person and through doing this, demonstrates that transformational processes are both cyclical and interactive in nature. Finally, a mature person who has the capacity to be an authentic agent is less likely to experience the emotional and ethical consequences of burnout.
CHAPTER 5: DISCUSSION

Summary of Findings

The focus of this thesis has been stress in rehabilitation professionals. An important assumption underlying this study is the belief that failure to adequately address emotional and ethical conflicts among rehabilitation professionals leads to high rates of burnout and its associated consequences for the individual employee, his/her organization and clients. The thesis goal was the discovery of an alternative model of rehabilitation service delivery that would address these issues and therefore, lead to a more compassionate and effective service for people with disabilities. Through its use of a qualitative, interpretive case study design to examine Jean Vanier’s thinking about relationships between individuals living with and without disabilities, the thesis has produced the transformational model of rehabilitation.

The transformational model of rehabilitation contributes to a better understanding of potential ways to reduce work stresses experienced by rehabilitation professionals. The model focuses on clinical relationships that are characterized by commitment, cooperation and compassion. These relationships enable a transformative process in personal identity which is characterized by increasing awareness and acceptance of key aspects within self and others. An important assumption of this model is that neither professionals nor clients are exempt from the expectation that they contribute to the relationship, that they enter a transformational process and experience its associated outcomes.

Transformational rehabilitation acknowledges that both professionals and clients are engaged in a lifelong process of increased maturity. Therefore, as growth and
development continue throughout the lifespan, both client and professional continue to mature in their personal identity. A mature person is an authentic agent. As individuals develop and express agency and authenticity when interacting with others, they provide others with the conditions needed for transformational processes and outcomes. In this way, transformational processes are maintained and promoted in self and other.

5.1 Comparison to Current Models of Service Delivery

Currently, there are four models which inform the delivery of rehabilitation services: the biomedical, the independent living, the client-centred and the community based rehabilitation model. Each of these models includes a particular perspective on the nature of the problem or issue which is being addressed, the type of relationship needed to address the issue or problem, the process of change and finally, the outcomes associated with the change process. The transformational model of rehabilitation is a conceptual model which acts as an alternative to these four main models. It shares features in common with each of these models, but also differs in important and significant ways. Through highlighting the similarities between transformational rehabilitation and the four models of service delivery, this section shows how the transformational rehabilitation model is related to these other models. In addition, through its discussion of the differences between transformational rehabilitation and these other models, this section demonstrates that transformational rehabilitation has the potential to make a significant contribution to the work of rehabilitation professionals.

Biomedical Model

As indicated, the biomedical model has its own particular understanding of the problem, relationship, process of change and outcomes associated with rehabilitation
efforts. There are commonalities which exist between the biomedical and the transformational model. The most significant of these is their shared concern that the individual with a disability achieve his/her highest level of functioning. Within the transformational rehabilitation model this means that individuals with disabilities mature as far as realistically possible for them. Within the biomedical model, this concept would refer to achieving independence in activities of daily living, including moving, eating, speaking or hearing.

Despite the fact that there are some commonalities between these models, there are significant differences as well. The most significant difference between these models is the way that neutrality and objectivity are either encouraged or discouraged within the professional. According to the biomedical model, the professional must remain objective and neutral in order to effectively perform his/her diagnostic and treatment roles (Määätä, 2006). A professional who gets emotionally close to his/her clients risks his/her ability to make accurate observations and conclusions about the patient (Määätä, 2006). Within the transformational rehabilitation model, interacting in a personal way with clients is part of the therapeutic environment provided by the professional. Compassion as exchange of emotions means that the professional does not remain aloof from the relational dynamics, but actively contributes to these through the strategic sharing of emotional reactions within the relationship.

In addition, the transformational model of rehabilitation encourages the professional to let go of the ‘professional as expert’ role. More specifically, the co-operative nature of the transformational relationship means that leadership roles are shared and therefore, an intentional effort is made to equalize the power relations. This equalization is further
supported by the requirement that professionals engage in a more personal way with clients. Personal engagement is facilitated when professionals let go of the masks that they wear. Clients contribute to this shift in roles through adopting a more active role within the relationship. Therefore, as the professional lets go of some of his/her expertise, clients respond through increasing their own participation and expertise. Consequently, relinquishing the expert role has implications for both client and professional.

As indicated through this discussion, these models do have some similarities. However, there are significant differences between them as well.

**Independent Living Model**

The independent living (IL) model shares much in common with transformational rehabilitation. Both models are interested in increasing the control that an individual with a disability has over his/her life. Both models are concerned about the power that professionals have to label and diagnose and have developed alternative ways of structuring provider-client relationships.

Despite the similarities between the IL model and transformational model of rehabilitation, there are two significant differences between these two models. First, the focus within transformational rehabilitation is on co-operation rather than independence. More specifically, through its definition of co-operation this model encourages acknowledgement and accommodation of difference. This process encourages inter-dependence within the relationship. Therefore, clients learn that differences are not sources of vulnerability but rather, a reason to work more closely together. Therefore, both client and professional actively contribute to the relationship. This is important as it promotes co-operation and inter-dependence within the relationship.
A second difference between these two models is found in their orientation toward growth and development. While transformational rehabilitation is concerned with self development and growth, it is also concerned that individuals who have experienced transformation promote this experience in others. Therefore, a key assumption of transformational rehabilitation is that its outcomes are transferred to other relationships. Within the IL model, there is a strong tendency to focus on the self for the sake of the self. The transformational model opposes this view of self-development as it argues that self-development is not a privatized affair and therefore, should benefit other relationships.

A final source of difference would be found in the IL model’s emphasis on the client as consumer or employer. Transformational rehabilitation argues that traditional rehabilitation models structure relationships in order to maintain distance and alienation between professional and client. Transformational rehabilitation is opposed to the alienation represented by the IL model’s emphasis on purchasing and contracting of professional services. Within the transformational model, the emphasis is on personal relationships and also, on a relationship between client and professionals which is co-operative and therefore, allows room for the contributions of all members within the relationship. Therefore, both client and professional have expertise which is brought to bear on the issues at hand and the expertise of each is valued and recognized within the context of the relationship.

**Client-Centred**

There are several areas of overlap between the client-centred and the transformational model. The most important commonality is the importance that both models place on the
nature of the relationship. In both client-centred and transformational rehabilitation efforts, relationships are the therapeutic activity or tool that the professional uses to promote change in a client. Both models consider the provision of unconditional regard as key to this relationship. In addition to a shared emphasis on the relationship as the sufficient and necessary condition for change, these models are both focused on personal growth in the individual living with a disability. While the terms used to describe the outcome of this growth are different, both models are concerned with personal identity.

Despite their similarities, these models differ in one significant and important way. This difference is related to the respective roles of professional and client within the relationship. Within the client-centred model, the client knows what represents his/her best interest. In order for the client to self-actualize, his/her decisions are given priority; they are respected and supported by the professional. Furthermore, the professional must remain neutral and not exert any particular influence over the client’s decisions and emotional process. The transformational rehabilitation model takes a different approach to the roles of professional and client.

Within transformational rehabilitation, both client and professional contribute to all elements of the relationship. The professional is more than just a facilitator of change within the client. More specifically, the transformational model believes that the professional is actively involved in promoting transformational experiences in others. Within a transformational model, the professional is a person and therefore, has preferences which shape and influence the work which is taking place. In addition, because the professional is engaging in a personal way, he/she is also expected to benefit from the relationship and to experience the process and outcome of transformation. The
transformational model insists that relational benefits are experienced by all members of the relationship and therefore, the clinical work is negotiated and takes into account the needs of both client and professional.

**Community-based Rehabilitation**

The community-based rehabilitation (CBR) model is similar to the transformational model of rehabilitation. Both of these models view the relationship as one of collaboration between client and professional. Both are interested in building the capacities of clients. Despite their similarities, these models differ in their definition of the problem. Within CBR, the problem is one of social processes and structures and therefore, takes on a political nature. Within the transformational model, the problem is one of personal identity and the lack of appreciation of one’s own unique identity.

The difference in problem definition means these two models also differ in the desired outcomes associated with the work which is being done. CBR is a political strategy which is focused on the development of local community structures in under-developed countries. Although CBR is more recently informing community development strategies in developed countries, its primary focus is with local community processes and structures. Transformational rehabilitation is concerned with personal identity and the development of relationships which promote maturity in individuals living with and without disabilities. While the transformational outcome of maturity as agency and authenticity is expected to have an impact on interpersonal relations, these impacts are felt at the relational and not the political or social level. Therefore, transformational rehabilitation does not have the same political or social impact that is found within a CBR approach.
In conclusion, the transformational model of rehabilitation is different from the four models of rehabilitation service delivery. It is different because it emphasizes maturity as the outcome of the change process. No other model places such emphasis on this concept. No other model emphasizes the importance of agency and authenticity. In addition, the transformational model emphasizes personal engagement and the exchange of emotions. This means that the professional is no longer a stranger in the relationship, but is known as a person. The transformational model acknowledges and accommodates differences and therefore, promotes inter-dependence. The relationship is expected to benefit both client and professional and therefore, both maintain influence over the dynamics, direction and work which is occurring. Each of these features distinguishes the transformational model of rehabilitation from the other four models of service delivery.

5.2 Comparison to Transformational Learning Theory

As a theory of adult learning, transformational learning theory proposes that adults use frames of reference, developed during childhood, to determine the meaning given to events. In other words, frames of reference act as a powerful lens through which adults comprehend and respond to the world around them (Brookfield, 2000; Mezirow, 1991). Transformational learning theory is particularly concerned with these frames of reference or belief systems because they are often used without awareness.

While transformational learning theory is primarily concerned with meaning perspectives and how these influence interactions and behavior, it is also concerned with developing a process which facilitates changes in these perspectives. As described by many authors who write in the area of transformational theory, the process begins when an individual is exposed to a disorienting situation or dilemma which is then thought to
initiate an active process of reflection upon his/her meaning perspectives. Through this critical reflection, the individual transforms what were previously taken for granted belief systems and also, develops a more permeable, negotiable and open set of beliefs about the world (Mezirow, 2000). The transformational process prepares adults for life in a democratic society, it produces adults who are capable of thinking independently and also, reflecting on the assumptions that both they and others are making.

The transformational process is a process concerned with adult education and learning. In addition, this approach relies on the educator’s own experience of transformation as a foundation for providing this to someone else. According to Cranton (1994), it is not possible to promote self-reflection and examination in someone else if this is not being practiced by the educator. Therefore, both participants within a transformational relationship are expected to enter and undergo the active examination and reflection upon meaning perspectives.

Although transformational learning theory is traditionally used as a theory of adult education, it has recently been applied to disability issues (Urbanowski, 2005; Gill, 2001; Reinders, 2000; Scorgie & Sobsey, 2000). In general, researchers who are currently applying transformational learning theory to disability studies recognize that this process involves a shift in the meaning perspectives within either the person living with the disability or, in the case of children with disabilities, family members (Urbanowski, 2005; Reinders, 2000; Scorgie & Sobsey, 2000). As many researchers in the field of disability studies have demonstrated, the experience of disability, in either self or family members, produces a shift in values and meaning perspectives (Gill, 2001; Reinders, 2000; Scorgie & Sobsey, 2000). More specifically, as Gill (2001) argues, the shift in
values and beliefs causes the individual to think differently about disability and the meaning of disability. This shift creates room for adaptation and adjustment to living with disability. Scorgie and Sobsey (2000) also found parents of children with disabilities experience similar transformations. Current research demonstrates that both individuals with disabilities and family members experience transformation through the development of more positive meaning perspectives.

The transformational model of rehabilitation shares many similarities with both transformational learning theory as it is applied to education and also, to individuals living with disabilities. Along with transformational theorists, the transformational model of rehabilitation believes that the process is concerned with meanings which are developed in childhood and which tend to act as unreflective filters in adulthood. The model also expects that both professional and client undergo the transformational process. All those who work with individuals living with disabilities need to reflect on their own experiences with disability and suffering and therefore, are expected to enter into a process which promotes this reflection.

However, differences emerge when discussing who is capable of transformation. As one of the main proponents of transformational learning theory, Jack Mezirow argues that adults must be intellectually and emotionally competent in order to engage in transformational learning (Mezirow, 2000). This argument rests on his assumption that in large part transformation is a rational process directed at belief systems. At least two of Mezirow’s colleagues have identified this focus on rationality as a problem because it excludes less articulate or insight oriented adults (Belenky & Stanton, 2000). This emphasis on transformation as a rational process and the exclusion which it produces
reflects the most significant difference between transformational rehabilitation and transformational learning theory. According to transformational rehabilitation, both disabled and non-disabled adults are capable of entering and experiencing the transformational process. For some adults, the content of transformation is focused on ideologies and beliefs. For other adults, it is focused on emotional and spiritual issues. Therefore, this model views transformation from a broader and also, more inclusive, perspective than transformational theorists like Jack Mezirow.

In addition to differences that exist between transformational rehabilitation and transformational learning theory, there are distinctions which need to be made between this model and the work done with regard to transformation and disability issues. The most important source of difference between this model and authors like Gill (2001), Reinders (2000) and also, Scorgei and Sobsey (2000), is its assumption that both professional and client must experience the transformational process. It is important to acknowledge that these authors understand that transformational processes lead to a shift in perspective on the value of a life lived with disability. They also see this as a shift in perspective which benefits both the individual living with a disability and his/her family members (Gill, 2001; Reinders, 2000; Scorgei & Sobsey, 2000). However, as the transformational model of rehabilitation proposes, the transformational expectation is extended to professionals. In this way, the meaning perspectives and belief systems that professionals hold regarding disability and suffering must also be examined. Therefore, the application of transformational theory to disability issues does not go far enough and as the transformational model of rehabilitation indicates, the professional cannot help
another person with the transformational process unless they have participated in the process themselves.

In conclusion, the transformational rehabilitation model is both similar to and different from the work of transformational learning theorists and also, that which has been done in relation to individuals who have disabilities. Through its arguments regarding how transformation occurs in individuals with disabilities and through its belief that transformation is concerned with emotional and intellectual issues, transformational rehabilitation has expanded the application and relevance of transformational learning theory to rehabilitation professionals.

5.3 Relevance to Stress in Rehabilitation Professionals

The transformational rehabilitation model makes a direct and significant contribution to stress in professionals who work with disabled individuals. Through presentation of these findings, the reader is given specific insights into how this model addresses burnout, compassion fatigue and moral stress in rehabilitation professionals.

**Burnout**

The transformational rehabilitation model addresses burnout but more importantly, through its particular emphasis on compassion, commitment and co-operation and authenticity, it promotes job engagement. As previously described, burnout is an emotional process in which the professional moves from the experience of personal exhaustion to depersonalization and finally, reduced personal efficacy in the workplace. On the other hand, job engagement includes a sense of recognition, a good fit between personal values and organizational values, being known as a person and finally, the experience of a just and fair work environment. The transformational rehabilitation model
addresses key aspects of the burnout experience and also, at the same time, promotes job engagement in the workplace.

This model addresses burnout in specific ways. As described in the literature review, emotional exhaustion is the first of three steps in the burnout experience. Emotional exhaustion is caused by the need to regulate emotions when working with clients. Both the repression of negative emotions and the over-expression of positive emotions lead to emotional exhaustion. The transformational model promotes authenticity when relating to others. Therefore, this model discourages the regulation and manipulation of emotions which are considered to be key contributors to emotional exhaustion and burnout. As the transformational model promotes integrity and honesty in presentation of self, its adoption should reduce emotional exhaustion in the rehabilitation professionals.

In addition to the way that emotional awareness and authenticity address issues associated with burnout, this model promotes job engagement. This model fosters relationships which are compassionate, committed and co-operative. Each of these elements contributes in a unique way to job engagement. Co-operation promotes an acknowledgement of differences that allows for accommodations of these differences. Co-operation as inter-dependence also promotes a distribution of work within the relationship. Commitment encourages personal engagement and covenant with clients and co-workers. Compassion as acceptance, love, forgiveness and the exchange of emotions promotes skills which are needed to maintain job engagement over the longer term. As discussed, this model provides an example of how job engagement can be achieved through particular kinds of relationships with clients and also, colleagues within the workplace. The model encourages job engagement through its integration of values
with community, social justice and fairness and through its encouragement of interdependent and interpersonal relationships.

Compassion Fatigue

As indicated during the literature review, there are two main understandings about compassion fatigue. The first understanding is that compassion fatigue occurs when a professional who has had previous life traumas is re-traumatized through exposure to the difficulties experienced by clients. In this way, compassion fatigue is viewed as secondary or vicarious trauma. A second explanation is that compassion fatigue occurs as a result of providing empathy to a client. Therefore, during the act of empathizing with a client, the professional is traumatized through the act of imagining the harmful life events of a particular client. The transformational model of rehabilitation directly addresses the experience of compassion fatigue through its emphasis on emotional awareness in the rehabilitation professional, through its recognition that personal history can be problematic for professionals and finally, through its recommendation that professionals attend to these issues.

More specifically, this model directly addresses compassion fatigue as it recommends that professionals recognize and process emotions as they occur in relation to clients. As professionals interact with clients, they are encouraged to notice and attend to personal reactions. This approach to emotional awareness buffers the professional from empathy fatigue in two ways. The model structures relationships in such a way that some emotional reactions are shared with clients. This encourages the professional to begin processing his/her own reactions by sharing some of these initial reactions with a client. In addition, this model encourages professionals to seek out mentors with whom these
reactions can be further discussed and processed. In this way, professionals are encouraged to attend to emotional reactions, share some of these with a client and then, process them more completely with a colleague or mentor.

The second contribution this model makes toward addressing compassion fatigue is its clear recommendation that professionals deal with their personal and family issues. This model recognizes that individuals who have had negative personal or family experiences can be re-traumatized through their relationships with individuals who have disabilities. This is based on the belief that the experience of suffering or pain in a client triggers memories of pain and vulnerability. Therefore, this model encourages professionals to address these issues prior to or during their work with disabled individuals. In doing so, this model addresses compassion fatigue as vicarious or secondary trauma.

**Moral Stress**

As indicated in the moral stress literature, there are two types of ethical dilemmas which most professionals confront at various points in their careers. The first is an ethical dilemma which is resolved through the application of professional and organizational codes of conduct. The second is an ethical dilemma which cannot be resolved through available codes of conduct and therefore, forces the professional to choose between what are in effect, two bad choices. These ‘no-win’ situations produce moral stress. While rehabilitation professionals experience both kinds of ethical dilemmas, this model is particularly relevant to the experience of moral stress in rehabilitation professionals.

More specifically, through its promotion of maturity as both agency and authenticity, this model provides a potential solution to the experience of moral stress. As indicated in the literature review, the professional who deals with moral stress must accept that life is
imperfect and that both anxiety and guilt are experienced when making difficult decisions. In addition, professionals must accept that life is a complex balance between joy and sadness, laughter and tears and that most situations in life should be approached from this more nuanced perspective. Promotion of authenticity in professionals ensures they understand that life is not perfect and more importantly, that they are not perfect. Authenticity promotes the recognition that there are limits in life and these limits can be found in both clients, but more importantly, within self.

In addition to the role that authenticity plays in reducing moral stress, mentors also act as a buffer when professionals experience ethical dilemmas. Within the transformational model, the professional is never expected to act independently or to carry moral stress without support of colleagues and peers. Therefore, as a reflective experience designed to examine internal aspects of self, the transformational process encourages ongoing learning from clinical situations and dilemmas. Professionals are not expected to have arrived at a single point of wisdom and therefore, continue to seek support and input from others. This feature of the model assists in reducing moral stress within the rehabilitation professional.

As indicated, through its emphasis on authenticity and the role of mentors, this model addresses some of the causes and consequences associated with moral stress in rehabilitation professionals. In addition, it makes a direct contribution to both compassion fatigue and burnout. Through the way that this model promotes exchange of emotions, personal engagement with clients and co-workers, inter-dependence and finally, its approach to agency and authenticity, the model deals with specific aspects of these three types of stress in rehabilitation professionals.
5.4 Theoretical Implications

Currently, both academics and individuals living with disabilities use the work of Michel Foucault, a post-modern theorist, to advance their critiques of the ways that professionals manage difference and identity and more importantly, their arguments that both professional and client are impacted by the management of these concerns within the clinical relationship. The transformational model of rehabilitation, through its approach to difference within the relationship and also, its recognition and support of personal identity in both professional and client, takes an important step toward addressing concerns regarding identity formation which have been expressed in the professional and disability literature.

Individuals living with disabilities are aware that they are assigned social or public identities of ‘not normal’, or ‘different’ and therefore, ‘other’ (Hughes et al 2005). These assigned identities are usually negative and based in stereotyped understandings about what it means to live with a disability. Consequently, according to some disability advocates, the professional and public response to otherness, or difference, as represented by disability, leads to the experience of mistaken identity (Gill, 2001). Individuals living with disabilities are sensitive to the ways that professionals, the general public and the media respond to their ‘otherness’ through imposition of the expectation that individuals with disabilities conform to dominant social expectations regarding ‘normal’ human behaviour. These normative expectations are often communicated by professionals through the diagnostic and treatment process. In this way, professionals impose ‘normalizing’ narratives on individuals with disabilities (Galvin, 2006; Haller et al 2006; Hughes et al. 2005; Gill, 2001). Individuals living with disabilities are aware that these
social processes impact on their ability to define and express a unique and personal identity (Hughes et al. 2005).

Agreeing with the critiques provided by individuals living with disabilities, Mackey (2007), Cushing and Lewis (2002) and also, Leonard (1997) argue that professionals are often guilty of imposing ‘normalizing’ narratives on clients. These narratives are designed to erase, reduce or minimize difference and therefore, promote homogeneity between marginalized groups and the dominant culture (Fisher, 2007; Leonard, 1997). However, Trainor (2003), using themes derived from Michel Foucault, points out that the relationship between client and professional is complicated because professionals are also subjected to and therefore, influenced by dominant cultural and professional narratives. More specifically, Mackey (2007) and also, Kaiser (2002) argue that formal professional education subjects both medical and rehabilitation professionals to socialization processes which produce a particular kind of professional identity. These socialization processes produce a professional identity which has internalized normalizing narratives and therefore, uses dominant professional theories and approaches in an unreflective and therefore, problematic way.

The concerns regarding identity which have been expressed by both academics and individuals living with disabilities reflect themes found in post modernity. From a post modern perspective, personal identity is the result of historical, social and cultural forces (Rapley, 2004; Leonard, 1997). Personal identity is no longer viewed as a permanent, given or fixed state but, as a characteristic which is open to change over time (Mackey, 2007; Hughes et al 2005; Kaiser, 2002). As these ideas relate to disability issues, the identities of both professional and individual living with a disability can no longer be
seen as permanent or static features of any particular individual (Mackey, 2007; Rapley, 2004). As Rapley (2004) states, personal identity is not a fixed object in the world but rather is a “... a status of being-in- the-world which is actively negotiated…” (p. 2).

Consequently, both individuals with disabilities and the professionals who work with them actively construct and express an identity which is open to development and change over time.

The transformational rehabilitation model contributes to the post modern conversation regarding difference and identity in professional client relationships. Rather than erasing or minimizing differences which exist within the relationship, the model promotes an inter-dependence which rests on difference. In addition, the transformational model of rehabilitation recognizes that personal identity is constructed and defined in relationships with others. More specifically, this model acknowledges that the identity of both client and professional are influenced by the relationship. In this way, the model integrates the post-modern recognition that identities are socially constructed and more importantly, that exposure to otherness promotes transformations in both professional and client. The transformational model of rehabilitation allows rehabilitation professionals the opportunity to identify the ways that their own identities shift and change in response to clinical relationships. In addition, through avoiding the imposition of professional or expert narratives on individuals with disabilities, this model facilitates the development and expression of personal identity in individuals living with disabilities. It recognizes that individuals with disabilities have unique identities and that these identities are not static, nor are they meant to be defined or assigned by professionals. Consequently, the
model addresses post-modern concerns with identity and difference that have been identified by professionals and individuals living with disabilities.

5.5 Organizational Implications

This model has several organizational implications. One of these relates to its recommendations for ongoing mentoring relationships. While many organizations recognize that new employees need to be supported while being socialized into the workplace, this responsibility is often neglected as the employee settles into work routines and expectations. The transformational rehabilitation model recognizes that providing care to someone who has a disability is stressful and demanding. This model encourages discussion of reactions and emotions in both new and seasoned workers. All employees are encouraged to access colleagues and to discuss the reactions and issues which are occurring as a result of their relationships with clients and co-workers. The need to discuss personal reactions is viewed positively and as an indication that the employee acknowledges he/she needs the ongoing help and care of others in the work environment.

More specifically, this model recognizes that professionals have emotional reactions to clients, both positive and negative. Most health care organizations prefer to minimize, normalize or neutralize the presence of emotions within the workplace (Ashforth and Kreiner, 2001). However, this model provides an example of how emotions can be dealt with in a more open and transparent way. Therefore, organizations need to consider the provision of educational opportunities which promote awareness of and support for these internal reactions to the clinical and organizational work which is being done.
The third and final organizational implication relates to job engagement. The transformational model of rehabilitation provides insight into the ways that relationships between colleagues and also, between clients and professionals support job engagement. More specifically, when organizational cultures encourage relationships which are committed, compassionate and co-operative, they are also supporting job engagement. Therefore, organizations which encourage personal engagement, covenant relationships, exchange of emotions and inter-dependence are promoting an internal culture that is conducive to job engagement. In addition, through its encouragement of agency in professionals, this model provides some indication of how autonomy and authority can be increased in rehabilitation professionals.

In conclusion, it is clear that the transformational rehabilitation model has a number of important organizational implications. It means organizations have a responsibility to promote mentoring relationships. In addition, in order to promote job engagement, organizational culture will need to encourage particular kinds of relationships within the workplace.

5.6 Clinical Implications

There are several important clinical implications which this model has for rehabilitation professionals. These are related to the model’s concern for personal identity, its definition of compassion, the participatory nature of the change process and finally, its emphasis on maturity.

Personal Identity

The transformational model of rehabilitation is concerned with personal identity. From a clinical perspective, professionals need to be aware that the onset of disability may
present a challenge to personal identity. When individuals with disabilities seek the services of a rehabilitation professional, they may need assistance in consolidating their personal identity with the experience of disability. Consequently, this model recognizes that individuals living with disabilities may need to gain insight into their own beliefs, thoughts and feelings as these relate to disability. A mature professional who experiences self as an authentic agent provides the relational environment needed to facilitate awareness and acceptance of self in the individual living with a disability. From a clinical perspective, professionals who work within a transformational model recognize that these are the kinds of issues which require further discussion and intervention.

Compassion

Within this model, compassion is unconditional regard and the exchange of emotions. Therefore, professionals are expected to demonstrate these qualities and more importantly, encourage them in clients. While unconditional regard is something all professionals would agree is important to relationships, most would not go so far as to include the exchange of emotions as part of compassionate care. Yet, compassion is more correctly defined as sympathy and the shared experience of emotions. This model believes that compassion as love can be achieved in relationships with individuals who have disabilities. This conviction that love is critical to compassionate relationships is shared by many others, including Martha Nussbaum.

Nussbaum (2001) argues that disinterested love is foundational to compassionate relationships. As Nussbaum discusses, compassionate relationships rely on a type of love which supports emotional reciprocity while allowing for separateness or distinctness in the other. Nussbaum links love and reciprocity to compassion and in doing so, accurately
describes the way this model uses these concepts. Nussbaum also emphasizes that this love which supports the ‘otherness of the other’ encourages agency through supporting the unique choices, talents and projects of the other. This model argues that compassion is acceptance, love and also, exchange of emotions. It is a love which promotes growth and authenticity in others and therefore, both supports and is supported by Nussbaum’s formulations regarding the links between compassion and love.

*Participatory Nature of the Change Process*

In order for this model to be successful, both professional and client participate in the transformational process. The transformational literature provides many examples of individuals with disabilities and their families engaging in this process. Depending on the extent of their impairments, individuals living with disabilities are confronted on a regular basis with the limits to their existence. The transformational process assists them in developing a meaningful existence within the experience of disability. However, there are few examples of how transformation applies to rehabilitation professionals.

Within the transformational model, the rehabilitation professional cannot provide good care to someone with a disability unless she/he has also experienced both the benefits and the challenges associated with the transformational process. Through this process, the professional becomes aware of and also, accepts that he/she has limits. Consequently, the professional is considered better able to accept the meaning and the reality of impairments in someone else’s life. This is an important feature of transformational rehabilitation as it avoids the imposition of unrealistic and unobtainable goals for someone living with a disability.

*Maturity*
As this model reconfigures the working relationship between a client and professional, it also impacts on the expectations that professionals have for their clients. As indicated previously, the transformational outcome is maturity, defined by a sense of agency and authenticity. The transformational model of rehabilitation defines maturity as both agency and authenticity and also, suggests that both clients and professionals experience the benefits of this outcome. More specifically, the professional who promotes agency in a client sees the individual living with a disability as someone who is capable of acting and also, someone who has rights and responsibilities. Therefore, professionals need to enter into conversations with clients and structure clinical activities which both build capacity to make decisions and also, promote action in clients. Viewing the client as agent means understanding that they have the capacity to choose between possibilities and to learn from the consequences of choices that have been made. This concept of agency also includes having a social conscience. Consequently, clients are encouraged to think about how their behaviours impact on others. As indicated, maturity is a complex concept. It is the outcome to which client and the professional’s work is directed and therefore, has a significant impact on the clinical relationship.

5.7 Research Implications

This current thesis project builds on the work of others who have looked at l’Arche and its particular approach to relationships (Pottie & Sumarah, 2004; Cushing, 2003; Cushing & Lewis, 2002). Through its articulation of the transformational model of rehabilitation, this thesis project makes a unique contribution to this literature. However, further research is required regarding particular aspects of the transformational relationship. For example, there is a need to clarify how rehabilitation professionals can
engage in a personal way with their clients while also ensuring that the focus remains on the clinical issues. There is also a need for further research which develops specific recommendations and guidelines regarding the exchange of emotions within clinical relationships.

In addition to continued exploration regarding particular elements of the transformational relationship, the concept of job engagement requires further attention. The research on stress, burnout and compassion fatigue has tended to focus on reducing these occurrences in the workplace. Rather than focusing on reducing the experience of stress, there is a need to look more closely at how to produce job engagement. What are the work conditions which increase job engagement? How is mentoring provided to older, more experienced employees? There is also a need to identify organizational strategies which will support the successful integration of concepts like values and recognition into workplace conversations.

While job engagement requires continued research, there is also a need to examine the transformational process as it relates to individuals living with disabilities. Given that there are four other models which inform service delivery and that each of these have a unique role to play in the delivery of services to individuals living with disabilities, there is a need to determine the relationship between the transformational model of rehabilitation and these other models. Is it feasible to use the transformational model in conjunction with these other models? In addition, there is a need to clarify whether this is a model that can be used in individuals who are newly diagnosed with a disability. Alternatively, is it a model which is more appropriately used with individuals who have
been living with disability for a longer period of time? As this model relates to individuals living with disabilities, there are several issues which require further study.

The final research implication for the transformational rehabilitation model relates to the transformational process and its implications for the workplace. According to this model, professionals are expected to undergo a transformational process. Therefore, there is a need to study how transformational processes occur in rehabilitation professionals. Practical issues which require further study include a closer examination of how professionals can engage in this process while also attending to demands found within the workplace. Organizations will benefit from a more detailed understanding regarding the transformational process and its impact on performance. Are there negative impacts experienced when a professional initially engages with his/her personal or familial issues? At what point does the professional begin to experience the benefits of transformational processes? These are the types of questions which future research will need to examine.

5.8 Study Limitations

Although efforts were made to anticipate weaknesses in the study design, some limits remain and these need to be identified. These limits include its choice of key informants and the lack of an explicitly religious perspective.

The current research has been limited by its choice of key informants. As described within the Methods Section, key informants were chosen on the basis of their familiarity with Vanier’s thinking and on their accessibility to me as a researcher. The decisions made with regard to key informants meant that there was a lack of frontline, consumer and international input. Frontline staff would likely have provided different
interpretations of Jean Vanier and the application of his ideas. Interviewing consumers would have provided a unique view of Vanier and his importance to individuals living with intellectual and other disabilities.

This study was also limited by its lack of key informants from the international level. Although several of the key informants were born and educated in the United States and at least two had traveled and worked at l’Arche communities in India, when interviewed, they were most often speaking from within a Canadian perspective on relationships with individuals living with disabilities. The lack of international perspective is a limiting factor. It means that this research has a western bias toward relationships with individuals who have disabilities.

A final potential limitation of this research is its lack of attention to the specific and explicitly religious messages which can be found in Vanier’s work. This research has been focused on Vanier’s approach to relationships. It made use of his thinking about spirituality, but not about religion. This choice was made intentionally in order to make the thesis results more accessible to rehabilitation professionals. This decision could be interpreted as a limiting factor because Vanier is viewed as a religious thinker by both professionals and members of the general public. However, Vanier does not limit himself in any way to this category. In his own words, Vanier has publicly stated on several occasions that he would rather work with someone who values the person with a disability but is not religious. Although there is much to be gained from looking at Vanier’s religious beliefs and practices, such a narrow interpretation of his work excludes him from contributing to larger spiritual and philosophical debates within the disability community.
5.8 Personal Statement Regarding Research

As I started this research journey, I was interested in learning more about myself, my colleagues and our experiences of stress over the past ten years. I finish this research having developed some important insights. The first insight is the value of personal engagement to reducing professional stress. I have concluded that it is what professionals have been trained ‘not to do’ which offers a potential remedy to their stress. I understand why the prescriptions against personal relationships are maintained within both organizations and also, professional schools of training. I am someone who has argued against developing personal relationships with clients throughout my professional career as a social worker and as a social work educator. However, I now understand that professionals need to interact in a more personal way with clients. More importantly, they need to be taught how to do this in a way that also maintains personal boundaries. While I recognize this concept of personal engagement requires further study and clarification, I also believe that continuing to do ‘more of the same’ will not resolve professional stress.

This thesis has developed my understanding of Jean Vanier. As I am finishing this thesis, I see Vanier from a much broader philosophical perspective. When I interviewed Vanier, I asked him whether he considered himself a postmodern thinker in the tradition of other French philosophers like Michel Foucault. Vanier responded by stating that he does not see himself as a great or creative thinker because he prefers to think of himself as a synthesizer of other people’s ideas. Vanier was not convinced he should be situated in relation to people like Foucault. However, I think he can and should be placed in the tradition of other, contemporary thinkers. He contributes a unique perspective on issues
of inter-dependence, vulnerability and also, personal identity to ongoing philosophical discussions. I have been intrigued by these themes in Vanier’s work and it has been an interesting process for me to place Vanier within this larger philosophical context.

**Conclusion**

The focus of this thesis has been stress in rehabilitation professionals. The thesis has examined Jean Vanier’s thinking about relationships between individuals living with and without disabilities to determine its relevance to stress in rehabilitation professionals. The thesis has demonstrated that Vanier’s approach to relationships between individuals living with and without disabilities makes a significant and worthwhile contribution to this topic. Professionals who choose to work within the transformational model of rehabilitation are working within a model that creates the internal conditions needed to reduce their experience of burnout. Maturity as agency and authenticity promotes emotional and ethical capacity in professionals. Together, these internal conditions have the potential to reduce burnout in rehabilitation professionals.
References


Canadian Institute for Health Information (2005). *Canada’s Health Care Providers Chartbook*. Ottawa, ON: Canadian Institute for Health Information.

Canadian Institute for Health Information (2001). *Canada’s Health Care Providers*. Ottawa, ON: Canadian Institute for Health Information.


Cutcliffe, J.R., McKenna, H.P. (1999). Establishing the Credibility of Qualitative


Disability and Society, 21 (5), 499-512.


Relevance of Edith Stein’s Concept of Empathy. *Nursing Philosophy, 7* (3), 3-10.


Redux or Romeo and Juliet Revisited: Embedding Terminology in a New Agenda for the Field of Mental Retardation. *Mental Retardation,* 40 (1), 65-70.


## Appendix 1-Books and Purpose

<table>
<thead>
<tr>
<th>Title of Book</th>
<th>Date published</th>
<th>Goal of book</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community and Growth*</td>
<td>1979</td>
<td>Clarifies conditions necessary for community life.</td>
</tr>
<tr>
<td>Heart of l’Arche</td>
<td>1995</td>
<td>Essential Elements of l’Arche spirituality</td>
</tr>
<tr>
<td>Our Journey Home</td>
<td>1997</td>
<td>Reflections on common elements of humanity</td>
</tr>
<tr>
<td>Scandal of Service*</td>
<td>1998b</td>
<td>Reflections on how Gospel of John touches individual hearts, affects personal relationships and community life.</td>
</tr>
<tr>
<td>Becoming Human</td>
<td>1998a</td>
<td>What it means to be human, human foundations of spirituality</td>
</tr>
<tr>
<td>Made for Happiness</td>
<td>2001</td>
<td>To make wisdom from Aristotle accessible</td>
</tr>
<tr>
<td>Seeing Beyond Depression</td>
<td>2001</td>
<td>Sympathetic approach to moving beyond depression</td>
</tr>
<tr>
<td>Finding Peace</td>
<td>2003</td>
<td>Reflections on need for peace after September 11,2001</td>
</tr>
</tbody>
</table>
# Appendix 2 - Key Informants

<table>
<thead>
<tr>
<th>Key Informant</th>
<th>Years aware of Vanier</th>
<th>First Exposure to Vanier</th>
<th>Educational/Professional Background</th>
<th>Current Involvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>21</td>
<td>Book</td>
<td>University-Theology</td>
<td>Internal-administration</td>
</tr>
<tr>
<td>2</td>
<td>32</td>
<td>Friend</td>
<td>University-Education</td>
<td>Internal-Administration</td>
</tr>
<tr>
<td>3</td>
<td>23</td>
<td>University</td>
<td>University-Counselling</td>
<td>Internal-Administration</td>
</tr>
<tr>
<td>4</td>
<td>20</td>
<td>Book</td>
<td>University</td>
<td>Internal-Administration</td>
</tr>
<tr>
<td>5</td>
<td>14</td>
<td>Flyer</td>
<td>n/a</td>
<td>Internal-Administration</td>
</tr>
<tr>
<td>6</td>
<td>9</td>
<td>l’Arche</td>
<td>University-Social Work</td>
<td>Internal-Administration</td>
</tr>
<tr>
<td>7</td>
<td>Over 30</td>
<td>Public lecture</td>
<td>University-Medicine</td>
<td>External-Friend</td>
</tr>
<tr>
<td>8</td>
<td>8</td>
<td>University</td>
<td>University-Social Work</td>
<td>External-Board of Directors</td>
</tr>
<tr>
<td>9</td>
<td>38</td>
<td>Church Group</td>
<td>University-Medicine</td>
<td>External-Advisor</td>
</tr>
</tbody>
</table>
Dear Dr. Vanier,

I am a doctoral student at Queen’s University and I am writing to inquire if, as part of my thesis research, I might have the privilege of an interview with you. I hope my thesis will study your work and writings intensively and am planning to derive themes for rehabilitation from them. Although we have not met, I have been aware of you and your work for many years. In my late teens, I had the opportunity to work with Anne and Steve Neuroth. They had just returned from living with you in France and started a series of group homes for adults with intellectual disabilities in Southeastern Ontario. I worked for four years in the group homes and established many rewarding friendships during my time there. My work within this community inspired me to pursue social work studies at McGill and University of Toronto.

In September 2003, I entered my first year of a PhD in Rehabilitation Therapy here at Queen’s University. The program is devoted to enhancing the lives of individuals with disabilities and to advancing research in the area of rehabilitation therapy. My thesis supervisor is Dr. Mary Ann McColl who has expertise in the area of spirituality and disability issues. I have also been fortunate enough to meet Hélène Ouellette-Kuntz, who has worked extensively in the area of intellectual disabilities and has agreed to be on my thesis committee. I feel that I have two very qualified mentors, who will be assisting and facilitating my work as it unfolds.

While re-reading your books over the past year, I was struck by the question you asked in Our Journey Home. In the book, you asked whether your model could be replicated in other organizations. Having worked extensively with adults who have had many different disabilities, I believe that the models we currently use tend to neglect key components of the caregiving relationship. Reconnecting with your books has convinced me that your model has a great contribution to make to the field of rehabilitation therapy. I am interested in building on your ideas and translating them into a theory which can be accessed by rehabilitation workers across Canada. I believe that the time is right to answer your question: Can this model be replicated in other organizations?

I value your input into my work and would appreciate two hours of your time. I would like to interview you in person, however, should this not be a possibility, I would also be prepared to interview you by phone. I am aware that you are coming to Kingston in the fall of 2004 and am hoping to be involved in the planning for your visit at Newman Centre, Queen’s University. Perhaps, you will consider scheduling an interview with me during your visit to Kingston. Finally, I would like to audiotape and transcribe the interview and will provide you the opportunity to give editing feedback on the audiotape.

I look forward to hearing back from you about this project and hope that we are able to talk in the near future. Please find attached, as well, my contact information.

Yours sincerely,

Donna Forster, M.S.W, M.P.A
Doctoral Candidate, Rehabilitation Therapy
Queen’s University Kingston Ontario
### Appendix 4- Key Informant Interview Format

<table>
<thead>
<tr>
<th>Question 1</th>
<th>What is your connection to Jean Vanier’s approach to caring for people with intellectual disabilities?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Question 2</td>
<td>How long have you been involved with or aware of this approach?</td>
</tr>
<tr>
<td>Question 3</td>
<td>Can you tell me how you became familiar with Jean Vanier and his thinking? Anything else? Have you read any of his books?</td>
</tr>
<tr>
<td>Question 4</td>
<td>What do you think are the key principles of the therapeutic model which Vanier is advocating in his thinking? By principles, I mean behaviors and attitudes and values that are demonstrated through interactions with people who have disabilities.</td>
</tr>
<tr>
<td>Question 5</td>
<td>How does it differ from traditional rehabilitation or models of care for people with disabilities?</td>
</tr>
<tr>
<td>Question 6a</td>
<td>Jean Vanier has written extensively about the importance of growth in both the caregiver and the person being cared for. Given that is difficult to change the organization of one’s character and personality, how do you account for the growth which you see in those who live and work in relation to Vanier’s philosophy?</td>
</tr>
<tr>
<td>Question 6b</td>
<td>Practically speaking, how do you think ‘equivalence’ is experienced in therapeutic relationships with individuals who have intellectual disabilities? By equivalence, I mean equality or sharing of power within the therapeutic relationship.</td>
</tr>
<tr>
<td>Question 6c</td>
<td>How do you think that an employee of l’Arche experiences their work life differently than a rehabilitation worker in a non-l’Arche organizational environment?</td>
</tr>
<tr>
<td>Question 6d</td>
<td>I am particularly interested in the stress that is experienced by those working with individuals who live with a variety of disabilities. Can you tell me how you think stress in workers is experienced and resolved in those who work within Vanier’s approach?</td>
</tr>
<tr>
<td>Question 6e</td>
<td>Jean Vanier argues that spirituality is a characteristic of human nature. Can you talk about how a faith based spirituality influences your work with individuals who have intellectual disabilities?</td>
</tr>
<tr>
<td>Question 7</td>
<td>If you were going to suggest ways that other rehabilitation service providers could integrate Vanier’s approach to or principles of care into their work, what would the key aspects be?</td>
</tr>
<tr>
<td>Question 8</td>
<td>When you think about Jean Vanier’s contribution to the field of intellectual disabilities, what would you say are his most significant contributions?</td>
</tr>
</tbody>
</table>
### Appendix 5- Interview with Vanier

<table>
<thead>
<tr>
<th>Elements of Therapeutic Relationship</th>
<th>Traditional Rehabilitation</th>
<th>Vanier</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is the Therapeutic Activity?</td>
<td>Activities/Technique</td>
<td>Relationship “Being With”</td>
</tr>
<tr>
<td></td>
<td>Experts provide/do</td>
<td></td>
</tr>
<tr>
<td>What is the Therapeutic Process?</td>
<td>Skill learning</td>
<td>Personal Transformation “Becoming Human”</td>
</tr>
<tr>
<td></td>
<td>Rehabilitation</td>
<td></td>
</tr>
<tr>
<td>What is the therapeutic goal?</td>
<td>Independence</td>
<td>Interdependence Community Authenticity “Being Human”</td>
</tr>
<tr>
<td></td>
<td>Assimilation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Normalization</td>
<td></td>
</tr>
</tbody>
</table>

Contrasting Core Components of Vanier with Traditional Rehabilitation

Professional rehabilitation therapists experience a number of different stressors in their work with individuals living with disabilities. I believe your thinking and writing about relationships directly addresses many of the stresses identified by these professionals. Therefore, I am hoping that my thesis work will increase the availability of your thinking and approach to rehabilitation therapists.

From reading your books and interviews completed thus far, here are key principles I have identified in your thinking.

**Principles:**

1) All human beings are engaged in a constant process of growth. This growth is transformational when it involves the development, recognition and expression of one’s authentic, real self. There is no fixed, end point for human beings, as they will continue to grow and transform themselves throughout the life span.

2) Transformational growth occurs within relationships that have certain qualities. These include compassion, commitment, co-operation, communion and competence. The assumption is that all those within the relationship contribute to the expression of these qualities.

3) Transformational growth produces human beings who nurture authenticity in themselves and others and who strive for inter-dependence in both personal relationships and community life.

I would like to start by asking you some questions which will ensure that I understand your thinking about relationships with individuals living with a variety of disabilities, including physical, mental and intellectual.

**Question One:**

Have I summarized your thinking fairly? How would you add to or expand on these three principles?
Question Two:
I have made assumptions about your thinking. For example, there is no endpoint as we are always challenged to grow in our reactions and competencies. We reach our endpoint at our death. What do you think about this assumption?

Question Three
People can grow and change but are not necessarily transformed by this growth. Transformation occurs when the structure of the self changes. What is your reaction to this?

Question Four
Not all relationships produce transformation. Controlling, authoritarian relationships are less likely to produce the kind of growth you are concerned with. In order to grow, people must be free to find their authentic or true self, which is only found within a guided, but not controlled, process. Am I correct in this assumption?

Question Five:
When talking about the key qualities of relationships, I think words like compassion and competence are easier to understand, but words like commitment, co-operation and communion are more provocative. What are your thoughts on this?

Question Six:
More particularly, I think that professionals will not understand the importance of these concepts to both the person providing the help and the person receiving the help. How would you help a professional understand the importance of personal growth as a precursor to helping another person?
Appendix 6

Sample of Reflective Journal Entries

October 25, 2004 Queen’s University Retreat-led by Vanier-. Vanier reveals that his inspirations have included people like Dorothy Day and Catherine Doherty. He states that ideology is problematic when it constrains the individual. Need a caring environment to grow. People with disabilities need to learn how to care, need to understand how they can help us; that they can be of help to us. Direct quotes from Vanier “I am happy” “I don’t have all the answers, but I do have a lot of questions”. “We can’t control others”.

December 12/04
Memos to self- I am writing these notes as reaction to the books I have read so far and as I get my questions ready for Toronto.

What comes up for me:
Growing to freedom: The basis of freedom is truthful acceptance of self? Truthful acceptance of self? Sounds like something we all have and need to connect with? Sounds like something very few people would achieve in life without years of therapy. Accepting self? How? Weaknesses? Strengths? History?

Communion: Accepting presence of another within one self as well a reciprocal call to enter into another? How does one keep boundaries around self intact while doing this? Wouldn’t there be a danger that the person would become immersed in the other and lose a sense of self? Is the idea to merge with another? Is this empathy or is it something different? What does it mean that the self emerges from this?

April/05
Notes to self about interviews
Organization is situated in United Church in Toronto. Have to buzz to get in (Toronto! Downtown!) Offices on upper floor of what was at one time the loft of the church. Look down on floor of church which is now meeting spaces. The space was quiet, everyone focused on their work. In cubicles. Somehow, expected more activity. Where is everyone? Noticed young man with Down’s Syndrome working in one of the cubicles, like everyone else! All those interviewed have read questions in advance. If unsure, tell me. Ate lunch with staff. Evident they are friends outside of work. Know each other’s lives.

December 3/05
Communion is self in other and other in self. Inserted note to self: June 2006. This is no longer my concept of communion. It really is about sharing of affect.

Re-reading first interview and thinking back to how shocked I was when told that they make fun of Vanier a lot. They all laugh at him. I could not believe they would do this at the time I was interviewing this person. Now, I understand. Am less confused as I realize we all take ourselves too seriously. (me, too!). Too seriously!!
Re-reading Interview #4. Wholeness an important concept. This is so different from postmodernism which compartmentalizes and divides everything. The dividing practices of post-modernity. Foucault. He would have something to say about all of this. Vanier and l’Arche encourage unity and wholeness. Inserted note: June/06: was reading O’Hara this weekend and it occurred to me that, perhaps, being whole is also dangerous. If you are whole, you are also self-contained and therefore, autonomous. Is this what Vanier is really saying or implying? Does this make sense? Inserted note: undated. For Vanier, wholeness is not same as completion or finishing or endpoints. Inserted note: October 06. Dividing practices. Bifurcation of self and other. Vanier recommending that ego is included as it is impossible to bracket self. This all relates back to phenomenology and bracketing of self. And Vanier seems to imply this isn’t possible nor desirable

December 7/05 Re-reading notes from Heart of l’Arche. Language of service to others. Very appealing to me however has associations with customer service. Vanier links concept of servant to service which is fine but also, has socio-economic and class associations.

Re-reading notes from Becoming Human. Vanier against making people with disabilities normal. Supports growth toward maturity. Which is different for each person. Normal is a cultural concept and therefore, implies normalization about control and programming of person with disabilities. Very different from Wolfensberger.

Jan 16/05
What is Vanier saying about people with disabilities?
Be open to their gifts. Allow client to develop according to his/her own goals and aspirations. Don’t impose. People with disabilities have their own intrinsic value and have responsibilities as citizens.

June/06
Reflecting on presentation at SEO-CURA meeting where I gave my research update. Thinking about counter-transference. Is it the client’s projection or therapists response? If therapist response, is it his/her own childhood being scratched at? Statement made at CURA that counter-transference provides the foundation for transformation. Do I agree with this? Is it that simple? Does it represent the reciprocity that Vanier argues in favor of? Also, with regard to relational empathy. Both client and therapist impact on each other. Therefore, counter transference and transference are the foundation for transformation.
Appendix 7- Coding Diagram

**Strategies**
Client and professional contribute to transformational relationships which are committed, co-operative and compassionate.

**Causal Conditions**
Within the relationship, exposed to suffering in self and others.

**Phenomenon-Transformational process of change**
Become aware of and address personal/historical issues

**Consequence**
Maturity Authenticity and agency

**Actors**
- Person with disability (client) and professional involved in developing transformational relationships, both experience transformational process and consequences of change process.
Appendix 8

Glossary of Terms

Affect- Affect is considered an umbrella term. It refers to feelings, emotions and desires which lead to behaviour (Sykes, 1986). More specifically, emotions are considered mental sensations and are considered the opposite of reason when based on instinct. Desires are defined as experiences or objects that one wants or that one expects to experience pleasure in having. Feelings represent the internal experience of an emotion. For a more detailed discussion regarding how emotions and intellect have been positioned as opposites of each other, refer to the term Intellect.

Burnout- As defined by Maslach et al (2001), burnout accumulates over time and is a response to workplace demands. It includes three steps which are emotional exhaustion, depersonalization and finally, a sense of reduce professional efficacy. Burnout is linked to the poor fit between personal and organizational values and therefore, also has an ethical component. For this thesis, burnout is both emotional and ethical fatigue.

Commitment- The process of involving, binding or pledging oneself (Sykes, 1986)

Causes - What produces or causes an effect, antecedents (Sykes, 1986)

Community - All associations of human beings who not only have some goal to achieve, like people in business, the army or a sports team. But who also help people to meet one another on a personal level, where there is dialogue, sharing openness and a true concern for others (Vanier, Our Journey Home, 1997, p.184)

Compassion- Pity or sympathy for another person (Sykes, 1986). Nussbaum (2001) also links empathy with compassion because she believes that in order to respond compassionately, an individual must first engage in the act of imagining him/herself in a similar situation. Furthermore, as both Nussbaum (2001) and Tessman (2005) indicate, there are important links compassion and compassionate behaviour. For example, in response to events like the Tsunami in South Asia, an individual would first imagine what it would be like to have his/her home and life taken away by a sudden cataclysmic event like a wave. Then, she would imagine her own reactions to this situation and this would create a sympathetic response. The sympathy generated would lead to sympathetic behaviours including donations of food, money or time. This example provides the link between compassion, empathy and compassionate behaviour.

Co-operation – Work which occurs together and which has a similar purpose or end (Sykes, 1986)

Covenant- According to Hamel (1994), covenant refers to relationships which are governed by a sense of fairness, justice, righteousness, charity and faithfulness. Coffey
(2006) clarifies that covenant is a term that has a medical and biblical lineage. As a medical term, it refers to relationships in which there is mutual commitment made to healing. As biblical term, it refers to God’s commitment to the Israelites. Sykes (1986) defines covenants as agreements or bargains which are made between two parties.

Intellect -The ability to know and reason, to understand and to have a motive or rationale for behavior (Sykes, 1986). Within philosophy and disability theory, the ability to reason is highly valued and within western culture, rationality is the key and defining feature of being human (Cottingham, 1998). Within western societies, rationality and emotionality, or intellect and affect, are often perceived as opposites. Consequently, an individual cannot use both reason and emotion to inform decisions. An individual who is rational is not emotional and the individual who is described as being emotional is not considered to be using reason. According to Nussbaum (2001), this is a false dichotomy. As Nussbaum demonstrates, emotions involve reason, are the basis for understanding and act as a rationale for behavior. Emotions have a foundation in cognition and reason and therefore, can be brought under rational control. Emotions are open to reason, understanding and debate.

Job engagement- Job engagement is closely related to burnout. Authors like Maslach et al (2001) argue it is the opposite of burnout. Job engagement describes the positive fit that exists between an individual and his/her work environment. Six factors which contribute to this sense of fit include workload, control, reward, community, fairness and values.

Job involvement-Some authors make a distinction between job engagement and job involvement. According to May (as cited in Saks, 2006), job engagement refers to the way someone is emotionally or intellectually involved with his/work place. However, job involvement refers to the way that one’s sense of identity is connected to the work one does. A professional may be involved or identified with his/her work but not engaged or involved with the larger organization.

Moral stress- As defined by Audi (2001), moral dilemmas are situations in which there are two equally compelling courses of action and for various reasons, neither can be engaged in. More specifically, moral stress occurs when a professional knows the right course of action but is prevented from engaging in the action due to organizational or professional constraints on behaviour (Kälvemark et al, 2004).

Outcome- Result, visible effect (Sykes, 1986)

Processes- Progress, course of action (Sykes, 1986)

Self- A person’s individuality or essence (Sykes, 1986). Disability, philosophical and ethical theorists debate the essential characteristics of the self in western society. As Koch (2004) states, some ethicists argue that self is defined by autonomy, self-determination and independence of action. Others argue that the essence of selfhood is relational. In other words, the self is defined by its relationships with others. The way that
self is defined has political implications as selfhood is closely linked to personhood and therefore, political and legal rights.

Social Justice-Liberal society guarantees citizens access to the resources they need to be independent and self governing (Audi, 2001). As Gilman (2001) states, liberal interpretations of justice are distinguished by impartiality, fairness and symmetry. However, a society which integrates a social justice perspective believes that individuals should not be treated with impartiality but, that their differences should be acknowledged and taken into consideration (Gilman, 2001). When an individual or community adopts a social justice perspective, they are distributing goods according to need and therefore, in a way which is preferential and specific to the needs of the particular situation.

Spirituality -Spirituality refers to animating principles/drives and their foundations in either God or philosophy. Spirituality was further defined by the moral qualities which form the character of an individual (Sykes, 1986). Spirituality is therefore distinct from religion. Religion is defined as behaviors and attitudes which are expressed in particular systems of faith and worship (Sykes, 1986).

Transformation- Making a change in the form, outward appearance, character or disposition of something (Sykes, 1986).