The Role of Mandates/philosophies in Shaping Interactions between People with Disabilities and their Support Providers

by

Christine Kelly

A thesis submitted to the Faculty of Graduate Studies of
The University of Manitoba
in partial fulfilment of the requirements of the degree of

MASTER OF ARTS

Interdisciplinary Master's Program in Disability Studies
University of Manitoba
Winnipeg

Acknowledgements

I would like to thank Dr. Deborah Stienstra for her guidance, insightful feedback and patience. I would also like to acknowledge the contribution of the other committee members, Dr. Nancy Hansen for sharing her time and experience, Dr. Pamela Cushing for her invaluable feedback, and Heidi Hellsten whose community experience helped ground the project.

A special thanks to Claire Atherton for her willingness to wake up from a nap and discuss theoretical frameworks, and her overall support throughout the year. Thanks to Shannon Keys, for her interest, advice and support and readiness to help whenever needed.

I would also like to express my gratitude to the Social Sciences and Humanities Research Council for funding this project.

Dedication

This thesis is dedicated to Dale Stevenson, ever supportive, patient, and of course, handsome.

Abstract

Support provision is a personal and important element of daily life for many people with disabilities. The study examines the ways in which organizational mandates and philosophies shape interactions between people with disabilities and support providers at two unique organizations: a L’Arche community for people with intellectual disabilities and a Independent Living Resource Centre. The project is framed with the social model of disability, the work of Titchkosky (2003) and human geography. Data was collected through semi-structured interviews, including a scenario component, with administrators at each location, people with disabilities using the services and support providers. The findings demonstrate that both organizations have strongly articulated philosophies that the participants are familiar with. The L’Arche model creates an environment that determines certain ways of interacting and while the IL participants amend the philosophy to reflect the daily reality of support provision.

Table of Contents

List of Tables

List of Figures

List of Appendices

Chapter One: Introduction and Theoretical Framework

In a variety of academic fields including social work, sociology, nursing and psychology, scholars have debated whether or not academic theories influence "practice" or daily life. In the field of disability studies, considerable attention has been paid to defining and refining models of disability, especially the language that should be used (Gabel & Peters, 2004; Linton, 1998; Rioux & Valentine, 2005; Shakespeare & Watson, 2002; Titchkosky, 2003). Much of the literature included in this research uses the term "philosophy" although the concept is closer to a "model."[1] To reflect the literature, the term "philosophy" is used alongside of "model," both of which refer to a loose grouping of ideas that aim to explain such concepts as "disability" or "support provision." Philosophies/models are formed with practical application in mind. Philosophies as such are perpetuated through academic and community literature.

For many people with disabilities, the way they are treated is directly related to the philosophical assumptions of the people around them. Many people with disabilities receive intimate support from other people in various areas of their lives; this type of interaction is called "support provision." If models influence practice, then the models that inform support providers will impact very personal areas of disabled people's lives. The relationship between philosophy and support provision is examined in this research project.

There are many philosophical approaches to support provision and this project examines how some of these philosophies play out in daily life. Support provision organizations are often centered around a mandate or mission statement.

---

[1] According to Oliver (2004), "Models are ways of translating ideas into practice" (p.19).

In the context of this research, a “mandate” is a formal, foundational statement or document outlining an organization’s general approach to disability and support provision; the mandate should influence administrative systems and one-on-one interactions. Ideally, people who embody the mandate should be hired, and both the staff and service-users should be familiar with the mandate and refer to it in daily decision-making. Indeed, Marouis and Jackson (2000) identify “mission statements of human service organizations” as a method of conveying important and complex information to staff and service users (p. 422). This research aims to establish a connection between mandates and support provision interactions, making the findings pertinent for creating and revising mandates and training modules.

Background

This project examines two support provision organizations and their philosophies: L’Arche, founded on L’Arche philosophy which is a spiritual and relational approach to support provision, and the Independent Living Resource Centre, founded on the Independent Living Movement and philosophy. The following section will provide a brief overview of the history behind both of these movements.

The Independent Living Movement

The Independent Living Movement is a key aspect of the broader disability rights movement (U of C, Berkeley, 2004). The Independent Living Movement emerged on college campuses in the United States in the late 1960s (Eustis, 2000), around the same time as L’Arche emerged in France. The first Centre for Independent Living (CIL) that served a non-student population was in Berkeley, California in 1972 (U of C, Berkeley, 2004). CILs spread all over the U.S., and by the

1980s, the movement extended into Canada (CAILC, 2003). In Canada, CILs are referred to as Independent Living Resource Centres (ILRCs). Both CILs and ILRCs have similar roles; according to the Canadian Association of Independent Living Centres (2003), ILRCs provide supports and services that encourage independence. The ILRC Winnipeg notes that each resource centre provides services to fill "the unique gaps that exist in that particular community" (ILRC, 2006). In Winnipeg, the ILRC offers education and support in four areas: individual advocacy, information and referral, peer support and independent living skills, and research and development (ILRC, 2006). One of the innovative programs offered at the ILRC Winnipeg is the Personal Attendant Community Education (PACE) program, which trains support providers in Independent Living philosophy as well as in the technical elements of support provision. The graduates are qualified as "Independent Living Attendants"[2] or ILAs and are referred to the consumers[3] and affiliated organizations for employment. The Independent Living philosophy is expanded upon in Chapter Two: Literature Review.

L'Arche

Cushing (2003) identifies a number of environmental factors that contributed to the emergence of L'Arche, including the societal unrest in the 1960s, the radical changes in the Catholic Church, the popularity of communal living, and the

---

[2] "Independent Living Attendant" is an ILRC Winnipeg term; in more general Independent Living literature, support providers are referred to as "personal assistants" or simply "assistants."

[3] The consumers are the people with disabilities who "consume" the services provided through Independent Living Resource Centres, including access to Independent Living Attendants. This term was chosen to emphasize user-control.

deinstitutionalization movement.[4] L’Arche was initiated by moral philosopher Jean Vanier in 1964 as an alternative to institutions. Vanier invited two men with intellectual disabilities to live with him in his home in France. It is interesting to note that “L’Arche itself was not founded with a clear set of goals and theories initially” (Cushing, 2003, p.119). The model and philosophy matured over time with the influence of many people and is now defined as “an intentional faith community and a caregiving organization for people with intellectual disabilities” (Cushing, 2003, p.119). Today, L’Arche is a worldwide federation of non-denominational communities (Pottie & Sumarah, 2004, p.4). Perhaps the most unique characteristic of L’Arche is that the core members[5] live, work and socialize alongside of the assistants. The L’Arche philosophy is explained further in Chapter Two: Literature Review.

Assumptions

I have lived and worked in a L’Arche community in Ontario for a total of eight months. Living in a L’Arche community has made me very critical of traditional group homes. Indeed, many of the group home-models that emerged out of the deinstitutionalization movement are essentially smaller-scale institutions (Gardner & Glanville, 2005). Compared to the average L’Arche community, many traditional group homes have poor “client” to worker ratios, highly regulated environments, and emphasize distant “professional” relationships over closer ones. Close relationships

---

[4] The deinstitutionalization movement argues for the elimination of large-scale institutions that house people with intellectual disabilities, both in a physical and psychological sense (Stroman, 2003).

[5] In L’Arche literature, “core members” are the people with developmental disabilities who live in L’Arche communities; they are considered the “core” of the community. Recently, some communities, including the one in this study, chose not to use this term and refer to people with developmental disabilities simply as “community members” or “members.”

can be beneficial to both worker and person with a disability (Bogdan & Taylor, 1992; Marouis & Jackson, 2000; Piercy, 2000). I have deliberately chosen more progressive organizations for this study as best practice examples which traditional group homes could perhaps learn from.

Theoretical Framework

This research project is informed and framed by three academic areas: the social model of disability, which is a broad understanding of disability; the work of Tanya Titchkosky, which is a more specific understanding of disability; and human geography, which is an academic field that further supports the importance of this research.

The Social Model of Disability

The emerging field of disability studies is theoretically grounded in the social model of disability (Finkelstein, 1980; Oliver, 1983, 1990). The social model is an evolving understanding of disability. Unlike mainstream understandings of disability, the social model argues that disability is a socially constructed phenomenon; people are primarily disabled by societal structures and attitudes and not necessarily by their biological impairments. This model acts as a political tool to orient policy, empower those with disabilities, and to overturn negative assumptions about disability. It calls for inclusion of people with disabilities in the research, policies and programs that affect their lives. The social model contrasts the traditional “medical model” of disability where disability is depicted as an individual problem caused by medical abnormality (Rioux, 1997). The medical model manifests in the ways people with disabilities are treated in daily life, as well as in the many negative representations of people with disabilities in the media (Cumberbatch & Negrine, 1992). For instance, employers often do not want to accommodate people with disabilities in the workplace, patients with disabilities regularly become spectacles in hospitals, and many children with intellectual disabilities are placed in segregated school systems. The medical model is demonstrated in all of these scenarios; it is assumed that the individual's disability is what prevents the person from participating daily life, and the disabling social contribution is not accounted for.

The social model has been a relatively successful political tool in terms of changing policy and overturning some of the negative stereotypes about disability. However, recently there have been substantial criticisms of this approach. Shakespeare and Watson (2002) note that disability activists present an "extreme" version of the social model that suggests disability *only* exists because of societal assumptions and barriers. The authors argue that it does not reflect the reality of the disabled activists who promote it (Shakespeare & Watson, 2002). Indeed, the main criticism of the social model is that it leaves out the lived experience of impairment.

The academic criticisms of the social model should not discredit it. Through a literature review, Gabel and Peters (2004) suggest that the current criticisms of the social model are a result of the changing and varied understandings of it. They suggest that the current understanding of the social model is "eclectic," that is, it is fluid and influenced by diverse theoretical frameworks (Gabel & Peters, 2004, p.586). Indeed, the existence of different versions of the social model in the UK and North America support the "eclectic" description. Gabel and Peters (2004) note that "resistance" is a common underlying theme to all the variations of the social model and suggest utilizing resistance theory as a way forward in the debate about the validity and practicality of the social model. Gabel and Peters (2004) explain:

> Simply put, the very premise of the social model is grounded in resistance aimed at social processes that oppress disabled people and as such, there is an implicit connection between the history of the social model and resistance theory. (p. 592).

Resistance theory was also heavily criticized when it first emerged in the field of education. Walker (1985) argues that early resistance theory romanticizes the actions of disruptive students in high schools by assuming their behaviour is linked to creating social change when in fact it may be for other motives. Sultana (1989) agrees that early resistance theory focuses on class domination over other inequalities, but argues that the theory has evolved to address some of these issues. Sultana (1989) explains that later theorists divide actions into “resistance” and “contestations” to distinguish between actions with the goal of social change against simply “acting out”.

The social model challenges people to think differently and creatively about disability, and is very important to the history of disability and the disability rights movement. For the purposes of this research, the eclectic social model is grounded by resistance theory; that is, the research is framed with the basic concept that some people consciously resist negative representations of people with disabilities as a mechanism of social change.

Tanya Titchkosky

As mentioned above, the social model is dynamic and open to interpretation; Tanya Titchkosky (2003) presents her interpretation in *Disability, self and society*. Titchkosky includes impairment in her writing as she starts from the daily experience of disability and works outward to discern what the cultural implications are of the experiences. The goal of the book is “to stay with disability as that which can reveal and illuminate society and so enlarge the understanding that we already have" (2003, p. 6). The idea that disability can "illuminate" society at large is similar to L'Arche philosophy and is quite powerful. The proposed research will use the daily experience of people with disabilities and their support providers to "illuminate" the ways in which mandates shape the world of support provision.

Another significant aspect of Titchkosky's book is that theoretical and physical "representations have real consequences for real people" (2003, p.134). Titchkosky's argument dulls the theory/practice dichotomy creating a new research space. She notes "these consequences go beyond the people who are being represented since there are consequences for those who make these representations as well" (2003, p. 135). Thus, it is important to examine the theoretical basis of service provision organizations, since mandates can be see as one of the many "cultural renderings of disability" (Titchkosky, 2003, p. 7). How disability is portrayed in the mandates of support provision organizations will have an impact upon daily life for people with disabilities and their support providers. In sum, this research is framed by Titchkosky's ideas that disability experience is culturally illuminating and that representations have real consequences for real people.

Human Geography

Human or cultural geography is "a series of intellectual – and, at core, politicized –engagements with the world. It is a style of thought, fixed in neither time nor space" (Anderson, Domosh, Pile, & Thrift, 2003, p. 2). Cultural geography explores human/environment relationships, with the understanding that "environment" can include abstract concepts of space, time and knowledge (Blunt, 2005; Duncan, Johnson, & Schein, 2004). The importance of one's space, both in terms of time and place is a significant concept for this research. Kriegel (1987) suggests "the self …exists within the geography it inhabits, a geography in which a sense of place and a sense of time are so intertwined that it is virtually impossible to distinguish one from the other" (p. 43). Geography deeply influences identity and thus the context in which support is provided has a direct impact on people with disabilities.

In the last twenty years, the traditionally exclusive field of geography has begun to include disability-related research and theory (Park, Radford, & Vickers, 1998). The new stream of research includes a variety of methods and approaches. It ranges from empirical studies (e.g. exploring the demographic distribution of certain disabilities) to more abstract explorations of the landscapes of disability (Park et al, 1998). Some of the more radical research along this vein echoes the social model by identifying how environments can "disable" individuals (Gleeson, 1999; Imrie, 1996; Sibley, 1995).

Group homes, independent-living arrangements, intentional communities, family homes and even large institutions are personal spaces for people with disabilities. All of these settings are "home" for people with disabilities. Duncan and Lambert (2003) argue,

> [the home is] perhaps the most emotive of geographical concepts, inextricable from that of self, family, nation, sense of place, and sense of responsibility towards those who share one's place in the world, home is a concept that demands thorough exploration by cultural geographers. (p. 395).

Disability is not often examined in studies of home. Imrie (2004a) argues "there is an urgent need to 'corporealise' the meaning of the home" (p. 746). Indeed, in concordance with Titchkosky (2003), impairment is integral to one's identity, and one's identity is connected to one's home. In addition, Sibley (1995) argues the home is a “locus of power relations” (p. 92). This research considers the significance of the setting of the home, both spatially and socially in terms of interactions between disabled people and their support providers.

Delimitations

This project does not examine all of the philosophical approaches to support provision, but only ones that echo the social model. The literature review covers four main perspectives: L’Arche philosophy, Independent Living philosophy, the feminist ethic of care, and holistic nursing. In consideration for time constraints and resources, the research portion of this project focuses on two organizations with clearly articulated philosophies: L’Arche and the Independent Living Resource Centre.

It was beyond the scope of the study to examine all of the different settings and contexts of support provision.[6] That is, it was not possible to examine the differences in support provision that is available in institutions, family homes, group homes etc. However, as this project is framed with a human geography approach, the significance of setting is not ignored. The differences between the “community model” of support provision employed in L’Arche communities and the “self-directed model”[7] employed by the Independent Living Resource Centre are noted in Chapter Six: Discussion.

---

[6] For an example of a context-oriented examination of support provision, see Morris, J. (1993). *Independent lives? Community care and disabled people.* London: Macmillan Press.

[7] Typically, self-directed support provision takes place within the private home of the consumer. This home may be a part of a formal independent living arrangement (e.g. Ten-Ten Sinclair in Winnipeg), or may be the consumer’s place of residence unaffiliated with any organization.

Finally, in an attempt to embrace a pan-disability approach to research, this project does not differentiate between the lived experiences of different impairments. Many people argue that the lived experience of different impairments varies drastically and thus impairments groups should be considered separately from one another (Deal, 2003; Scott-Hill, 2004). Some argue that data from participants with varying capacities to respond to research questions may not be comparable (P.J. Cushing, personal communications, July 7, 2007). However, others argue that fragmenting disability into different impairment groups is politically counter-productive and often ends up excluding more and more people (Corker, 1998). For this research, all people with disabilities who require support in day-to-day life are examined as a group.

Statement of Purpose and Research Question

The purpose of this research is to explore the question: In what ways do the mandates of support provision organizations shape the interactions between people with disabilities and their support providers? “Interactions” includes decision-making by both support providers and people with disabilities, the formality and regulation of the exchange of services, and all other components of a support provision relationship (see Chapter Two: Literature Review). Some derivative questions the research addresses are:

- What outcomes can be used as evidence of the role of the mandate in shaping the interactions between the two groups?
- Do theoretical support provision perspectives manifest in organizational mandates?
- To what extent do people adjust the mandate to suit their own goals and contexts?

- Do the mandates challenge disabling societal assumptions?
- What is the role of the IL environment and L’Arche environment in shaping the interactions?

If it can be established that the mandates of support provision organizations have an important role in shaping the interactions between people with disabilities and their support providers, then this research could have direct implications for the composition and revision of such mandates.

The research question is founded on the basic social model premise that disability is a social construction and mandates can be considered one of the contributing factors to this construction. Negative constructions of disability must be resisted in order to improve the social situation of people with disabilities. Further, the research builds on Titchkosky’s idea that “cultural renderings,” such as mandates, have real consequences for real people. The research question attempts to discern *what* the consequences are in the context of support provision interactions. Indeed, “contexts” are also important; the research took place within the homes of people with disabilities in line with the human geography notion that context in general, and home in particular, can add to an understanding of an individual’s worldview (Sibley, 1995).

The following chapter explores support provision literature in order to situate this study.

Chapter Two: Literature Review

Perspectives on Support Provision for People with Disabilities

Chapter Two is a literature review of some of the key approaches to support provision, including the two that are examined in this study. For many people with disabilities, assistance from other people is a significant part of daily life. The relationship between a disabled person and his or her assistant is a complex one. There are many theoretical approaches to support provision that debate the role assistants should play and how support provision relationships should function. Through a literature review of the dominant theoretical approaches, this chapter addresses the question: What are the components of a support provision relationship? The chapter also addresses the concrete implications of the approaches.

It is important to explore the theoretical approaches to support provision as these approaches directly inform models of practice by organizations and individuals. Indeed, theoretical approaches to support provision guide practice in tangible ways and often in very personal areas of a person's life. The application of these theories does not just impact the way a disabled person relates to his or her assistant on a professional level, but may also influence the way an assistant treats the body of a person with a disability.

Terms

There are a number of different terms used to describe people who provide support to disabled people, including caregiver, nurse, attendant, aide, personal assistant and Independent Living Attendant. Chapter Two uses the relatively neutral terms "assistant" and "support provider." Outside of the author's voice, the paper uses the terms common to the field in discussion. For instance, “nurse” is used in discussion of the nursing philosophy. The phrases “person with a disability” and “disabled person” are used interchangeably throughout the paper referring to the one receiving support.

There is a range of theoretical approaches to support provision, four of which are examined in this literature review. The four approaches are: Independent Living philosophy (based in the social model and the human rights approach to disability), the feminist ethic of care, L’Arche philosophy, and holistic nursing. The approaches were selected because they represent the variety of perspectives, while leaving out the more extreme ends. This research is founded on the social model; the more medically minded approaches to support provision are not relevant since they contribute to negative constructions of disability. Broad themes emerge across all of the approaches that can be considered the “components of a support provision relationship.” As emerging from the literature, the components are: understanding of independence, mutuality and type of relationship, value of the disabled person, value of the assistant, and power dynamic.

Aside from the theoretical approach, support provision is influenced by the context in which it is provided. Support provision may take place in a group home, institution, hospital, family home, or independent living situation; each environment has unique aspects that influence the way support is provided. Some of the settings have bureaucratic structures in place that inform the way assistants carry out their work. It is beyond the scope of this literature review to consider all of the implications of the various settings, but some attention is paid to context.

Understandings of Independence

How people understand independence is a key component to support provision relationships. Helgoy, Ravneberg and Solvang (2003) demonstrate “there is not only one, but a variety of ways in which disabled people [and presumably, nondisabled people,] define independence” (p.485). Helgoy et al (2003) outline three definitions of independence as interpreted from interviews with people with disabilities. The definitions they identify are also apparent in some of the theoretical approaches to support provision. In the first definition, a person is independent if he or she is “able to perform practical tasks alone or without direct help” (Helgoy et al*,* 2003, p. 473). The concrete, action-based definition is the traditional and most common understanding of independence. Decision-based independence is understood as “being able to make decisions about one’s own life, to be in charge in daily life, regardless of how this is being accomplished” (Helgoy et al, 2003, p. 473). Here the emphasis is on control over decisions and not on the ability to perform concrete actions. This definition takes larger structures into account, as there is an understanding that making decisions has societal implications; that is, being a “decision-maker” is socially desirable. The article also identifies a third view that is “characterised by a situation of powerlessness and resignation” (Helgoy et al, 2003, p. 473).

The Independent Living Movement (ILM), which in many ways has become the voice of the Disabled People’s Movement (DPM), has decision-based independence at the core of its support provision philosophy. Informed by human rights philosophy and the social model, the ILM has four main tenets:

(1) All human life is of value

(2) Anyone, whatever their impairment, is capable of exerting choices

(3) People who are disabled by society have a right to assert control over their lives

(4) Disabled people have the right to participate fully in society

(Morris, 1993, p. 17).

IL philosophy acknowledges that action-based independence is simply not feasible for some bodies, but this does not mean that these individuals should be depicted as dependent and burdensome (Morris, 1993; Shakespeare, 2000). The ILM promotes decision-based independence as a political statement, demonstrating that people with disabilities can exert control over their lives. The statement is made through advocating for direct payment schemes, which is where disabled people are given money directly from the government in order to employ their own personal assistants (Shakespeare, 2000). Shakespeare (2000) explains: “People with impairments can be independent if they are able to employ others to provide the assistance which they need in order to achieve their goals” (p.63). Direct payment schemes invert conventional power imbalances and challenge depictions of disabled people as “dependents.”

The Feminist Ethic of Care and Interdependence

Interdependence is an alternative to the understandings of independence presented in Helgoy et al’s article. It is more philosophical in nature and encompasses both action-based and decision-based independence. Interdependence refers to the idea that no one is truly independent. Feminists in particular embrace the idea of interdependence as opposed to traditional understandings of independence. The earliest form of the feminist ethic of care was a reaction to justice-based ethics; justice-based ethics are based on the notions of autonomy and independence, which feminists see as misogynist concepts. Gilligan (1982) and Noddings (1984), pioneers of the feminist ethic of care, both directly responded to Kohlberg's stages of moral development, which is an example of justice-based ethics (Kohlberg, 1981; Botes, 2000). Kohlberg's stages describe moral reasoning as a linear process (Thomas, 1997). Kohlberg's theory is applied though moral judgment interviews, where people listen to a series of dilemma stories and their responses are evaluated to determine their moral stage (Rest, 1994). In the late 1970s, the University of Minnesota developed a multiple choice test called "The Defining Issues Test (DIT)" to make the test results more consistent (Rest, 1994).

Consistently, when women are tested on Kohlberg's scale they typically do not score past the third level (out of six). Building on the earlier work of Gilligan (1982), Noddings (1984) questions Kohlberg's justice-based ethics her book *Caring: A feminine approach to ethics and moral education.* Noddings (1984) suggests that women have a different approach to ethical decision-making than men. She says, "women often define themselves as both persons and moral agents in terms of their capacity to care" and "at the foundation of moral behaviour…is feeling or sentiment" (Noddings, 1984, p.40, p. 92). Noddings argues that Kohlberg's stages place too much emphasis on autonomous (i.e. masculine) moral decision-making, and do not reflect women's reality.

As the ethic of care evolved, the notion of alternative decision-making matured into the idea of interdependence, also referred to as "dependence" (Kittay, 1999, 2002; Manning, 1992). They argue that women make ethical decisions based on the perceived impact on the people around them and not based on abstract notions of justice. The link to other people is what distinguishes interdependence from independence. Feminists argue that interdependence is a realistic depiction of life; Nicki (2002) summarizes the modern feminist understanding of interdependence:

> [C]ontrary to cheerful over-optimism, dependency and vulnerability are widespread in human life. People depend on others for a wide range of services for meeting basic needs. They are involved in intricate webs of relationships comprised of family, friends, coworkers, doctors, dentists, and all those who provide services to render smooth their day to day functioning. (p. 270).

Or, as Kittay (1999) states “dependency is inescapable in the life history of each individual” (p. 29). Interdependency includes both daily interactions and decision-making and has direct implications for the feminist approach to caregiving.

Just as the early feminist ethic of care emerged in response to traditional notions of independence, later feminists reacted to the DPM’s reinterpretation of independence. Feminists writing on care argue that the DPM should move away from the concept of independence altogether. They argue, “the DPM has adopted a pragmatic and materialist interpretation of care that is commensurate with its masculinist ethic and idealizes masculinist notions of autonomy” (Hughes, McKie, Hopkins, & Watson, 2005, p. 263). The feminists argue that refocusing independence on decision-making does not challenge the oppressive and unrealistic nature of the original concept, and in fact supports disabling mainstream assumptions about “normalcy” that contribute to disabling people (Davis, 1997).

L’Arche and Interdependence

L’Arche philosophy also embraces the idea of interdependence but, unlike both feminism and the DPM, most assistants and people with impairments in L’Arche have not historically engaged in formal political action. L’Arche does claim to be counter-cultural, so in this circumstance, “political” refers specifically to involvement in the DPM and participating/organizing public protest and advocacy. Indeed, while individuals affiliated with L’Arche may be politically active, L’Arche communities formally do not “lobby policy makers with regard to the civil rights of people with disabilities” (Angrosino, 2003, p. 938). This is a key difference from both the feminist movement and the DPM, who actively engage in politics. However, this is similar to ILRCs that “do not engage in collective advocacy” but rather focus on supports and services (CAILC, 2003).

Recently, L’Arche Canada has acknowledged the need to become more politically active in promoting the L’Arche model. This shift is most clearly seen in the Strategic Plan for the Zone (L’Arche Canada, 2003) and the Identity and Mission Process (L’Arche Canada, 2007). For instance, the plan identifies that L’Arche must “Extend the vision in society” (L’Arche Canada, 2003). Aside from this recent development, the unique philosophy in L’Arche communities can generally be seen as “counter-cultural” to traditional group homes as well as to the DPM rather than “political.” In a study of L’Arche philosophy, Angrosino (2003) notes “L’Arche prefers not to immerse itself in the prevailing political culture but rather to stand apart” (p. 938). L’Arche counter-culturalism can be considered a grassroots, “lived” advocacy rather than formal political protest.

Many assistants and core members reflect the counter-cultural aspect of L’Arche by embracing, and even publicly promoting, the alternative lifestyle and values associated with living in a L’Arche community. The most apparent counter-cultural value of L’Arche communities is the rejection of the idea that “independence” is the ultimate goal for people with disabilities is. Cushing (2003) explains:

> Mainstream policy and agencies rank maximizing personal independence as a key priority in rehabilitation for people with intellectual disabilities. …

> [L'Arche communities] believe that autonomy is possible in an interdependent or community setting. (p.146).

Since the notion of independence is so integral to the ILM, the feminist/L'Arche notion of interdependence is at odds with the ILM. However, where the feminist literature engages in debate with the ILM, L'Arche takes a more subtle counter-cultural stand by presenting its philosophy without directly referencing IL literature.

Aside from politics, L'Arche propagates a model of interdependence that is remarkably similar to the feminist understanding. Jean Vanier, the founder of L'Arche and the primary articulator of L'Arche philosophy, comments, "Each one of us needs to feel appreciated and understood; we all need help" (1998, p. 37). People need each other for a variety of reasons and that the need to belong is fundamental to the human experience (Mosteller, 1996; Vanier, 1998). In the context of L'Arche, the concept of interdependency is counter-cultural and primarily used to explain the human condition. L'Arche literature directly comments that interdependency is difficult to achieve (Mosteller, 1996). It is difficult because people have to overcome assumptions about independence and to acknowledge their dependency on others. The feminist version indirectly makes the same point by arguing that society is interdependent, but does not always function as such as seen in the lack of supports for caregivers (Kittay, 1999; 2002).

Summary and Relevance: Independence

As demonstrated by the literature, there are a variety of understandings of independence. The foundation of the ILM is decision-based independence. Feminists on the other hand posit the alternative notion of interdependence. They argue that the traditional notion of independence, and even the IL's reinterpretation of independence, reinforces disabling cultural norms. L'Arche communities also demonstrate the counter-cultural notion of interdependence, which in L'Arche literature must be carefully balanced with individual desires to be "in control" (i.e. independent). Building on Titchkosky (2003), the way independence is understood has direct implications for support provision interactions. For instance, if a support provider understands independence in terms of action, he or she may emphasize rehabilitation or physical therapy. A person's interpretation of independence is also influenced by the context; for example, if the setting is an intentional community, a person may be more likely think and act from the notion of interdependency. This research explores the ways in which the mandates shape the participants' understandings of independence.

Relationship and Mutuality

A second component of support provision relationships is the type of relationship promoted. Bogdan and Taylor (1992) have shown that close relationships between disabled and non-disabled people in non-institutionalized settings serve to humanize (vs. dehumanize) people with disabilities. Similarly, Piercy (2000) conducted a study of home health aides and older clients. Piercy (2000) concludes:

> The results of this study show that when close relationships, particularly friendships, are formed between client and aide, status and power differentials are reduced, clients are satisfied with the work performed, and aides feel valued as persons. Family-like relationships also can be empowering to both clients and aides provided that boundaries that are set and maintained are mutually agreeable to both parties. (p.383).

A key component to close relationships is the notion of mutuality (Bogdan & Taylor, 1992). Cushing (2003) defines mutuality:

> Mutuality is a condition of mutual respect, understanding and support that can be cultivated between two people in a relationship. By definition mutual relations are fruitful or growthful for both people. Mutuality can arise in a normal relationship between friends or family, but can also be developed in relations with instrumental or political dimensions, such as those between caregivers and their charges although these present more layers of complexity.

Thus, mutuality is a form of reciprocity that acknowledges that people can be "repaid" in alternative ways (SteinhoffSmith, 1999). This does not mean applying value to activities and "reducing them to their exchange values" but rather recognizing what others have to offer in more abstract terms (SteinhoffSmith, 1999, p. 23). In practice, Marouis and Jackson (2000) note that "relationships between service users and workers lie on a continuum, with mutually supportive relationships between service users and workers at one end, and physical and psychological abuse at the other" (p.411). Some of the perspectives of support provision place great emphasis on mutuality and personal relationships, while others grapple with how relationships should function in a professional setting.

The Independent Living Movement and Relationship

Since the Independent Living Movement advocates for direct payment schemes, relationships take on a distinctly professional tone. In direct payment schemes, "The relationship becomes a business arrangement between the disabled person, who is the employer, and the assistant who is the employee" (Watson, Hughes, Hopkins & Gregory*,* 2004, p. 337). Any emotional aspects are removed as the support environment is also the work environment. Even though support can be very personal, the assistant is required to act in a professional and detached way. Shakespeare, Gillespie-Sells, and Davis (1996) argue that assistants "have a responsibility to ensure that assistance is exactly that, assistance, and that no judgments are made about the nature of the assistance required" (p. 38). This logic attempts to legitimate support provision in economic terms and to ensure that the disabled person has absolute control over his or her body.

The social model has often proven to be a more extreme philosophy in theory than how it is in practice (Shakespeare & Watson, 2002). On the issue of professional relationships with assistants, "there is already some evidence that disabled people and their assistants do not experience personal assistance in purely contractual, unemotional and instrumental terms" (Watson et al*,* 2004, p. 338). In a study of 31 relationships between Japanese consumers and their support providers and Independent Living philosophy, Yamaki & Yamazaki (2004) found

> Participants expressed a desire to develop close relationships with their assistants and, in fact, many felt close to them. At the same time, however, they demonstrated a strong concern with maintaining a certain distance from their assistants and took precautions against becoming overly involved. (p. 38).

Yamaki and Yamazaki's (2004) study demonstrates how consumers and support providers grapple with an inclination to form close relationships versus the professional relationships advocated in IL philosophy. The detached and unemotional relationship advocated in the ILM literature is not always what occurs in daily life. Indeed, the Personal Attendant Community Education (PACE) program includes teaching about the relational aspect of support provision (ILRC Winnipeg, n.d.). This indicates that the more extreme interpretations of Independent Living philosophy do not always trickle down to the front lines of support provision, where relationships manifest in a much more complicated way.

The ILM and the feminist ethic of care conflict in their expectations about professional relationships. Hughes et al (2005) explain:

> In developing a masculinist approach to care, the DPM seeks to promote autonomy for disabled people but eliminates emotion from the caring process by transforming it into a formal, contractual, exchange relationship. These obvious concessions to the male imaginary are problematic. (p. 271).

Feminists argue that like the use of the term independence, the emphasis on contractual relationships does not challenge systemic oppression. In fact, in the case of direct payments, many feminists feel that this scheme propagates discrimination against female support workers. On the other hand, the ILM feels the feminist ethic of care has a "tendency…to idealise the caring role and to develop an almost essentialist idea of women as carers" (Shakespeare, 2000, p. 73). The feminists see the ILM as perpetuating value-laden language while the ILM writers see the feminists as romanticizing personal care.

Mutuality and Relationship in L'Arche and the Feminist Ethic of Care

The feminist ethic of care posits that all humans are interconnected and our primary goal is to engage in caring relationships (Manning, 1992). It is argued: "the act of providing care, especially if repeated routinely over time, in fact *creates* relationships" (Watson et al, 2004, p. 333, italics in original). The focus on personal relationship resonates with L'Arche philosophy. Within caring relationships, traditional understandings of exchange fall short, resulting in the expression of mutuality. Feminists believe mutuality must extend beyond "conventional understandings of relationships between equals within liberalism," to include the idea that exchange can take place in intangible ways (Kittay, 2002, p. 261). In Kittay's (2002) work, she refers to her disabled daughter as an example. She explains that with a glance and a smile, her daughter offers more to her dependency workers than if she could physically return the actions that they do for her (Kittay, 2002). Thus, in the feminist ethic of care, close relationships are the foundation of care work and these relationships are mutually beneficial.

The idea of mutuality as an alternative to direct exchange is very similar in L'Arche literature. Mutuality and personal relationships are central components to L'Arche philosophy and practice. Cushing and Lewis define mutuality as “a daily attitude or ongoing mode of relating to all people” (2002, p. 179). It is assumed that every person has something to offer, and that tangible and intangible exchanges take place in personal relationships on a daily basis. Mutuality has significant implications for the valorization of people with disabilities, whose ability to contribute to relationships is often underestimated (Wolfensberger, 2000). Cushing and Lewis comment: “[it is difficult to] unlearn normative beliefs and stereotypes surrounding people with developmental disabilities as ‘passive recipients of care' (2002, p. 182). Close relationships are encouraged in L'Arche, and this is an element that sets it apart from traditional group homes, where employees are often requested to draw clear boundaries between employee and “client.” Vanier (1998) insists that living together and engaging in personal relationships are fundamental aspects of L'Arche communities. It is understood that forming personal relationships is the key to providing high quality care that will benefit both the core member and the assistant (Cushing & Lewis, 2002, p.174). Indeed, Bogdan and Taylor (1992) have identified mutuality as a key element of close relationships which can be beneficial for people with disabilities. Thus, in L'Arche philosophy and in the feminist literature, mutuality, relationship, and care are inextricably linked.

Individual Pathology, the Biopsychosocial Model and Relationship

In the field of disability studies, the “medical model” or “individual pathology” is depicted as an outdated and damaging approach to disability (Oliver, 1990). This model situates disability within the individual. Some of the characteristics of this approach are: defining disability in opposition to a non-disabled “norm,” a focus on prevention and “fixing” disabilities, and an overall view of disability as a social burden (Rioux, 1997). Individual pathology underpins mainstream assumptions as well as the majority of academic research. In terms of support provision, an individual approach leads to rehabilitation and segregation. Or, in more extreme examples, the individual approach underlies both historic and modern eugenics. More subtle elements of this approach exist in the biopsychosocial approach (as embodied in holistic nursing).

The biopsychosocial approach is the nursing field’s attempt to move away “from the male dominated, reductionist, disease oriented medical approach” (Wynne, Brand, & Smith, 1997, p. 471). Similar to the social model, this approach acknowledges that there are a variety of influences that impact a person’s health and well-being. Also known as “holistic nursing,” it is based on an “acceptance that health is determined and defined by interrelated social, psychological and biological factors” (Wynne et al, 1997, p. 471). Unlike the social model, the biopsychosocial model includes consideration for the daily experience of illness, injury and disability. Earle (2001) explains, “in this approach, the lived subjective experience of health and illness are deliberately blurred with more objective pathologies of the patient” (p. 434). Unfortunately, there is no clear definition or primary literature source on the biopsychosocial model, and this impacts the way the model is (or is not) put into practice (Imrie, 2004b). The move towards holistic nursing echoes many of the sentiments of the feminist ethic of care (e.g. emphasis on feeling, rejection of traditional interpretations of care, etc.).

Moving towards a more holistic approach has opened a debate about how nurses should relate to their patients. There is no question that relationships with patients are central to nursing (May, 1991; Ramos, 1992). Nurses occupy a "low-status" role, and there is an effort for nurses to valorize their role by relating to their patients in a "professional" manner (Shakespeare, 2000). When nurses attempt to be professional they often end up focusing on the instrumental elements of care, that is, physical concerns such as administering medication (Woodward, 1997). Professionalism in this sense conflicts with the expressive elements of care, which are emphasized in the holistic model. The expressive elements of care include the emotional aspects of nursing such as concern for the patient and interpersonal connections (Woodward, 1997). The literature grapples with this tension: "The modern idea of the nurse-patient relationship, as one of closeness and commitment could be just as dangerous for both partners, as the old detached one" (Webb cited in Sourial, 1997, p. 1190). The holistic nursing model supports the concept of a more personal relationship, but breaking the habits of medical professionalism is difficult for many nurses. A second example of grappling can be seen in the following quote: "While self-interest is not a legitimate consideration, caring none-the-less provides mutual benefit to carer and cared-for alike and some consider reciprocity a vital element within caring relationships" (Woodward, 1997, p.1000). There is an implication that reciprocity is an illegitimate aspect of nursing because it is not professional in the traditional, medical sense.

Just as the nursing literature grapples with the issue of professionalism, so do practicing nurses. In Ramos’ (1992) research it is demonstrated that nurses relate to patients on three levels: task-oriented, a combination of practical and emotional, and a reciprocal level. The nurses interviewed had experiences at all levels, and there is a sense that there are unique relationships in a nursing setting, the primary goal of which is therapeutic. One significant finding is that the nurses feel that emotional distancing, or professionalism, is essential for delivering good care (Ramos, 1992). This is in sharp contrast to the L’Arche and the feminist literature that argues that close relationships result in better support provision. Ramos’ research also has implications for the other components of support provision relationships, and is discussed later on.

Summary and Relevance: Relationship and Mutuality

Throughout the different perspectives on support provision, the emphasis on mutuality and relationships varies. Professional-contractual relationships are promoted in IL literature, but closer relationships may exist in reality. Like the social model, the IL literature is more extreme in theory than in reality (Shakespeare & Watson, 2002). Feminists and L’Arche are at odds with the ILM as they both promote close relationships based on mutuality. The nursing literature grapples with whether nurses should be distant and professional, or engage with their patients on a more personal level. As basic human geography suggests (Anderson et al, 2003; Duncan et al, 2004), nurse/patient relationships are greatly influenced by the setting in which they take place. Theoretical representations may or may not influence the way people relate, as relationships could be more connected to personality. However, context does play a role in shaping relationships as some support provision environments will encourage and reward certain ways of relating. How "relationship" is understood is an integral component of support provision interactions; this research examines the role of the mandate in shaping the relationship between a disabled person and his/her support provider.

Value of the Disabled Person

The value attributed to the person receiving support varies across the literature on support provision. This area is particularly important since people with disabilities are a traditionally silenced group. Overall policy and the media have depicted people with disabilities as child-like "dependents," especially in relation to support provision (Finkelstein, 1981; Shakespeare, 2000). The depiction of dependency is much more damaging than the notion inter/dependency embraced by feminists and L'Arche.

The ILM and the Value of the Consumer

Challenging conventional depictions of people with disabilities as dependents is why "Control over the personal assistance that is required to go about daily life is crucial" (Morris, 1993, p. 23). As explained in social role valorization theory, direct payment schemes create new, empowered roles for people with disabilities (Wolfensberger, 2000). The consumer occupies the new role of the citizen; Hugman (1991) explains, "The concept of the citizen is of someone who is not only the actual or potential user of professional services, but who is also involved democratically in the control of those services" (p. 43-44). In advocating for direct payment schemes, the ILM represents people with disabilities as citizens in support provision relationships. In practice, people with disabilities demonstrate higher satisfaction with consumer-directed services over traditional services (Askheim, 1999; Beatty, Richmond, Tepper, & DeJong, 1998). The consumers are given a voice and control over their services, ensuring that “The disabled person is an active participant in the relationship” (Watson et al, 2004, p.336). Since the concept of the citizen is founded on human rights theory, it has political implications for many areas outside support provision. In sum, people with disabilities are highly valued in IL literature.

The Role of the Cared-for in the Feminist Ethic of Care

As discussed earlier, close relationships are central in the feminist ethic of care. Within these relationships, it is recognized that “the cared-for plays a vital role” (Noddings, 1984, p. 73). Yet, in spite of the emphasis on relationship and interdependence, the cared-for is largely missing from the feminist literature. Early in the development of the ethic of care, feminists wrote primarily about children and parenting. As the writing evolved, the depiction of the cared-for as dependents who cannot speak for themselves continued. The early definition of care reflects this positioning on the cared-for: “to care may mean to be charged with the protection, welfare, or maintenance of something or someone” (Noddings, 1984, p. 9). Indeed, this understanding of care extends to the modern ethic of care. In the modern ethic of care, women’s innate capacity to care is described as: “intuitions [that] prioritize the needs of the dependent over the needs of the dependency worker” (Kittay, 1999, p. 52). This paints not a paternalistic picture of care work, but what can be called a “maternalistic” picture. The care provider is expected to make decisions and choices based on what is believed to be in the “best interest” of the cared-for.

Manning (1992) discusses the issue of knowing how and when to care, and she feels the answer is rooted in the recognition of suffering. Linking support provision to suffering furthers the stereotype that disabled people are sick and pitiful. Indeed, both the early feminist ethic of care and the modern version depict the cared-for as a dependent incapable of making decisions and suffering as a result of his or her “condition.” The cared-for is depicted in stereotypical ways and the ILM criticizes the feminist ethic of care for this portrayal (Morris, 1993; Shakespeare, 2000).

Core Members in L’Arche Communities

L’Arche considers people with intellectual disabilities to be the focal point of the communities, referring to them as “core members” (Nouwen, 2000, p. 40). The homes, programs, and communities all gravitate around the core members. On the value of the core members, the Charter of L’Arche says:

> The aim of L'Arche is to create communities which welcome people with a mental handicap [sic]. In this way, L'Arche seeks to respond to the distress of those who are too often rejected, and to give them a valid place in society. (L’Arche Canada, 1993).

L’Arche is a Christian organization although those of other religions and those who do not follow a religion are welcome to live in L’Arche communities. The central positioning of the core members is philosophically based in the beatitudes found in two of the Biblical gospels. They proclaim ideas such as “Blessed are the peacemakers, for they will be called the children of God,” and “Blessed are you who weep now, for you will laugh” (*NRSV,* Matt. 5:9, Luke 6:21). The beatitudes honour and hold up those who are considered “lesser” by the majority of society.

The beatitudes are interpreted and expanded upon in a handout from the L’Arche Daybreak community in Richmond Hill, Ontario. It says, “the fundamental basis of L’Arche spirituality…[is that the] poor are prophetic, calling us to compassion” (L’Arche Daybreak, 2003). Basically, close relationships with the marginalized of society can be a fulfilling experience for both people involved. Within the communities, the core members are thought to "possess qualities of welcome, wonderment, spontaneity, and directness….they are a living reminder to the wider world of the essential values of the heart" (L'Arche Canada, 1993). The spirituality and philosophy emerges from relationships with the core members, thus implying that core members are highly valued as unique individuals in L'Arche communities.

What are the implications of representing people with intellectual disabilities not as equals, but as sites of spiritual inspiration? Cushing (2003) further explains the role of core members in L'Arche philosophy:

> [The philosophy does] not intended to idealize disability or portray people as holy innocents: … people operating directly from the heart can be as angry and violent as they are kind. It is the *less mediated* quality of their spiritual yearnings that makes them seem more authentic to others. (p. 146).

Even with this qualification, people with intellectual disabilities are considered "*more* authentic" which still raises the core members above the assistants (Cushing, 2003, p. 146). Over-valorization of people with disabilities can contribute to generalizations about this group, albeit more positive generalizations than what currently exist in the mainstream. Although the almost reverential status of core members in L'Arche communities does contribute to high social status, this status is contained to the communities. In addition, there is an exclusionary aspect to this valorization as learned through L'Arche history. Only people with intellectual impairments live in L'Arche communities, and even some of these people are not welcome, primarily those with violent tendencies (Cushing, 2003; Vanier, 1995). This criteria is understandable as L'Arche has a legal obligation to protect safety and well-being of the core members and assistants who live in its communities. L'Arche's unique philosophy does serve to valorize people with disabilities, but in a limited way.

Holistic Nursing and the Role of the Patient

The theoretical biopsychosocial model places the patient central in nursing. Holistic nursing aims to attend to all elements of a patient's health, and is done so through individualized patient care (May, 1991). As nursing moves towards a more holistic model of practice, the role of the patient is being redefined (Davies, Laker, & Ellis, 1997). Traditionally, the patient has occupied a passive role; unfortunately, it is difficult to change this role as seen in another current nursing topic. In a review of literature on non-compliance, Playle and Keeley (1997) question why the topic of non-compliance is so popular in the nursing literature. They find that "Non-compliant behaviour is seen as problematic, because it contravenes professional beliefs, norms, and expectations regarding the 'proper' roles of patients and professionals" (1997, p. 304). These traditional roles include the assumption that the patient will do what the "expert" recommends and the idea that the patient is ignorant and not to be trusted (Playle & Keeley, 1997). In addition, as seen in studies of day-to-day interactions between nurses and patients, nurses reinforce passive roles by continuing to exert considerable control over patients (Hewison, 1995; Ramos, 1992). The traditional role of the patient is largely maintained in practice. Indeed, Waterworth and Luker's research suggests that even when trying to challenge traditional roles by involving patients in medical decision-making, it is found "that some patients are more concerned about 'doing what is right' and about pleasing the nurse than about participating in decisions concerning care" (cited in Davies, Laker & Ellis, 1997, p. 412). Thus, even though the biopsychosocial model presents an alternative role for the patient, the literature has not shown it to manifest in nursing practice.

Summary and Relevance: Value of the Disabled Person

The value and role of the person receiving supports fluctuates across the theoretical perspectives to support provision. The ILM challenges conventional depictions of people with disabilities by asserting the new role of the citizen; that is, a person who contributes to and controls the services he or she utilizes. The feminist literature claims the cared-for is central, but the disabled voice is largely missing. People with developmental disabilities are central in L'Arche philosophy; in fact, they may be over-valorized in these communities. In holistic nursing, a new patient role is theorized but rarely manifests in practice. As the social model argues, societal understandings of people with disabilities are a disabling factor. The context and the theoretical value of people with disabilities impacts they way they are treated and see themselves. For instance, if the disabled person is depicted and behaves as an "employer" then the support provider will likely follow his/her instructions without argument. However, if the person with a disability is depicted and behaves as a suffering patient, the support provider may be more likely to be condescending and make decisions on the patient's behalf. Chapter Six: Discussion looks at the role of the person with a disability within support provision interactions.

Value of Person Providing Support

Another component of support provision relationships is the value attributed to the support provider. The literature is conflicted about whether support providers occupy a vulnerable or powerful role. The reality is they occupy both, and must grapple with the tension between the two roles. The following analysis examines how support providers are represented in the various theoretical approaches to care.

The Role of the Personal Assistant in the Independent Living Movement

The ILM’s proposal for direct payment schemes raises concern about the protection of personal assistants. In many systems, the assistants are employed directly, and there are no bureaucratic systems in place to protect their rights. Indeed, Hughes et al (2005) note: “despite its significance as an emancipatory mechanism, the system of direct payments reverses rather than abrogates the master/slave relation” (p. 263). In Britain “Legally, personal assistants employed to work in the home are classed as ‘domestic servants’ and as such are excluded from the limits on working hours” (Shakespeare, 2000, p. 68). Watson et al (2004) agree that the direct payment scheme has a high potential to exploit the assistant (p. 338). It should be noted that the risk for assistant exploitation is dependent on the context and degree of regulation in the system. Ungerson (2004) evaluated the empowerment and independence of care-workers and disabled people in ‘cash for care schemes’ across five European countries. She found “the outcomes of cash-for-care systems vary considerably,” that is, in some cases the social rights of the assistants were not respected (Ungerson, 2004, p. 210). This risk flows both ways as in some contexts the consumer was not empowered by the system.

Assistants are vulnerable to exploitation partially because they are largely untrained. Shakespeare (2000) notes that disabled people in the UK actually prefer and seek out untrained staff. The reasoning behind this is that “trained experts” often provide support based on textbook methods. In reality, these methods may not work for certain disabilities, and overall, the consumer wants to train his or her assistant. This logic that leads to more extreme statements such as: “we feel that the less experience they have the better…we know what needs doing they don't need to know, they just need to be told" (Interview, cited in Morris, 1993, p. 33).

While the ILM attempts to create an emancipatory system where the consumer has total control, it may do so at the expense of the personal assistant. In theory, the assistant is essentially a servant and must follow directions without questioning. The implications of the ILM's positioning on personal assistance can be seen in the example of facilitated sexuality. Facilitated sexuality is a controversial and very personal area of support provision. Facilitated sexuality includes helping a consumer prepare for, engage in, or arrange for sexual activity; assistance with masturbation; and assistance finding information on topics related to sexuality and sexual health (Earle, 1999). Earle (1999) did a small study that showed that overall participants with disabilities defined sexuality as a "need" whereas personal assistants defined it as a "want." This is significant because some personal assistants are uncomfortable facilitating sexuality. The rift has implications for provision of care, as the disabled students in Earle's study felt their needs were not being met, while assistants felt this area was beyond the requirements of their job (1999). This issue raises the question, whose rights and comfort levels should "count" more, the personal assistant or the consumer? Earle (1999) concludes that personal assistants must facilitate sexuality as part of their job, but does concede:

> [T]he moral and emotional rights of those providing assistance must also be considered. It goes without saying that personal assistants should not have to facilitate sex unwillingly, to expect them to do so is a disservice to the disabled person and places an unacceptable moral obligation on the personal assistant. (p. 320).

Even with this concession, it is clear that within support provision relationships as outlined in the ILM, the consumer takes priority, even at the expense of the worker.

Shakespeare (2000) notes “It would be deeply unfortunate if the liberation of disabled people from dependency contributed to the exploitation of another disempowered section of the population” and yet he, nor Earle, offer any solutions to this issue (p. 68).

Feminist Ethic of Care: Central Positioning of Dependency Workers

The position of the carer is particularly significant for feminists since it is largely agreed upon that women make up the majority of care-providers (Kittay, 1999, 2002; Noddings, 1984). In addition, caring as a line of work is associated with a number of negative assumptions and stereotypes. Hugman (1991) summarizes the generalizations about caring: “Caring for is seen as less expert, it is women’s work, it is work done by black people, it is work which ‘anybody could do’ (but which not everybody does or wants to)” (p. 12). In light of the feminization of care and the negative associations with it, many feminist writers feel that care providers are vulnerable to exploitation (Kittay, 1999, 2002). Morris (1993) notes that some feminists have taken this to extreme, particularly those who suggest that disabled people in informal caring situations should be relocated to residential care in order to relieve the carers.

There are also less extreme interpretations of this approach, such as the work of Ungerson. Ungerson writes about the blurred line between formal and informal care, and the precarious balance between the role of the support provider and the person receiving care, particularly on the backdrop of the increasing implementation of ‘cash for care’ schemes (1997, 1999, 2004). She concludes that exploitation of the worker is not inevitable, but is highly dependent on the context and degree of regulation of the schemes (Ungerson, 2004). Thus, the mechanisms of cash for care schemes and respite systems should be considered very carefully (Ungerson, 2004).

Feminist attempts to improve the status of female caregivers have evolved into two streams. The first is the theoretical notion of *doulia* and the second is embodied in the Carers' Movement in the UK. *Doulia* is a principle of natural diversity developed by Kittay (2002); it is an attempt to validate the work of caregivers. Kittay (2002) defines *doulia* as a concept "by which the larger society supports those who care for the 'inevitably dependent'…a principle of justice that embraces those excluded by the contractual model of reciprocation" (p. 270). Kittay subverts systematic oppression by developing a unique perspective that advocates for paying carers well, and valuing their societal role. Kittay's work echoes Wolfensberger's (2000) social role valorization, although her work remains largely theoretical at this point.

Parallel to Kittay's theoretical work is the Carers' Movement. The Carers' Movement seeks to improve the status and rights of "informal carers" (i.e. unpaid, support providers, often female relatives or friends). The Association of Carers in the UK focuses their efforts on lobbying for respite services (Briggs & Oliver, 1985; Heron, 1998). Instead of advocating to pay informal carers like some feminists suggest, the Carers' Movement places emphasis on temporary "relief" services (Briggs & Oliver, 1985). The ILM criticizes the Carers' Movement since it depicts disabled family members as 'burdens." In addition, some disability activists argue emphasizing the rights of informal carers overshadows the rights of disabled people (Morris, 1993). In an interview, a person with a disability said, "to my mind, the more you increase the rights of carers, the more you take them away from disabled people" (Shakespeare, 2000, p. 40). It is assumed that rights are promoted/infringed in a zero-sum way. There is no real evidence for this logic, but this type of criticism against the Carers' Movement is common.

Assistants in L'Arche Communities

In L'Arche practice and philosophy, it is understood that both assistants and core members benefit from engaging in close, personal, relationships of mutuality. L'Arche is an environment where core members and assistants alike thrive and grow. Angrosino (2003) explains: "The home is not a place where 'abled' assistance take care of the 'disabled' and are paid for doing so; it is a place where the special dignity and spiritual gifts of each resident are recognized and celebrated" (p. 937). L'Arche communities actively create supportive and comfortable environments; many former and current assistants indicate that the L'Arche environment is transformative (L'Arche Canada, 2005; Mosteller, 1996; Nouwen, 2000). A 2005 L'Arche publication says,

> L'Arche invests much in the assistants and friends who help provide support to people with developmental disabilities in its homes and day settings. It does so because the quality of life of the people with developmental disabilities is directly affected by the way caregivers think and relate and view the world. … L'Arche encourages caregivers to take responsibility for their personal growth. (L'Arche, p. 14).

In practice, L'Arche "takes care" of assistants by providing workshops, training, opportunities for counseling, and a flexibility and openness in terms of requests to move houses or time off. Cushing (2003) discusses how prevention of assistant burnout was incorporated into the basic tenets of L'Arche:

> L'Arche learned early on that this holistic, relationship-based caregiving lifestyle is only sustainable if the caregivers are physically and emotionally healthy. This requires a special system of supports for them. … This led to implementation of supports like extended vacation periods away from community, spiritual guidance, and medical resources. (p. 139).

> Conversely, in conventional employment terms L'Arche does not treat its employees well. Primarily, assistants are required to devote themselves to L'Arche by moving in and working long hours. Aside from the physical strain, assistants are not paid well relative to the salary offered by other support provision agencies. In addition, many communities have rules that infringe on personal decision-making, such as "no overnight guests."

Assistants are aware of the "working conditions" before they move in, and new assistants are encouraged to think of L'Arche as a lifestyle choice rather than as a job. As mentioned before, most assistants speak positively of their experience living at L'Arche. If the assistants are not concerned with material working conditions, than L'Arche is a nurturing environment. In this case, valuing the support providers does not come at the expense of the core members, as they remain highly valued.

Nurses in the Biopsychosocial Model

Holistic nursing emphasizes the multiple factors that influence a patient's health; the model also implies that nurses have a role to identify and attend to these factors. In the literature, there is a sense that the nurses' role is to confirm that "patients are more than discrete parts, deviant genes or disease labels" (Newell, 2000, p. 234). In the biopsychosocial model, the nurse is responsible for labeling, identifying and caring for the multiple components that influence a patient's health (Cribb, Bignold & Ball, 1994). The patient is there to provide background information, but it is the nurse who is largely in control of the interactions and decisions. In Ramos' study (1992) of nurse-patient relationships, "The nurses described feeling responsible for controlling the direct and temper of the bond" (p. 500). May (1991) had similar findings, and noted that the nurses felt responsible to control interactions, and also felt this control is important for administering good care. Control over interactions spills over into judgements about decision-making. The nurses in

Ramos’ study determined “how many and what kind of decisions [can] be delegated safely to the patients” (1992, p. 500). It should be noted that much of the literature in the nursing field is aimed at nurses working in hospitals, where disabilities are often illness-related and/or temporary. This setting is very different from a group home, and yet the implications of the model are still pertinent. The biopsychosocial model is theoretically grounded in a way that allows nurses to maintain control over interactions with patients. The nurse retains his or her traditional “professional role” and truly holistic caring does not occur.

Summary and Relevance: Role of the Support Provider

The literature on support provision is conflicted about the role of the support provider. The IL direct payment schemes may empower the consumer at the expense of the support provider; however the degree of oppression is influenced by the context (i.e. how regulated the arrangement is) and by the approach of the individuals involved in the relationship. As many carers are women, the feminists focus on valuing support providers through the concept of *doulia* and the Carers’ Movement. On the backdrop of demanding working conditions, L’Arche philosophy attempts to promote a nurturing environment for the assistants. In holistic nursing, the nurses are responsible for identifying the various factors that contribute to a person’s health and well-being. The role of “identifier” gives the nurses power and results in maintaining the traditional nurse role. Supporting human geography (Sibley, 1995) and Titchkosky (2003), the context and representation of support providers impacts the way they are treated and the way they view themselves. For instance, in a L’Arche setting support providers are valorized; L’Arche assistants are likely to think highly of their work and the core members are likely to treat the assistants with respect. The ways in which mandates shape the roles of support providers is examined in this research.

Power

Another component of support provision relationships is the balance of power. Historically the relationship between helper and helped has been characterized by an “asymmetrical power relationship favouring the professions” (Helgoy et al, 2003, p. 476). However, the literature is beginning to recognize that power relationships are not fixed. The scales of power can tip or balance. In addition, there are many external factors that can influence a power dynamic, including specific procedures required by an organization. This dynamic is identified below in each of the areas of interest.

Decision-making Power in the ILM

In Independent Living philosophy it is recognized that all power and control has traditionally been in the hands of professionals. The ILM literature is largely concerned with the potential for assistants to abuse their power at the expense of people with disabilities (Shakespeare, 2000). However, the literature does not acknowledge the potential for disabled people to commit power abuse. The ILM literature focuses on the fact that support providers have a tendency to “take charge” of the disabled person (Morris, 1993). Indeed, ”taking charge” can be seen in the feminist ethic of care and nursing. French (1994a) argues, “To be truly effective, health and welfare professionals must relinquish their power and control and work closely with disabled people under their direction” (p. 111). Thus, the push in the ILM is not for a power balance, but a role reversal (Helgoy et al*,* 2003).

The power philosophy is most clearly apparent in the direct payment plan. The ILM’s direct payment scheme “effectively reverses the balance of power between ‘carer’ and ‘cared-for’ to the extent that this terminology becomes redundant. … there is little doubt that this system works for disabled people.” (Hughes et al, 2005, p. 263). The IL philosophy advocates for the consumers to have all the power, as such the assistant is represented as a servant whose actions must be entirely based on the instructions of the disabled person.

Feminist Ethic of Care and Power

The ethic of care challenges many traditional assumptions, including notions of independence and justice; however, the ethic of care does not challenge the conventional power imbalance that exists within care relationships. A feminist definition of care is a good example: “To care, we feel, requires some action on behalf of the cared-for” (Noddings, 1984, p. 10). There is a sense that the carer uses her own judgment to make decisions and then acts on behalf of the cared-for (Kittay, 1999). This aspect of the ethic of care has been picked up and criticized by the ILM. Morris (1993) notes: “Caring *about* someone does not bestow the right to make choices for them, to curtail their autonomy” (p. 152). The ILM feels the feminist ethic of care allows carers to occupy traditional power-rich roles and silences the voice of the cared-for.

Depicting the carer as “in control” carries into the informal Carers’ Movement, where it is amplified. In the Carers’ Movement, carers are not only identified as being in power positions, but it is implied that they *should* be in these positions. For example, Briggs and Oliver’s book (1985) features carers sharing their personal experiences. In this book, “There is a frequent complaint from carers that their right to relief is in the hands of the dependent" (p.107). When a carer is in need of rest from caring work, the cared-for must give consent to enter into temporary hospitals. The Carers' Movement sees this as a problem as often the cared-for does not give consent. The power is largely in the hands of the carer, and when the balance shifts, it leaves the carers feeling like they lack control. In this situation, the carers are frustrated because they legally do not have the power to make decisions on behalf of the cared-for that would relieve their own burnout. Since it is presented as a problem in the Carers' Movement it implies that the carer should be able to make the decisions.

The ILM criticizes the Carers' Movement heavily on the issue of power. Morris (1993) points out, "using friends or relatives as unpaid carers means that the disabled person is unlikely to be able to play an equal role in personal relationships or to participate fully in society" (p. 27). Indeed, the power relationship becomes very complex when the carer and cared-for are intimately related.

In later feminist writing on the ethic of care, the issue of power is addressed. Kittay (1999) says, "The inequality of power is endemic to dependency relations. But not every such inequality amounts to domination" (p. 34). Kittay recognizes that power is a complex and fluctuating notion. She points out that power can flow back and forth, and in some circumstances "the charge [the person with a disability] can exert a certain tyranny" over the dependency worker (Kittay, 1999, p. 34). She argues that with the right philosophy and principles of justice, a relative power balance can be achieved and maintained.

L’Arche: Power Negotiation

In L’Arche literature, it is recognized that power imbalances are inherent to support provision relationships; however, there is also a sense that these imbalances can be challenged and with conscientious effort, balanced out. The literature makes strong references to “negotiating” or “struggling” to balance power in core member/assistant relationships. Part of the struggle stems from living in community. According to Mosteller (1996), the key challenge of living in community is having to give up aspects of individual control. The idea of letting go of control/power in exchange for cooperation is a common theme in L’Arche literature (L’Arche Canada, 2005; Pottie & Sumarah, 2004). The difficulty “letting go” is also apparent in Cushing and Lewis’ examination of relationships between core members and assistants (2002). They find that “both caregiver and care receiver learn to negotiate the ambiguity of having power-related interactions while also trying to be friends” (2002, p.177). Indeed, Pottie and Sumarah’s (2004) L’Arche study of friendships between people with developmental disabilities and people without found that having a sensitivity to power relations is essential to real friendships. Consistently, throughout the L’Arche literature, there is a clear sense that “negotiating ‘power with’ instead of ‘power over’ [is] difficult and tentative” (Cushing & Lewis, 2002, p.186).

Holistic Nursing and Power

The issue of power is particularly important in the field of nursing because “disabled people have begun to view professionals as part of their experience of oppression” (Goodall cited in Northway, 1997, p. 737). There are two main issues around the power held by nursing: the first is the potential for nurses to abuse their power and the second is the systematic power inequality nurses face. Hugman (1991) identifies two main forms of professional power: material power (control over daily life) and ideological power. This is a similar distinction made by the biopsychosocial model that identifies two forms of caring: practical and emotive. By fleshing out ideas of power and caring, the biopsychosocial model creates a complex yet concrete understanding of power and power abuse. Power abuse means not only obvious violence and abuse, but also “the everyday practices of a well intentioned, liberal society” (Young cited in Northway, 1997, p. 738). The subtle understanding of power explains why many nurses and professionals are unaware that they are exercising power (Hugman, 1991). Hewison (1995) observed nurses and patients in a small hospital for the elderly; this study sought to analyze power interactions as mediated through language. In Hewison’s data, “It was found that nurses exert a lot of control over interactions” and this power occurred on multiple levels in various forms (1995, p. 75). One of the more interesting and subtle forms that Hewison identifies is the use of “terms of endearment” (1995). Nurses may feel they are acting out of altruism, which the literature defends is a sound motivation for becoming a nurse (Woodward, 1997). Unfortunately, Shakespeare (2000) has noted well intentioned altruism can lead to power abuses. He says, “With the motivations of sympathy and generosity, and the urge to improve difficult situations on behalf of the other, comes a tendency towards control” (Shakespeare, 2000, p. 59). Thus nurses have a difficult position to deal with. In one sense, they must demonstrate care and compassion while also avoiding the subtler, often altruistic-based, manifestations of power imbalances.

A second issue relevant to nursing practice is the relatively low role they hold in the medical hierarchy. There is often power acting upon them from overhead; they must be accountable to “higher-ups” and adhere to bureaucratic procedures. There are certain “routines and procedures” that may influence the way they behave (Helgoy et al*,* 2003, p. 477; Covington, 2005; May, 1997; Ramos, 1992). These routines may or may not require a nurse to exercise power over the patients. Referring to the nurse-like attendants in residential hospitals, French (1994b) notes “Staff who have direct contact with disabled residents are usually at the bottom of an authoritarian hierarchy where they are virtually forced to behave in the way that they do” (p. 119). French is writing from an Independent Living perspective and the above quote acknowledges the systematic structures that influence the way nurses must behave in certain settings. Thus, French’s work demonstrates that the disabled community does not reserve the application of the social model to its own constituency as it shows how the nurse’s role and responsibilities can also be socially constructed by procedures and settings.

Summary and Relevance: Power

The literature on support provision demonstrates that power relationships are not fixed and are influenced by context. In order to fulfill a political agenda, the ILM argues for a power inversion within support provision relationships, giving all the power to the person receiving support. On the other hand, feminists express a “maternalist” emphasis on alleviating the ‘suffering’ of the cared-for. The Carers’ Movement takes the issue of power one step further by promoting the decision-making authority of informal carers

The issue of power is more complex in L’Arche and nursing literature. In L’Arche power is regarded as something to “negotiate” within the support provision relationships. Holistic nursing addresses both power abuse by nurses and the power inequalities they face that are built into many nursing settings. Power is a clear example of the human geography notion that contexts influence identity and actions (Anderson et al, 2003; Duncan et al, 2004). For instance, in many hospital settings nurses are required to work within time constraints, which could lead to making decisions on behalf of the patients instead of taking the time to consult with them. Power inequality is also one of the primary disabling factors identified in the social model. This research examines how the power balance within support provision interactions are shaped by the mandate of the organization.

The following table summarizes the findings of the literature review, and proceeds the conclusion of the literature review.

Table 1: Literature Review Summary

	ILM	Feminist Ethic of Care	L'Arche	Holistic Nursing
Independence	- decision-based independence as a political means of challenging stereotypes - embodied in direct payment schemes	- political reaction against assumed autonomy and justice based morality - inter-dependency is a natural fact of life	- apolitical but counter-cultural inter-dependency that is not easy to achieve (a struggle to balance with personal control)	- no direct discussion of independence
Mutuality and Relationship	- professional and exchange based relationships - in reality, personal relationships may exist	- acknowledges alternative forms of reciprocity - caring is innate and emotion-based - day-to-day nature of care creates personal relationships	- every person has a "gift" to contribute to mutually beneficial relationships - close, personal relationships are the foundation of the community	- multiple factors contribute to a patient's health, nurses should care for all parts - struggle over whether nurses should act "professional" or relate to patients on a personal level
Value of disabled person	- central position of people with disabilities to counteract stereotypes	- disabled people are largely missing from the literature - depicted as dependents, charges, or burdens	- given the title "core members" as disabled people are the 'core' of L'Arche communities - over-valorized?	- bio-psychosocial model challenges traditional passive patient role– does not manifest in practice

(Table continued…)

	ILM	Feminist Ethic of Care	L'Arche	Holistic Nursing
Value of support provider	- direct payment schemes places total control in hands of disabled person - potential for exploitation and abuse of assistant	- close attention to the rights of the carer, who is usually a woman - Carers' Movement + *doulia* highlights this	- assistants are nurtured and personal development is promoted vs. - assistants are not paid well, some strict rules	- theory encourages joint decision-making -in practice, nurses maintain control over interactions & decision-making
Power	- power in terms of decision-making - role reversal: disabled person has all the power	- does not challenge traditional care-giving power dynamic: carer has/deserves all decision-making power	- power is dynamic and must be constantly negotiated	- nurses exercise professional power - actions may be dictated by systematic procedures

Literature Review Conclusion

The literature on support provision is diverse and multi-layered. The research in this project deals with some of the many gaps in the literature in order to address the research question: In what ways do the mandates of support provision organizations shape the interactions between people with disabilities and their support providers? The gaps that are addressed are:

- The ILM literature represents assistants as servants, there is a need for more work on whether this representation manifests within support provision interactions.
- L'Arche philosophy grew primarily out of practice, and L'Arche philosophy largely appears to translate into practice. More research is needed to confirm if and why the L'Arche model is successful at ensuring its philosophy “trickles down” to the front lines of service provision.
- From the literature, it is clear that flexible understandings of independence, reciprocity, roles and power are key to positive support provision interactions. This flexibility reflects the reality of daily life and ensures that both assistant and disabled person feel valued and respected within the relationship. This research explores how the mandates of support provision organizations challenge conventional understandings of these terms, and how flexible and complex definitions are conveyed to support providers and disabled people.

The literature review demonstrates that support provision interactions are shaped by the components of a support provision relationship: both parties' understanding of independence, the endorsement of a certain type of relationship, the value attributed to the person receiving support and the person providing support, and understanding and use of power. The study uses these components to help evaluate if support provision philosophies manifest in organizational mandates, and examine the ways the mandates shape support provision interactions.

Chapter Three: Methods

The project methods stem from the theoretical framework outlined in Chapter One. The social model and Titchkosky's work inform the interview questions. In line with human geography (Anderson et al, 2003; Duncan et al, 2004), the research pays attention to where the interviews took place and their context. The methods aim to answer the primary research question: "In what ways do the mandates of support provision organizations shape the interactions between people with disabilities and their support providers?" In addition, they attempt to address the gaps in the support provision literature as identified in Chapter Two: Literature Review. This chapter reviews the setting of the study, data collection, interview analysis, and validity.

Setting of the Study

Two models for service provision were examined in this study: L'Arche and the Independent Living philosophy as embodied in the ILRC Winnipeg's Personal Attendant Community Education (PACE) training program. The L'Arche community is also located in Winnipeg, Manitoba. Human geography calls for research methods that attend to context. L'Arche communities intentionally cultivate a sense of home and community; IL arrangements are a more naturally occurring home environment for consumers. "Home" is a place filled with social implications; to enrich the results, the interviews took place within the homes of the participants.

Data Collection

There were fourteen participants in this study: two administrators, two Independent Living Attendants, two L'Arche assistants, and eight consumers/members with disabilities. Using multiple perspectives in data collection, or “triangulation,” aims to add depth to the information. Green and Thorogood (2004) state that including multiple perspectives and data collection methods cause “the whole research programme [to] move[] towards a richer understanding” (p. 207).

The social model calls for research that explores societal assumptions and other structures that may “disable” a person. The multiple methods examine whether each group contributes to or lessens disabling attitudes. The four main data collection procedures are detailed below.

Mandate Summary

The first source of data was the organizational documents and wider body of literature. Building on Titchkosky’s idea that representations of people with disabilities matter, it is important to look at the theoretical perspectives behind the mandates (2003). This step summarized the main points of the philosophy/mandates into one-page documents (see Appendix B and C). Relevant committee members approved the documents to ensure that they accurately portray the philosophies. The documents were used as a reference point in the analysis of the participants’ understanding of the philosophy.

Prior to participant recruitment, letters were sent to the heads of both organizations with a description of the research. Questions and/or concerns were addressed in follow-up phone calls. The Community Leader at L’Arche was concerned about privacy and requested that the researcher and project supervisor sign an internal confidentiality agreement. The heads of each organization recommended participants for each of the following phases.

Mandate Implementation: Administration

The second data source was an administrator at each location; information was collected through semi-structured interviews. Semi-structured interviews are the most effective method of finding information on a specific topic while still allowing for valuable insights that often occur in tangents (Singleton & Straits, 2005). One administrator at each location was interviewed; only one person was interviewed in consideration of time and scope of the project. The interview took place in person and informed consent was received (see Appendix D). See Table 2 for interview questions.

Mandate Implementation: Assistants

The third source of data was collected from the support providers at the two locations. Two support providers at each location were interviewed; one long-term employee and one short term one. In an ethnography exploring the motives and experience of L'Arche caregivers in Canada, Cushing (2003) defines a long-term assistant as someone who has been employed for over two years and a short-term assistant as someone who has worked one to two years for the same organization. This research used Cushing's definition of long and short term for the purposes of participant recruitment. The organizational head recommended the participants and each individual chose whether or not he or she wanted to participate. Program leaders likely recommended "best" examples of assistants; thus, the analysis is based on those who best actualize the training. In addition to the brief interview,

Table 2: Interview Questions for Administration

1. In what ways do core members and assistants (consumers/ILAs) interact? (Prompts: Household responsibilities? Personal care? Socializing?)

2. What is the philosophy your organization is founded on? Do you have a mandate or formal statement of this?

3. What is the purpose of the mandate? What do you “use” it for? What do you expect your staff to use it for?

4. Do you use your mandate when hiring staff? How? What type of people do you hire?

5. How is the philosophy conveyed to your staff? (Prompts: training, handouts, how often?)

6. In your view, how important is the mandate to your organizational functioning?

7. Is violation of the mandate basis for dismissal?

8. Do you think your staff are aware of the mandate? Do you think it influences the way they interact with core members/consumers? Should it? In what ways?

9. Do you think the consumers/core members are aware of the mandate? Do you think it influences the way they interact with assistants/ILAs? Should it? In what ways?

scenarios[8] were presented to the participants to find out the ways in which the mandate shapes the interactions. The scenarios describe situations that demonstrate the tension between the values represented in the organizational mandate and the reality of support provision relationships. This type of interviewing elicits decision-based responses that, for the purposes of this research, help to indicate if mandates influence interactions. The main drawback of this method is that some participants may exhibit a “response bias tendency,” that is, they may articulate answers that are perceived to be socially desirable (Singleton & Straits, 2005). All participants were encouraged to answer as honestly as possible, and indeed the scenarios proved to be rich sources of information. Originally, the scenarios were designed to “fill in the gaps” of the interview questions, but it turned out that they provided the most intriguing insights and perspectives. See Table 3 for assistant interview questions and Table 4 for scenarios**.** Interviews took place in person and informed consent was received (See Appendix D).

Mandate Implementation: People with Disabilities

It is essential to include the perspective of the people receiving support. The social model calls for inclusion of people with disabilities in the research about them. Similarly, Titchkosky’s work (2003) suggests that the lived experience of disability is culturally illuminating, thus people with disabilities are a valuable source of information. In this study, people with disabilities are involved in the committee as

---

[8] The scenario method is adapted from Laurence Kohlberg’s “dilemma story” technique. Kohlberg defines a moral dilemma as “a state of disequilibrium characterized by the unresolved conflicting claims of individuals” (1981, p. 280). In practice, it means describing a scenario to participants and allowing them to respond about either what they themselves would do or what the character in the story should do.

Table 3: Interview Questions for Assistants

1. What are the ways you interact with core members/consumers (Prompts: Household responsibilities? Personal care? Socializing?)

2. Do you know the philosophy or mandate your organization is founded on? Can you summarize it in your own words?

3. How did you learn the mandate? (Why don't you know the mandate?)

4. Is the mandate practical? That is, can you "use it" in your interactions? How do you use it? (Prompts: refer back to responses in #1. Decision-making? Type of relationship? Educating other people about your work? Environment?)

5. Do you think the consumers/core members you support are aware of the mandate? Do they use it in their interactions with you? Do they use it differently than you do? (Examples) How could they use it?

Table 4: Scenarios for Assistants and Consumers

Scenario	Questions and prompts
1. Dignity of risk/consumer control Jenny is supporting Helen. They have known each other for a long time, and are very close friends. Helen is very small, has an intellectual impairment, is non-verbal and needs assistance in most things, Helen is able to walk and communicates her needs by guiding her assistants to what she wants, for example the sink for a drink of water, the fridge for a snack, or the bathroom. Sometimes, Helen does not want to take medication. She takes anti-seizure medication and vitamins. One day, Helen refuses to take all her medication. Jenny tries to convince her that she should take it, but Helen still won't open her mouth. After trying for a half an hour, Jenny holds Helen gently, but firmly and forces her to take the medication.	Did Jenny make the right choice? What *should* she have done? What would the IL/L'Arche mandate have said she should done? Do you think Jenny would have been responsible if she hadn't forced the medication and Helen had a serious seizure? Do you think she would have been/should have been fired? Would it make a difference if Jenny didn't know Helen for so long?
2. Role of the consumer/core member Carol supports Roger. Roger has a mild intellectual disability and Cerebral Palsy. He needs more physical assistance than social assistance. He has poor fine motor skills and needs help eating and dressing. Roger is a very popular man and has a job at a small accounting office. Part of his job is to host lunch meetings with other local accounting offices. Roger developed a set of rules for when he and Carol are in public. He requires Carol to be quiet unless directly spoken to, walk slightly behind him, and dress in business attire. He does not introduce Carol to other people.	Are Roger's rules appropriate? Why or why not? What would you change? What would the IL/L'Arche mandate say about these rules? Is Roger being disrespectful? What should be the role of the assistant/ILA?
3. Role of the attendant Darryl is Joyce's personal assistant. Joyce is a busy professional in a wheelchair. She has	Did Darryl make the right choice? What *should* he have done? What would the IL/L'Arche

minimal arm control and no lower body movement. While working the night shift, Darryl pulls a muscle in his back quite badly. His shift is not over for six more hours. He knows he will have to roll over Joyce, every two hours as she already has some severe bedsores. Darryl does the rolls for Joyce, and in the morning, is in serious pain.	mandate have said he should done? How can you decide whose health is “more important?” Should the assistant be making these decisions? What if this decision makes Darryl unable to work for a long period?

well as research participants. Using a similar approach to the assistant interviews, three consumers receiving services from PACE graduates were interviewed and asked to respond to scenarios (see Table 4). Recruitment took place via recommendation of who was most available (convenience sampling), and the interviews took place in person. Informed consent was received from the IL participants (see Appendix D). None of the consumers from the ILRC had subsitute decision makers. See Table 5 for interview questions.

Mactavish, Lutifyya and Mahon (2000) demonstrate that focus groups are a successful data-collection tool for people with intellectual disabilities. Mactavish et al (2000) also suggest that smaller groups are more effective (four people instead of the usual six to ten) as it "ensure[s] that the participants [have] sufficient time, opportunity, and support to discuss their perspectives" (p. 226). A focus group was conducted (see Table 6) and plain language scenarios (see Table 7) were presented to five consenting members with disabilities in a L'Arche home. Four of the members verbally participated in the discussion. All the members lived in the same house, creating a comfortable environment for them. They also all agreed that the House Leader, who was also a participant, would attend the focus group and help facilitate the discussion.

The process for involving people with intellectual disabilities was different since this population is identified as "vulnerable" (Manitoba Government, 1992). On the issue of substitute decision makers (SDMs), the original plan was to contact the any SDMs and invite them to attend an information session. However, L'Arche was very proactive about this aspect. Prior to the research, the Community Leader approached a House Leader to ask if the house might be interested in the study. The Community Leader also met with the members with disabilities and explained the

Table 5: Interview Questions for Consumers

1. What are the ways you interact with the ILAs who support you? (Prompt: Household responsibilities? Personal care? Socializing?)

2. Where do you live? What's it like? Have you lived in any other organizations/arrangements? What was it like there?

3. Do you know the philosophy or mandate that the Independent Living Resource Centre is founded on? Can you summarize it in your own words?

4. Do you know if the ILRC has a formal mandate of the philosophy? Do you know it? How did you learn the mandate? (Why don't you know it?)

5. Is the mandate/philosophy important to you? Is it part of why you chose to employ ILAs?

6. Is it important for you to hire people who adhere to this philosophy?

7. Is the mandate practical? That is, can you "use it" in your interactions? How do you use it? (Prompts: refer back to responses in #1. Decision-making? Type of relationship? Educating other people? Environment?)

8. Do you think the ILAs who support you are aware of the mandate? Do they use it in their interactions with you? Do they use it differently than you do? (Examples) How could they use it?

Table 6: Plain Language Focus Group Questions for Members

1. [topic: Interaction] What do you do with the assistants you live with? What do they do for you? What do you do for them?

2. [topic: Comparison to other settings]. Have you lived anywhere other than at L'Arche? What was it like there? Was it different from L'Arche? How? Is it important that L'Arche is different from other places? Why?

3. [topic: L'Arche philosophy] Does everyone know who Jean Vanier is? Why did Jean start L'Arche? What's L'Arche all about?

4. [topic: Mandate] Do you know what a mandate is? (Explanation: A mandate is the summary of the basic ideas behind a place, for L'Arche, it's a paper on what Jean Vanier says). Do you know the L'Arche mandate? If yes, how did you learn about the L'Arche mandate?

5. [Mandate importance] Is it important for L'Arche to hire assistants who understand the L'Arche mandate, what Jean Vanier says?

6. [Mandate implementation]. Do you do what Jean Vanier says when you are with your assistants? Give me examples. (refer back to question #1)

7. [Mandate implementation] Do you think the assistants know the mandate (what Jean Vanier says)? Do you think the assistants do what he says when they are with you? (why or why not?)

Table 7: Plain Language Scenarios for Members

Scenario	Questions and prompts
1. Dignity of risk/consumer control Helen is a Core Member and Jenny is an assistant. They have known each other for a long time, and are very close friends. She is very small, doesn't talk and needs help with most things. Helen is able to walk and tells her assistants what she wants by showing them. For example, she pulls her assistants to the sink for a drink of water, the fridge for a snack, or the bathroom. Sometimes, Helen does not want to her medicine. She takes medicine for seizures anti-seizure and vitamins. One day, Helen refuses to take her medicine. Jenny tries to convince her that she should take it, but Helen still won't open her mouth. After trying for a half an hour, Jenny holds Helen gently, but firmly and makes her take the pills	Did Jenny make the right choice? What *should* she have done? What would Jean Vanier have said she should done? Do you think Jenny, would have been in trouble if Helen didn't take the medicine and she had a seizure? Do you think Jenny would have been/should have been fired? Would it make a difference if Jenny didn't know Helen for so long?
2. Role of the consumer/core member Carol is an assistant for Roger. Roger needs some help eating and dressing. Roger is a very popular man and has a job at a small accounting office. Part of his job is to host lunch meetings with other local offices. Roger came up with a set of rules for when he and Carol are in public. He asks Carol to be quiet unless someone speaks to her, walk slightly behind him, and dress in nice clothes. He does not introduce Carol to other people.	Are Roger's rules fair? Why or why not? What would you change? What would Jean Vanier say about these rules? Is Roger being rude to Carol? What should be the role of the assistant?
3. Role of the attendant Darryl is Joyce's personal assistant. Joyce is a busy professional in a wheelchair. She has minimal arm control and no lower body movement. While working the night shift, Darryl, hurts his back. His shift is not over for six more hours. He knows he will have to roll over Joyce, every two hours as she already	Did Darryl make the right choice? What *should* he have done? What would Jean Vanier have said he should done? How can you decide whose health is "more important?" Should the assistant be making these decisions?

has some severe bedsores. Darryl does the rolls for Joyce, and in the morning, he is in a lot of pain.	What if this decision makes Darryl unable to work for a long period?

Participants were allowed to read the scenario themselves after it had been read out loud. Only the pertinent questions and prompts were used, depending on the responses. Visual aides were used during the focus group.

research to them. The members were interested, so the House Leader independently contacted next of kin and SDMs for verbal consent for all members. Since this was done ahead of time, upon meeting with the researcher, the House Leader did not think it was necessary to host a preliminary meeting with the SDMs or the members. An ethics revision was submitted and passed. Thus, instead of an information session, the research team went to the L'Arche home for an informal supper prior to the focus group to build rapport, which is important for conducting focus groups with individuals with intellectual impairments (Mactavish et al, 2004).

Informed consent from the participants with intellectual disabilities was obtained through the "assent and consent form," which is based on a version of the "supported decision-making model" (Bach & Rock, 1996). This model acknowledges that most people make decisions in consultation with others (Bach & Rock, 1996). The advocate and potential participant reviewed the plain language "assent and consent" form and made a decision together (see Appendix E). On the evening of the focus group, consent (or assent where appropriate) was explained to and confirmed with each participant. Afterwards, consent forms were mailed to the three official SDMs, which were both returned with signatures. See Table 6 for the plain-language focus group questions.

Two aides assisted in conducting the focus group. The researcher facilitated the discussion, one aide acted as a "graphic facilitator" as recommended by Mactavish et al (2004; 2000), and the second aide took notes. The focus group was video recorded for review and transcription purposes only.

The focus group proved challenging in terms of drawing out relevant information. This could be due to a number of reasons:

1. Plain language. Although plain language considerations were made, the questions were still too complicated for the participants. This was particularly true for the scenarios, which were much too complex for the members. Responses were elicited through changing the characters in the scenarios to people that the members knew.
2. Time of day (a Sunday evening). Some of the participants were tired, and one fell asleep for a portion of the focus group.
3. Underdeveloped rapport. The House Leader explained that the Friday of the same weekend, a long-term friend of the house hosted a similar meeting looking for member input on a forthcoming revision to the community mandate. Based on notes from this meeting it appears as though the members were much more articulate at this meeting. In addition, the presence of the House Leader (someone with strong rapport with the participants) was an essential element in understanding each other and facilitating discussion.

Thus, for future focus groups with people with intellectual impairments, particularly those that live together, it is recommended that the researcher carefully compose plain language questions. During the formation of the questions it would be beneficial to elicit the help of a person who works closely with the potential participants. The questions should include names of people and places the participants are familiar with. It is also recommended that the time of day is chosen carefully, perhaps aiming for weekend afternoons. Finally, multiple visits are recommended in order for the researcher to get to know the group and their communication style. The researcher should also consider having a close friend of the group help with or lead the verbal facilitation.

Interview Analysis

The data was analyzed to determine how the mandates shape the interactions between the people with disabilities and their support providers. Using “open” coding, the interviews and focus group discussion were coded based on the ways of interacting, understanding of the philosophy (compared to “philosophy summaries” see Appendix B and C), other aspects of the philosophy (learning, purpose of the philosophy, etc.), the different components of a support provision relationship as identified in the literature review, scenario responses, and context. It is important to note that even though some categories reflect interview questions, the entire interviews were searched for relevant information to include in the categories. Through this method it became apparent that the scenario responses held a lot of information relevant to other categories. The open codes were further refined using Strauss’ axial coding method (1987). Strauss (1987) explains that axial coding is when the researcher codes “intensively and concertedly around single categories” resulting in more detailed sub-categories (p. 64). Whenever possible, the categories were formed using “in vivo coding,” which is when a category is derived from “the terms used by the actors in that field themselves” (Strauss, 1987, p. 33). This method ensures that the coding categories reflect the values embedded in the participants’ language.

Finally, Miles and Huberman's (1994) “data display” technique was used to create the conclusion diagrams (Figure 3 and 4 in Chapter Seven: Conclusions). This technique attempts to provide "an organized, compressed assembly of information that permits conclusion drawing" and was explained by Berkowitz (1997) as an important step after data reduction.

Validity

This research project contains multiple methods (interviews, scenarios and a focus group) and multiple data sources (organizational documents and literature, administration, staff, and people with disabilities). Having such a diverse approach potentially increases the validity of this research. Triangulation is used to “gain a broader and more secure understanding of the issues” (Maxwell, 2005, p.94).

Once the initial analysis of the data took place, participants had an opportunity to verify the results. “Respondent validation” or “member checking” is when participants are given the opportunity to respond to the data and results of the study (Maxwell, 2005, p. 110). In this project, respondent validation took place via telephone, email, and an in-person group meeting with the participants with intellectual disabilities. Participants had the opportunity to respond to initial findings documents, which were early drafts of Chapter Four and Chapter Five in this document. The L’Arche context caused some difficulties for confidentiality during this step, as the participants could potentially identify each other through the quotes in the findings chapter. Prior to circulating the document, this issue was explained to all the participants via email or though the House Leader for the members. All participants consented to circulating the draft. Feedback from the participants was taken into consideration during further revisions and analysis.

Maintaining the confidentiality for the Administrators in the final draft also became a concern, since the report contains information about their places of work. The Administrators both agreed in writing to the increased risk of identification.

The findings yielded from the research process outlined in this chapter are reviewed in the following two chapters.

Chapter Four: Independent Living Findings

Chapter Four addresses the primary and secondary research questions presented in Chapter One for the IL data. The primary research question is: “In what ways do the mandates of support provision organizations shape the interactions between people with disabilities and their support providers?” The first step in answering this question is to identify the how people with disabilities and their support providers interact. Secondly, this chapter examines the participants’ understanding of the IL philosophy and other general aspects of the philosophy in order to infer how the philosophy is/is not shaping the interactions. The connections between how the participants interact and how they understand the philosophies are used to address the research question in Chapter Six: Discussion.

Next, the findings address a secondary research question: “Do theoretical support provision perspectives manifest in organizational mandates?” The question is answered by comparing the participant responses to the literature review findings, that is, the components of a support provision relationship as identified in Chapter Two.

The chapter then summarizes the IL participants’ responses to the scenarios, which proved to be rich sources of information and made significant contributions to the other findings. Finally, the chapter analyzes the interviews for comments relating to context in order to reflect the human geography framework of the research.

Ways of Interacting

Allowing the participants to identify the ways they interact is a key step in addressing the primary research question: “In what ways do the mandates of support provision organizations shape the interactions between people with disabilities and their support providers?" In the interviews, the participants were asked directly "What are the ways you interact with the ILAs (relevant term used) who support you?" The responses to this question became the coding categories in the analysis, which were then applied to the rest of the interview. Additional categories emerged in some responses although some of the participants did not directly identify them.

There are five main ways of interacting (see Table 10 in Chapter Six: Discussion for summary) that are apparent in the Independent Living data. The first way is labeled "directing/following instructions." This interaction happens when the consumer directs the ILA in various tasks. In many of the examples provided by the participants, a specific activity was not mentioned and the participants spoke generally of instructing. The second interaction identified by the IL participants is labeled "helping." Helping interactions are when the ILA performs specific personal care tasks for the consumer. "Negotiating" is the third way of interacting. Although "negotiating" was not a term used by the participants, the term is used to reflect a circumstance that was commonly referenced by the participants: situations where the ILA attempts to convince the consumer to do things, which in the ILA's opinion, are in the best interest of the consumer. Many of the examples of negotiating interactions concluded with a directing interaction, as the ILAs acknowledged that the consumer has the final word in terms of decision-making. The IL participants also identified "training/employing" activities, which refer to occasions where the consumer teaches the ILA, usually about personal care. This type of interaction also includes the consumer acting formally as an employer by doing activities such as scheduling and payroll. Finally, "socializing" includes any fun or extracurricular activities that take place between consumer and ILA. These activities constitute the "lighter" side of personal relationships.

There is a sixth type of interaction that was inferred by some of the participants, but never directly spoken of; this category is termed by the researcher “emotional care activities.” These activities are more abstract than socializing, and include sharing personal information, providing advice and support through day-to-day life and major decision-making. Emotional care can be considered the “deep” side of personal relationships. It is important to examine emotional care for comparison sake with the L’Arche data, as well as to add to the debate between IL literature and the feminist ethic of care. The participants’ responses and different focuses are explained below, and the significance of these categories is expanded upon in Chapter Six: Discussion.

IL Administrator

The IL Administrator had well-developed responses regarding the interactions between ILAs and consumers. The Administrator focused on the relationships between the directing, helping and training/employer activities. The IL Administrator said,

> Basically the consumers are the persons with disabilities who are in control of directing and managing all aspects of their care needs. So in doing that, the ILAs or Independent Living Attendants, are responsible for meeting the care needs under the direction of the consumer. And that could be anything from recreation, to communications, to personal care needs, to social interactions…whatever the person’s needs are to support them in the community.

Within this quote, the Administrator mentions “control” and “directing” (directing), “care needs” (helping) and finally the “managing” aspect (training/employing). At other points, the Administrator mentions additional training/employer activities such as creating a job description, interviewing, hiring, training and scheduling. The

Administrator did not mention negotiating activities or socializing activities; the Administer made no reference to emotional care activities. In the member-checking phase, the IL Administrator argued that socializing and emotional care are important interactions but were not mentioned because they are left up to the discretion of the consumer.

Independent Living Attendants

The ILAs both mentioned four of the five main categories, and implied the emotional care category. They emphasized specific “helping” activities as the main way of interacting with the consumers. They both mentioned the “directing” element of support provision interactions, with the Short Term ILA even classifying himself as “a tool to make sure that “[the consumers] lives run smoothly and their independence is always protected.” Each attendant gave one example of “negotiating” interactions. For example, in response to the second scenario, the Short Term ILA said, “If it’s something that really really needs to get done, you keep convincing and you keep working really hard to do it.” The negotiating activities tie into the emotional care category. The ILAs must “care” about the consumers on some level, otherwise they would not bother negotiating but would simply follow the directions of the consumer. However, it was also clear that negotiating interactions were secondary to following the directions of the consumers. For example, the Long Term ILA said, “I can suggest to them [to do their own dishes], but in actuality, if they want me to do those dishes, then you know what? I’m doing those dishes.” Despite recognizing the importance of following directions, neither ILA mentioned training/employing interactions. Both were aware that some of the consumers they work with are directly involved in the PACE program, but did not acknowledge this role in the interviews. Finally, socializing was recognized as a type of interaction, but a distinction was made between during and after work. The Long Term ILA said, “You know, I work 7-3 and I don’t have [a] problem saying, [‘Let’s] get together at 5:00, do you want to go meet somewhere for coffee?’ That’s our business, you know, but that’s not a work thing.”

As for inferences of emotional care, aside from the negotiating references, there was a sense that emotions for each other were inevitable. The Long Term ILA said,

> Because like there are times, you know, one’s falling down cracking his head. I go home and I’m thinking like…is he going to be okay? … I work with these people and I see them everyday you know. Some of them don’t have family and some of them look at the staff as being family. … I think it goes kinda both ways. You develop a relationship with those people you know, [on] a one-on-one basis.

The second idea was that consumers *should* emotionally support ILAs and vice versa. For instance, the Short Term ILA said, “I mean it’s kind of like being able to put yourself in their position and examine [how] you [would] want to be treated.”

Consumers

Like the ILAs, the consumers emphasized “helping” activities. They were all PACE trainers and were proud of interacting with support providers in this way. Only one of the consumers mentioned negotiating activities, and this person has the most developed understanding of IL philosophy. He has been involved in the Independent Living Movement and the quest for suitable living arrangements for many years. The same consumer mentioned socializing activities, and like the ILAs, he felt that there should be a distinction between a work relationship and a social relationship. Consumer II said,

> I don’t make it a point to use these people that work for us as my social life, but not that I ignore them if we are out in the public. We go periodically down here, to the Pony Corral [a restaurant] in the summertime and sit out on the patio and have a few beers together and stuff. I mean, that’s okay.

All three of the consumers mentioned the importance of directing activities; one consumer explained that the difference between ILAs and other support providers is that “They follow my directions…better” and the other two expressed that the ILA is “only there to assist.”

The consumers implied emotional care activities; two of them mentioned the dangers of being “too close” to attendants and two mentioned the need for two-way respect within the relationship.

Key Points

- Only one participant mentioned all five ways of interacting (Consumer II). The two other consumers and the Administrator left out negotiating interactions, the Administrator also left out the social interactions, and the ILAs left out the training/employing interactions.
- The Administrator emphasized the connections between the types of interactions, with particular focus on the directing, helping and training/employing interactions.
- The ILAs and consumers focused on specific helping interactions and on directing activities.
- Emotional care activities were implied by the ILAs and consumers, but there was no direct mention of this type of activity.
- Overall, following directions is the most important interaction.

Understanding the Philosophy

The participants’ understanding of the philosophy and other general aspects of the philosophy are examined in order to deduce how the philosophy is/is not shaping their interactions. The participants' understanding of the philosophy was evaluated through comparing the interviews to a summary of the philosophy (see Appendix B). Thus, the connections between the interactions and their understanding of the philosophy are the outcomes used to address the secondary research question: "What outcomes can be used as evidence of the role of the mandate in shaping the interactions between the two groups?" The links between the two categories are explored in Chapter Six: Discussion. In addition, this section helps to answer a secondary research question: "To what extent do people adjust the mandate to suit their own goals and contexts?"

The Administrator, ILAs and consumers' understanding of the philosophy was evaluated using the five principles of Independent Living philosophy identified in the IL philosophy summary (see Appendix B). Unlike the L'Arche material, the participants referenced a specific document that is "up on the wall" at the ILRC. This document contains the five principles identified in the summary and was seen by the participants as a comprehensive summary of IL philosophy.

The Administrator and one of the consumers explained the philosophy the most completely, mentioning all five elements many times (taking risks, making choices, promoting integration, accepting responsibility and promoting consumer control). The Administrator had a strong emphasis on the consumer control aspect of the philosophy. The Administrator said, "[The ILAs] probably wouldn't know the mission statement word for word…but they would definitely know the underlying concept[] of consumer control." Consumer II also explained all five principles, but focused on making choices and accepting responsibility.

Like the Administrator, the Long Term ILA focused on consumer control. An example comment is, "when you get down to the nitty gritty, the tenants are the actual bosses because it's the tenants' organization, that … had started it. There was a group of them that came together and started it. So you know, when you sit down, they're the ones that decide." Wrapped up in this response is the idea that the consumers own the organization and thus are able to control the services. The Long Term ILA did not identify the "taking risks" aspect of the philosophy.

The Short Term ILA also did not directly mention community integration, but it can be inferred since the ILA works for consumers in the community and not in a group home. The Short Term ILA focused on making choices. He said, "Independent Living philosophy is all about being free, being independent, all about being able to make choices."

Consumer I did not go into great detail about the philosophy. Her focus was on being in control of her attendants and services. She left out the community integration principle. As mentioned earlier, Consumer II gave the most comprehensive response. Consumer III emphasized consumer control and did not include accepting responsibility as an element of IL philosophy.

Key Points

- No pattern along role groups
- Even though the affiliates of the ILRC identify a specific document (the five principles posted "on the wall") they emphasize different elements and some left out various aspects. The inconsistency in the philosophy may demonstrate that the philosophy is expressed differently in various living arrangements and by different people.

Other Aspects of Independent Living Philosophy

The IL participants were also asked about the purpose of the philosophy and how they learned it. The findings in this section help identify what is unique about IL philosophy and answer a secondary research question: “Do the mandates challenge disabling societal assumptions?” The participants were largely in agreement about the purpose of the philosophy; all participants mentioned at least one of these categories: the philosophy is used 1. to change negative attitudes about people with disabilities, since it has a greater societal relevance and 2. to support the consumers’ role as “employer” and the consumers’ living arrangements. There was also a sense that people with intellectual disabilities face different barriers in applying the IL philosophy; this response came up in the Administrator, Short Term ILA and Consumer II’s interviews. The Short Term ILA said, “unfortunately in my experience people with intellectual impairments … they aren’t given the same benefit of the doubt, the same ability to choose, you know, it’s almost like a different ball game than just a physical impairment.”

Interestingly, two consumers and the Administrator made a distinction between knowing and living the philosophy. Consumer II said, “I have respect for people who practice it, and I don’t have respect for people who just pay lip service to it. I can make a philosophy about how you have to treat your dog, doesn’t mean that you’re going to do it.”

As for learning the philosophy, all the participants mentioned a poster “on the wall” at the ILRC that is a reference point for the five main principles. Secondly, they also all mentioned the PACE program as the way that ILAs learn the philosophy. None of the consumers could specifically remember how they themselves learned the philosophy, although the Administrator mentioned that all ILRC volunteers participate in a brief training session. All consumers in this study were ILRC volunteers. Their own answers suggested that they just knew it intuitively. For instance, when asked how she learned the philosophy, Consumer I said, “I’ve been living it for 20 years." All of the consumers and one of the ILAs directly expressed this sense of intuitively knowing and living the philosophy.

Even though an "origin story" is not central to the IL philosophy, the participants emphasized the importance of the history of the ILRC in Winnipeg and the PACE program. The Administrator, Long Term ILA, and two of the consumers referenced the historical element.

Key Points

- The purpose of the IL philosophy is to change attitudes and support the consumer role and lifestyle. This was consistently expressed.
- People with intellectual disabilities face difference barriers in applying the IL philosophy.
- The philosophy is taught to ILAs in the PACE program and maintained by public documents "on the wall" at the ILRC. The consumers had a brief training session, but felt they "knew" the philosophy intuitively.
- The histories of the ILM and PACE are important to the community.

Components of a Support Provision Relationship

In order to address the literature gaps and the secondary research question: "Do theoretical support provision perspectives manifest in organizational mandates?" the participant responses were compared to the literature review findings. The literature review determined five components of a support provision relationship which are: independence, mutuality and relationship, value of the disabled person, value of the support provider, and power (for summary of IL literature, see Table 8).

The IL Administrator most closely reflected theoretical IL literature. Like the literature, the Administrator explained independence in terms of decision-making and advocated for professional support provision relationships (i.e. either trainer/student

Table 8: Summary of IL Literature

Component of support provision relationship	ILM literature
Independence	- decision-based independence as a political means of challenging stereotypes - embodied in direct payment scheme
Mutuality and Relationship	- professional and exchange based relationships - in reality, personal relationships may exist
Value of disabled person	- central position to counteract stereotypes
Value of support provider	- direct payment schemes places total control in hands of disabled person - potential for exploitation and abuse of assistant
Power	- power in terms of decision-making - role reversal: disabled person has all the power

or employer/employee). Indeed, professional relationships are further emphasized by the fact that the IL Administrator did not mention social activities or emotional care in the original interview. In congruence with IL literature, the Administrator also placed a high value on the person with a disability by speaking about ILRC programs which are mandated to be consumer driven. However, upon questioning, it is clear that this role is more convoluted for people with complex disabilities; the Administrator said, “the people that are living in the institutions are not the people we are training ILAs to support.” In the same way as much of IL literature does, the Administrator depicted the ILAs as employees who must act as a tool for the consumers. The only concern for the well-being of ILAs from the IL Administrator was the comment: “many of [the ILAs] have stated how they prefer this model because it’s working for the person who’s going to be receiving the care and supports in the community and they know how to address their needs.” According to the IL Administrator and conventional IL literature, the power in a support provision relationship should rest with the consumer.

The ILAs and the consumers expressed a slightly more flexible understanding of the components of support provision relationships, which supports the findings of some of the recent IL studies in the literature review. The group largely agreed on their interpretation of the components. In terms of independence, decision-based independence was consistently expressed, that is, defining independence as the ability to make decisions (Helgoy et al, 2003). The Long Term ILA and Consumer II also reflected the traditional action-based understanding of independence, which is when independence is understood as being able to physically perform tasks for oneself (Helgoy et al, 2003). There was a sense that professional relationships should be sought, with the acknowledgement that “bonds” may inevitably form between the consumer and ILA. The Short Term ILA said, “When you work around someone so often…there’s bonds that are usually made.” However, even though these bonds are inevitable, the group felt that social relationships should be seen as “extracurricular” and emotional care was never directly mentioned. There were comments from both ILAs and two consumers about how being “too close” to each other can lead to problems, such as abuse or the tendency to “cross[ ] some boundaries.” This concern was most apparent in the responses to the first scenario where the characters are described as “close friends.”

As for the value of the disabled person, both ILAs agreed with traditional IL literature by expressing respect for people with disabilities, including respecting them as employers. The ILAs and two of the consumers also recognized the vulnerability of people with disabilities, making this respect all the more important. On the other hand, the ILAs were consistently seen as a “tool” by all participants, but a “tool” to be respected, which is a step beyond the depiction in traditional IL literature. For instance, in response to the second scenario where a consumer makes unreasonable rules for an ILA, the participants felt that ILAs need to be respected more than what the scenario describes. One ILA said, “I don’t feel […that] I should just be a walking doormat;” however, it was also clear that the ILA role is specific and ILAs should not overstep the boundaries of that role. Finally, the component of power was very clear. Just as in traditional IL literature, all the participants agreed that power in the support provision relationship should be in the hands of the consumer. Also, as mentioned in the ways of interacting, the ILAs expressed some occurrences of “negotiating” where the ILA would try to convince the consumer to do something, but leave the final decision up to the consumer.

Key Points

- The IL Administrator almost directly reflected the literature on the components of support provision relationships.
- The consumers and ILAs had similar responses that reflected a more flexible understanding of the components, particularly around relationships, the role of the support provider and power.

Scenarios

The scenario responses proved to be rich sources of data. The responses help demonstrate how the participants interpret and apply the philosophy and in many cases, demonstrate their understanding of the philosophy. The scenario responses also revealed interactions that the participants did not directly identify and reinforced the ones that were. A summary of the scenario responses follows.

Scenario One: Dignity of Risk vs. Health Concerns

In brief, Scenario One describes an assistant forcing a nonverbal consumer to take medication that will prevent her from having a seizure (for full scenarios, see Table 4 in Chapter Three: Methods). Like many other responses in this interview set, the IL participants had very similar reactions to the first scenario, particularly in terms of the main ideas with some variance in the details. For instance, all five participants felt strongly that forcing someone to take medication is unacceptable and that the consumer would ultimately be responsible for her decision if she chose to refuse the medication. Despite agreeing that the behaviour is unacceptable, they varied in terms of whether or not an ILA would be fired. The Long Term ILA and Consumer I felt Jenny (the ILA) should be fired, while the Short Term ILA and Consumer II argued that she would not be fired due to the lack of ILAs and the context (i.e. if it was a “shared care” facility or a self-managed arrangement). Again, despite the consensus that the consumer should be responsible for her decision, the Short Term ILA and Consumer II felt this was a very “gray” area, especially in consideration the character’s intellectual disability, which raises the issue of “competence.” Another main idea that four of the participants mentioned was the use of negotiation as a more appropriate response to the scenario.

The participants disagreed more on the issues of seeking outside help and the impact of the characters’ close relationship. Seeking outside help was offered as a solution by the Short Term ILA and Consumer III, who are actually both affiliated with organizations where back-up help or supervisors are always available. Consumer II mentioned seeking outside help as a good idea, but acknowledged that it would really depend on the arrangement. Finally, two participants did not see the close relationship as changing the scenario, while the Short Term ILA and Consumer I felt that having a close relationship could actually make abusive situations such as the one in the scenario more likely to occur. Consumer II thought that a close relationship would make the ILA’s behaviour even more inexcusable because she should know the consumer well enough to avoid confrontation.

Scenario Two: Consumer Control

The IL participants expressed a few concepts in response to Scenario Two which, together, create the idea of finding a balance between respecting support providers and keeping them in appropriate roles. In brief, in Scenario Two a consumer makes a set of rules for his attendant, some of which could be interpreted as disrespectful. Four participants (except the Short Term ILA) thought at least one of the rules was “rude” or “inappropriate,” in particular the rule where the consumer would not introduce his ILA. The Long Term ILA expressed not wanting to feel like a “doormat” which can sometimes happen in this field. Indeed the consumers were aware of this, as all three indicated that it is very important to acknowledge and introduce their attendants. However, this was balanced against the idea of an “appropriate” role for ILAs. One consumer said, “I mean you don’t want some attendant, you know, talking and interfering with you[]…if you’re setting up lunches and you’re entertaining other people eh? But you do want people to know who they are.”

The two variances were the Short Term ILA and Consumer I, whose responses represent opposite extremes. The Short Term ILA had no problem with any of the rules. He said, “I think Roger’s rules are absolutely appropriate. I think a person has a right to set how they want as far as their attendants are, especially in public” whereas Consumer I thought that there should be no such rules and that “Carol should be a part of the meeting because she’s part of his life.”

Scenario Three: Role of the Assistant

The final scenario gleaned some interesting responses from the IL participants, who largely agreed in their responses. Scenario Three describes a situation where an assistant is injured and working on his own; the consumer, who also has health concerns, is in need of physical assistance that may exacerbate the assistant’s injury. All five participants mentioned that outside help should be sought, although three participants acknowledged that there would not always be someone available. They all also expressed the idea that in the end, Darryl (the ILA) has an obligation to roll Joyce (the consumer), even at the expense of his own health. This comment was buffered with comments about the importance of the ILA. The Short

Term ILA said, “being an attendant is an incredibly important job. Your consumers’ lives are often depending on you doing your job and being where you need to be at that time.” There were two other comments that suggested that consumers’ health concerns are more serious than those of ILAs, reflecting a common stereotype of disability.

Key Points

- Regarding the first scenario, the IL participants, felt that forcing medication is unacceptable, negotiating is a more appropriate response, and that the consumer would/should ultimately be held responsible for refusing medication. These responses reflect Independent Living philosophy.
- The second scenario was more complicated for the participants. They expressed the need to respect support providers balanced against having appropriate roles for them. Two of the participants presented more extreme responses, demonstrating the variance on this issue. Indeed, the potential mistreatment of attendants is an issue that is highly debated between IL scholars and other disciplines, primarily the feminist ethic of care.
- The participants felt Darryl (the ILA) should seek outside help in the third scenario, although some acknowledged that this is not always an option. They also all agreed that if outside help is not available, the ILA would have to put the consumer’s health over his own.
- The scenario responses present an interesting perspective on the “role of the attendant” debate between IL literature and the feminist ethic of care.

Context

Due the human geography framework of this project, it is important to analyze the interviews for comments related to “home” and the surrounding environment (Blunt, 2005; Domosh, 1998; Duncan & Lambert, 2004; Imrie, 2004a). This section aims to address one of the secondary research questions: “What is the role of the IL environment in shaping the interactions?”

The consumers in this study lived in different buildings, all of which included IL philosophy in their policies. The consumers lived in units among groups of single-dwelling apartments in a larger building or complex. One of these complexes was strictly for people with disabilities, and the two other buildings were mixed. The tenants shared support providers among the units within their building, and the level of support available varied among the settings. There were PACE graduates employed among the support providers at all of the locations. The ILAs worked in different settings. One was a “direct-hire” ILA who worked for self-managed consumers and the other worked in a building such as described above.

All IL participants mentioned that the context of the IL arrangement has an important influence on who is really “in charge.” That is, the consumer should be the “boss” according to IL philosophy but in many situations there are also managers, coordinators, and other support providers influencing the dynamic. Secondly, the consumers acknowledged that the context would influence how protected they are, particularly in terms of having a “back-up.” The ILAs mentioned the same need for back-up staff in relation to their own protection and well-being. The Long Term ILA and Consumer II mentioned this issue from both perspectives, and the Administrator did not mention either.

With the exception of the Short Term ILA, all of the participants felt that IL philosophy is best applied, and perhaps can *only* be applied, in a “community setting” as opposed to a group home or institution. For instance, while explaining IL philosophy the Long Term ILA said, “[If I was a consumer and] I need to go grocery shopping you know, I can go grocery shopping. Can you help me phone Handi-transit? You know, as opposed to in a nursing home, you know, it’s all brought to you.”

An interesting point that was only raised by the IL Administrator was that the context will decide the actions of support providers to a certain extent. The IL Administrator said, “There are lots of organizations that hire our staff that wouldn’t follow our mission statement. So these graduates might be asked to do work that is different than the way we would ask them to do it.” The implication here is that organizational rules will ultimately override IL philosophy.

Another interesting element raised by all three consumers is the fact that the context of the support provision relationship will influence, and in some cases dictate, their schedules.

Key Points

- Context influences to what extent the consumer is the “boss” in support provision relationships.
- Context will influence how protected both the consumer and ILA feel.
- IL philosophy is best applied, or perhaps can *only* be applied, in community settings.
- Organizational structure may impede the application of IL philosophy.
- Contexts may influence consumer’s ability to plan their own schedule.

Summary of IL Findings

This chapter presented the IL findings in order to address the primary and secondary research questions outlined in Chapter One. In sum, the participants identified five main interactions: directing/following instructions, helping, negotiating, training/employing, and socializing. Emotional care is a sixth type of interaction that was implied by the participants but never directly spoken of. An examination of the participants’ understanding of the philosophy demonstrates that the participants identify the philosophy in very concrete terms (“on the wall”) and learn it in a limited time period. However, although they largely agree on the purposes of the philosophy, they understand the philosophy in different ways. In addition, in comparison to the literature review, the Administrator reflects an understanding of the dogmatic IL philosophy while the support providers and consumer support the recent literature that the philosophy is adjusted in practice. The scenario responses also support this tendency. Finally, the variance in IL contexts influences the application of the philosophy. The relevance of these findings in relation to the L’Arche findings is expanded upon in Chapter Six: Discussion.

Chapter Five: L’Arche Findings

Parallel to the approach in Chapter Four, this chapter utilizes the L’Arche Winnipeg findings to address the primary and secondary research questions as outlined in Chapter One. The primary research question explores the ways in which philosophies of support provision organizations shape the interactions between people with disabilities and their support providers. Thus, this chapter initially explores how the participants interact. Secondly, the chapter explores the participants’ understanding of L’Arche philosophy and other general aspects of the philosophy. In Chapter Six: Discussion, the relationship between the first two categories demonstrates where the philosophy is/is not shaping the interactions. This chapter then compares the findings from the L’Arche Winnipeg data to the findings of Chapter Two: Literature Review. Chapter Five also includes summaries of the participants’ responses to the scenarios, which are good examples of how participants in this community apply L’Arche philosophy to daily life. Finally, the chapter concludes with a discussion of the relevance of the L’Arche context in order to address one of the secondary research questions: “What is the role of the L’Arche environment in shaping the interactions?” It is important to note that L’Arche Winnipeg is one of twenty-six L’Arche communities in Canada and the findings in this chapter may not be generalizable to the other communities.

Ways of Interacting

As discussed in Chapter Four: Independent Living Findings, the ways of interacting help answer the primary research question of this project. There are five main ways of interacting apparent in the L’Arche Winnipeg data (for summary, see Table 10 in Chapter Six: Discussion). First, the participants identified life-sharing activities, which are characterized by “relational” or “family like” activities. These activities include sharing personal information, exchanging advice and emotional support in day-to-day life, and major decision-making. Life-sharing can be considered the “deep” side of personal relationships and is paralleled in the IL data with the elusive “emotional care” interaction. Secondly, just as in the IL data, the L’Arche participants identified “helping interactions.” Helping interactions occur when assistants physically assist and care for the members with disabilities. This type of interaction is characterized by a clear distinction between the assistants and the members. Thirdly, “supporting” interactions are when the assistant and member work together. The “supporting” category includes household tasks and personal care activities that members and assistants intentionally do together, even though the assistant might be able to complete the same tasks more efficiently independently. Unique to the L’Arche data, the participants identified “praying/spiritual activities.” This category refers to formal group prayer and reflection on L’Arche literature, which typically has strong spiritual elements. Finally, as in the IL data, the L’Arche participants engage in “socializing” activities. Socializing interactions are any fun or extracurricular activities that take place between a member and an assistant, community member, or friend of L’Arche. These activities constitute the “lighter” side of personal relationships. How the participants presented the categories is explained below, and the relevance of the interactions is expanded upon in Chapter Six: Discussion.

L’Arche Administrator

The L’Arche Administrator emphasized life-sharing and supporting activities. The Administrator was careful to explain that there are practical responsibilities to living in a L'Arche community but added that those tasks should be addressed with a supporting approach. She also stressed that engaging in life-sharing is the most important responsibility for assistants. An example comment from the Administrator is, "The most important thing is how you share your life together, like when you are not helping them with something, but just enjoying time together." The L'Arche Administrator presented a down-to-earth view of life at L'Arche: "life in L'Arche isn't always flowery and ideal. We strive to live up to certain ideals, but we aren't always successful."

Long Term Assistant

The Long Term Assistant clearly identified relational activities (which fall under "life-sharing") as his primary way of interacting with members. He said,

> [I interact with the members] in a number of ways, primarily relationally because as a House Manager I have a tendency to oversee the administration of the house, and so … there are fewer ways in which I'm involved in a person's actual routine. Sort of bathing, cooking, supporting with household tasks, that it seems to take a backseat right now because my time is occupied with other tasks. But I do always remain in contact with the members with a disability in sort of knowing, trying to get a sense of how they're feeling, how their days have been, what they're excited about, what might be bothering them. Or what they might be happy about and trying to support the assistants also in knowing them and facilitate the relating as it happens … with other people.

It is interesting to note that when an assistant gains seniority, s/he also gains administrative duties. With the exception of life-sharing, the other interactions become less frequent and are seen as less important for senior assistants. Overall, the relational activities are seen as more difficult to master and more important than the other ways of interacting. The Administrator's comments regarding grounds for dismissal support this: "for example, if the person just isn't interested in relationships with people and they're not even doing their job as an assistant, that can't go on indefinitely." The Administrator's quote suggests that the traditional support provision tasks are secondary to relationships. In addition, House Leaders are responsible for facilitating assistant relationships and interactions. Thus, long-term assistants and House Leaders are considered 'relationship experts' within the community.

Short Term Assistant

The Short Term Assistant clearly stated that friendship is the most important way of interacting with the members for her. It is categorized under "life-sharing" since her emphasis was on the deeper, abstract outcomes of relationships. She said,

> The most important thing for me at L'Arche, it probably is like the friendships that I develop. Of course, not with every member with a disability, you know as much as you can develop them with every other person either, right? But with some of them, and the kind of joy, kind of acceptance that they are able to express. It's very life-giving for me.

The Short Term Assistant did not mention prayer or social activities throughout her interview.

Members

The members varied in their examples of ways of interacting, but amongst the group, all five ways were mentioned at one point. As a group, the members with disabilities emphasized socializing since they all gave examples of social activities. For example, one consumer said, "[We] go out. We went out for supper yesterday." In addition, this category yielded the most examples without prompting.

Key Points

- Each "role group" (Administrator, assistants and members) identified all categories, which increases the validity of the findings.

- On the other hand, the emphasis was different for each group: the Administrator's overall emphasis was on supporting and life-sharing, both assistants emphasized life-sharing and the members focused on socializing.

Understanding the Philosophy

The Administrator, assistants and members' understanding of the philosophy was evaluated using the five elements identified in the L'Arche philosophy summary (see Appendix C). In brief, the five elements are: the origin story, mutual relationship, faith and religion, community, and social change. This step is integral in addressing the primary research question. Linking the participants' understanding of the philosophy to their interactions provides an indication of how the philosophy is shaping those interactions. The link between these two categories is a primary element of the analysis, and therefore addresses one of the secondary research questions: "What outcomes can be used as evidence of the role of the mandate in shaping the interactions between the groups?" The outcomes are analyzed in Chapter Six: Discussion.

Interestingly, when speaking about the philosophy, the L'Arche participants did not reference a specific mandate or formal document. The participants were aware of these documents, but there was no single document that they regarded as the central summary of L'Arche philosophy.

The Administrator and the Long Term Assistant explained the philosophy the most completely; they mentioned all five elements at least once. The Short Term

Assistant mentioned all elements with the exception of the origin story, which is surprising since it is so prevalent throughout L'Arche literature. This cluster of participants had a strong emphasis on the mutual relationship category. Their explanation of mutual relationship was complex and thorough; they mentioned equality, respect and valuing one another's opinion, friendship, and recognizing each other's gifts. There was a sense that understanding mutual relationships is the key to "getting it," that is understanding L'Arche philosophy. The idea of "getting it" was mentioned by the Administrator who explained that new assistants may be encouraged to leave if they do not engage in meaningful relationships with the members.

As for the members with disabilities, explaining the philosophy was difficult due to the abstract nature of the topic. There were plain language considerations attempted; however, it still proved to be a difficult topic. From the limited material, the focus was on faith and religion and community.

The complex and in-depth explanation of the philosophy from the Administrator and the assistants contrasts the few words from the members with disabilities. When asked if the members in the Winnipeg community have formal training in the philosophy the way assistants do, the Long Term Assistant explained,

> I would say there's more of an indirect [training] for the members. That basically … [the assistants'] attitudes and opinions are formed and… we are then encouraged to form the members as we can. Basically that through our own actions and our own behaviours, daily, that the members begin to gain a sense of selves, that we treat them as selves; as individual people who are worthy of trust and love and hope. And that we, in learning these ideas share them with the members throughout our daily lives.

This implies that members already "get it" to a certain extent and it is the assistants who must be taught and "formed" in order to fit into the L'Arche lifestyle (Cushing, 2003). Indeed this is supported by L'Arche literature which valorizes people with development disabilities. They are seen to “possess qualities of welcome, wonderment, spontaneity, and directness….they are a living reminder to the wider world of the essential values of the heart” (L’Arche Canada, 1993).

Key Points

- Although there are many L’Arche documents, the participants did not reference a specific document when explaining the philosophy. It was understood more in terms of general “philosophy” rather than a specific “mandate.”
- The Administrator and the assistants had a good grasp of the L’Arche philosophy. Their thorough explanation was focused on the mutual relationship element of the philosophy.
- Members did not articulate the philosophy well and there was a sense that it is more important for the assistants to be able to articulate the philosophy clearly.

Other Aspects of L’Arche Philosophy

The L’Arche Administrator and assistants were also asked about the purpose of the philosophy and how they learned it. These other aspects explain why L’Arche philosophy is distinctive and address one of the secondary research questions: “Do the mandates challenge disabling societal assumptions?” Overall, the implicit purpose of the philosophy is to change the attitudes and behaviors of the assistants. According to the Administrator, the explicit purpose of the philosophy is to act as a tool for assistants. The values within the philosophy provide guidelines for hiring and weeding out assistants as well as support the lifestyle in L’Arche communities, including the low wages and alternative values. The Administrator said,

> Our philosophy is key to how we function, because what we do is not a job, it’s a way of life. It’s more like a vocation. Without the philosophy, and internalizing those beliefs, it doesn’t make any sense to work as hard as we do while earning much less than we would doing similar work elsewhere.

Amongst the Administrator and the two assistants, the philosophy was not seen as a tool for the members with a disability; they all answered with uncertainty about whether or not the members know the philosophy. As for the assistants, they suggested the purpose of the philosophy is to explain the L'Arche lifestyle, particularly when describing the differences between L'Arche and traditional group homes.

According to the participants, the philosophy is learned in many ways and on many levels; there are initial orientation sessions, formal courses in the practical elements of support provision offered by outside organizations, formation sessions[9], accompaniment sessions,[10] and experiential learning. In sum, the philosophy and lifestyle are constantly being taught and revisited.

The Administrator expressed an interesting point that is mentioned in some of the IL interviews: the idea of "knowing" or "living" the philosophy before coming to L'Arche. The L'Arche Administrator said,

> I used to work in a group home that was run by an agency. While I was working there, I did things exactly the way I did things after coming to L'Arche. … For example, you would use a similar approach while helping someone with a bath or with their laundry. Hopefully you are going to be respectful while promoting the person's independence. You would want people to do as much as they can for themselves, whether they are living in a L'Arche home or an agency group home. The major difference between the two is the fact that we share our lives together (the assistants live in the home) in L'Arche and encourage relationships to develop between the assistants and the members with a disability. In an agency, we would be seen as "staff" and "clients" and as staff, we would be encouraged to keep our relationships with our clients on a professional level. To me it seemed

---

[9] "Formation" is a L'Arche term for philosophical training and spiritual/religious reflection.

[10] "Accompaniment sessions" are one-on-one meetings for assistants with experienced L'Arche persons. The purpose of these sessions is to support and challenge first year assistants and counsel/support assistants who stay beyond the first year.

> natural to develop friendships with the people I was supporting, since I was eating with them, sleeping in their house and spending so much time with them.

Both assistants and the attendant did not express any direct purpose of the philosophy for the members with disabilities; the members confirmed this since they did not mention any use for the philosophy. The members learned about L'Arche philosophy through books and reflection with their house.

In conclusion, the L'Arche philosophy is used primarily by the assistants; it is vast, multi-layered, and fluid, which contrasts the Independent Living philosophy, which is concrete and taught at one time.

Key Points

- The values in the philosophy to help hire and weed out assistants who do not "get it."
- The philosophy supports the L'Arche lifestyle, including working conditions.
- The philosophy is not seen as a tool for the members with disabilities.
- Assistants continually learn the philosophy in many ways, demonstrating that the philosophy is vast, multi-layered and fluid.

Components of a Support Provision Relationship

This section explores comments in the L'Arche interviews and focus group relating to the components of a support provision relationship as identified in Chapter Two: Literature Review. As such, this section deals with one of the secondary research questions: "Do theoretical support provision perspectives manifest in organizational mandates?" The components identified in the literature review are: independence, mutuality and relationship, value of the disabled person, value of the support provider, and power (for summary of the L'Arche literature, see Table 9).

Unlike L'Arche literature, the L'Arche Administrator, Long Term and Short Term Assistants did not mention the term “interdependence” at all. However, in their earlier descriptions of daily interactions, the idea of interdependence was demonstrated by the emphasis placed on supporting each other and fostering a sense of community.

This group directly reflected L'Arche literature on relationships, they were consistent and clear with their description of the relationships that are encouraged in L'Arche.

Consistent with the literature review, this group of participants places high value on people with disabilities, to the point where the Short Term Assistant would put the members' health over her own if she had to. There is one point of tension with the literature: it describes the members as valuable teachers, possessing “gifts” but in the Winnipeg community they are not directly or formally included in “formation” activities (i.e. teaching or learning the philosophy), or hiring assistants. This speaks to a tension between over-valorizing and incorporating the members with disabilities on an organizational level. The Winnipeg community seems to be aware of this tension, as according to the Long Term Assistant, the members are currently being consulted on the new mandate.

In terms of the role of the assistant, the three participants were open about the low wage they receive in comparison to other support provision organizations. There was a sense that not caring about money demonstrates “proper” motivation of an assistant. In addition, L'Arche assistants feel protected and supported by the community setting. Specifically, when discussing the Scenario Three, where an

Table 9: Summary of L'Arche Literature

Component of support provision relationship	L'Arche literature
Independence	- apolitical but counter-cultural interdependency that is not easy to achieve (a struggle to balance with personal control)
Mutuality and Relationship	- every person has a "gift" to contribute to mutually beneficial relationships - close, personal relationships are the foundation of the community
Value of disabled person	- people with disabilities are given the title "core members" as they are the 'core' of L'Arche communities - over-valorized?
Value of support provider	- assistants are nurtured and personal development is promoted Versus... - assistants are not paid well, some strict rules
Power	- power is dynamic and must be constantly negotiated

assistant must choose between his health and the member's, the L'Arche assistants were not concerned. The Long Term Assistant said, "I mean there's a way in which L'Arche you know, we don't work in these sort of settings. You know, we always work in homes where there are several people available at all times."

Finally, power was not a term that was directly referenced by most of the L'Arche participants, with the exception of one member. Amongst the other participants, the emphasis on "supporting activities" in the interactions demonstrates an effort to negotiate power. That is, the assistants make efforts to support the members with daily tasks and include them in daily decision-making. The notion of "negotiating power" is consistent with L'Arche literature (Cushing, 2003). Indeed, when discussing Scenario One where Carol, the assistant, forces Helen to take her medication, both assistants were very uncomfortable with the idea of asserting power over a member. The Long Term Assistant said, "I mean, we always end up resorting to like a hierarchy when it's necessary to making sure that everybody is accountable…but really at the end of the day, nobody sort of exists as dominant and no other as submiss[ive]." Both agreed that they would not force an individual under any circumstances to take medication. The answers demonstrate that any scenario like this would be taken with care and in consultation with other community members, supporting the idea that power imbalance is carefully negotiated in L'Arche communities.

The members with disabilities did not articulate the components of a support provision relationship in the same way; however, like the ways of interacting, all five components were touched upon by at least one participant. There was mention of decision-based independence, and an earlier emphasis on supporting activities (interdependence). As for mutual relationships, two participants spoke of assistants as “friends.” In terms of the value of the disabled person, one member described the difference between L’Arche and an institution where she had lived in the past: “It’s different because at L’Arche you have your own room, your own bath, your own pills and your own things. You can do everything in L’Arche. Go to work.” This quote demonstrates that the member feels like she has freedom and she is valued at L’Arche whereas it was different elsewhere.

The members had a lot to say about the value of the assistants. They expressed care and concern for their assistants. For instance, their responses to the scenario where an assistant injures his back included comments such as “[If] your back hurts you should go to bed” and “Help his back. Massage.” They also touched on the idea of celebrating an assistant’s birthday and even that assistants “need more money.”

Finally, although indirectly, the members with disabilities had many comments relating to power. The one direct reference to power was when a member said, “my mom told me I can’t get married because I don’t [have] enough power to get married.” Thus, this participant demonstrated some awareness of her vulnerability as a person with an intellectual disability. There were some inconsistencies, perhaps indicating the precarious power negotiation that takes place on a daily basis in L’Arche communities. For example, when one member was asked why she moved from a L’Arche apartment to a L’Arche home, she was not able to answer the question. It could be speculated that the member was not involved in the decision-making around this move, or perhaps it was a difficult question to answer. Another example came from speaking about House Meetings, which are supposed to equally involve members with disabilities. One member pointed out that the House Leader is “in charge.” By pointing out the House Leader, the member acknowledged that there is a hierarchy at L’Arche, even though the community attempts to level it out as much as possible. In response to the scenario where the person with a disability makes rules for their assistant, the members had a difficult time conceptualizing making rules for someone else. They gave examples of rules people had for them (bed time, appropriate clothing, etc.). When the scenario was reworded to include people they knew (i.e. the researcher making rules for their House Leader), there was consensus that the rule-maker was being “bossy.” Power is complicated in the lives of the members with intellectual impairments and the lack of clear responses from the members on this topic may indicate that power is not a set hierarchy in L’Arche communities, but something that is fluid and negotiable.

Key Points

- The Administrator and assistants largely reflected the same interpretation of the components of a support provision relationship as found in the literature. Indeed, even the tension between over-valorizing and meaningful inclusion was touched on. Some of the variances, for example the lack of the concept of “interdependence,” are not complete gaps as practices of these concepts are reflected in other responses.

- The members had less to say about the components of a support provision relationship. Their responses generally reflected the literature, particularly in regards to relationships and the role of the assistant. The other components are present, but more indirectly. It seems as though the members may not be able to articulate the concepts of valorization, interdependence and power negotiation. This suggests that the assistants may be applying the philosophy to the members with a disability in L’Arche communities.

Scenarios

The scenario responses are good examples of how the participants apply the philosophy in daily situations, and also provide details that support many of the other findings categories. A summary of the L'Arche participants' responses to the three scenarios follows.

Scenario One: Dignity of Risk vs. Health Concerns

In brief, Scenario One describes a situation where an assistant forces a member to take medication that will prevent her from having seizures (for complete scenarios, see Table 4 and 7 in Chapter Three). Both the Long and Short Term Assistants found this scenario difficult to respond to. They agreed that the "forcing" element is unacceptable and they both recognized the tension between decision-making/independence and health. The assistants said that they would use/have used consultation with the community to deal with similar situations. The Short Term Assistant said it was important to explain to and negotiate with the member and then fall back on the community if that did not work. The Long Term Assistant spoke about a situation where he had to "hide" a member's medication in a snack. "But I think at that point it was approved that this would be the method that we give to her, … via her substitute decision maker, her physician, our health care coordinator. It wasn't just something we did without thinking." Thus, the L'Arche community and other relevant individuals help assistants make difficult decisions. The member was not included in the consultation, although the Long Term Assistant explained that this particular person would refuse the snack if it had been known that there was medication in it.

The members did not really respond to this scenario, and the House Leader suggested that it was because this particular group has no problem taking medication and understand the importance of doing so. Understanding the importance of medication was reflected by one of the members: “[you take pills] because you don’t want to be sick.”

Scenario Two: Consumer Control

The second scenario involves a situation where a person with a disability makes a set of rules for his attendant, and some of the rules could be considered disrespectful. The L’Arche assistants both had very strong reactions to this scenario. The Long Term Assistant was indignant and felt the situation is wrong because of the relationship element. He said,

> If he truly cared for her, I mean, he wouldn’t subject anyone to that sort of manipulation …If Roger cared for Carol there, he would simply enjoy her company and her presence and wouldn’t necessarily try to determine her way of acting.

Although the assistant spoke of mutuality, equality and recognized the member’s autonomy, he had a moment where he thought the person should not have an attendant if he is capable of making such rules. The Short Term Assistant was also offended by this situation. She recognized the member’s autonomy, but felt the member and the assistant should be treated equally. She explained that just as in the last scenario, someone should not have the dominant role:

> In the same way that this Jenny wouldn’t be supposed to force … the issue, I think that also Roger … he tries to understand that none of us is really in the position to … make these kind of rules for other people.

Again, the members with disabilities had a difficult time responding to this scenario. One did not respond at all, two members gave examples of rules other people had for them, and at one point, three gave off-topic answers. Their responses imply that the concept of “making rules” for someone else, particularly an assistant, is foreign to them. Indeed, clear answers to this question only came when a new scenario was imagined where two non-disabled people made rules for each other. The group agreed that that would be “mean” and “bossy.”

Scenario Three: Role of the Assistant

Overall, the third scenario provoked the clearest responses. In the third scenario, an assistant is by himself and injuries his back; the member needs physical care that may worsen the assistant’s injury. The Long Term Assistant was not overly concerned since L’Arche intentionally exists as a community. The community is a support for both members with disabilities *and* assistants. The Short Term Assistant also recognized the community as a support for assistants, and noted that physical burnout does not seem to be as much as a problem in L’Arche as perhaps it is in other places. On the other hand, she stated that emotional burnout is an issue. In the end, she reluctantly conceded that if the assistant had no other choice, he would have a responsibility to take care of the health of the person with a disability.

This scenario was also easy for the members to respond to. Without much prompting, they thought the assistant should “go to bed!” or get a “massage” to take care of his back. They also mentioned that the assistant should “Get somebody else” to help out.

Key Points

- The assistants would rely on the community to help them make difficult decisions such as described in the first scenario.
- The members did not really respond to the first scenario, perhaps because they understand the importance of taking medication.

- Assistants found the second scenario offensive. Since L'Arche is founded on mutual relationships, there should be no dominant person in the relationship.

- The second scenario was difficult for members to envision, perhaps because they have never made rules for their support providers. They only responded clearly when the scenario was changed to include two non-disabled people that they knew, to which they thought the rules would be inappropriate.

- The third scenario was not an issue for the L'Arche assistants, who saw the community element of L'Arche as a support to prevent such situations.

- The members very clearly thought the assistant in the third scenario should take care of himself, and other members of the community should be called to help.

Context

One of the secondary research questions of this project is: "What is the role of the L'Arche environment in shaping the interactions?" Indeed, this research includes human geography in the theoretical framework and has a particular focus on the home context (Blunt, 2005; Domosh, 1998; Duncan & Lambert, 2004; Imrie, 2004a). The L'Arche Administrator and assistants clearly recognize L'Arche homes as unique places where shared, identifiable experiences take place. For instance, the Short Term Assistant said, "I came to the house [and I had] the typical L'Arche experience." In addition, there were numerous comments from all the participants that differentiated L'Arche from other support provision contexts. The Administrator said,

> We are funded by the Manitoba government and we function as an agency offering a service, but we do have our own unique kind of spin on it. We live as a community and there's a spiritual component to it as well. That's how we are different from a typical residential care providing agency.

The community structure of L'Arche is the key distinguishing feature from other contexts. The participants identified different implications that come along with the community structure, such as: the potential for people to "hide" from the outside world, a concentration of human and material resources, a social network, an emotional support network, and a religious/spiritual element.

Key points

- L’Arche homes are unique spaces, which are distinct from other living arrangements for people with intellectual impairments.
- The unique community structure of L’Arche has both positive and negative implications for community members.

Summary of L’Arche Findings

The key L’Arche findings were presented in this chapter. The findings categories aim to address the primary and secondary research questions outlined in Chapter One. To begin, the L’Arche participants identified five main interactions: life-sharing, helping, supporting, praying/spiritual, and socializing. In terms of the participants’ understanding of the philosophy, the Administrator and assistants had a strong grasp of the philosophy and represent it as a vast, overarching set of concepts learned on many occasions in a variety of ways. The members with a disability did not articulate the philosophy as clearly. The L’Arche participants generally reflected the components of a support provision relationship as outlined in the literature review. The scenario responses supported L’Arche philosophy and some of the distinguishing characteristics of the L’Arche model. Finally, comments relating to the L’Arche context presented L’Arche communities as distinct places. The relevance of the L’Arche findings are compared and contrasted with the IL findings in Chapter Six: Discussion.

Chapter Six: Discussion

The discussion section compares many of the findings of the L’Arche data and the Independent Living data. This chapter is guided by the theoretical framework outlined in Chapter One, which includes the social model of disability, the work of Titchkosky (2003) and human geography. First, Chapter Six briefly explores the significance of how closely the participants’ responses align with the components of support provision relationships as identified in the literature review. Part two examines the overall differences in the nature of the two philosophies. The distinctions between the philosophies help to explain how they manifest within support provision contexts. The third part addresses the primary research question through an analysis of how the participants interact in relation to the philosophies and the participants’ understanding of them.

The similarities and differences between the types of interactions are rich sources of information, particularly when linked to the philosophies. These overlaps and spaces represent the influence of the philosophy in daily life. It is argued that the IL philosophy shapes interactions only in certain cases, such as directing, training/employing and to a degree, helping. Other interactions, such as emotional care, negotiating and to an extent, socializing, adapt the philosophy in ways that may contest elements of IL philosophy. In the community context, L’Arche participants engage in life-sharing, helping, praying, supporting, and socializing, all of which are consistently shaped by the philosophy.

Analysis of the Components of a Support Provision Relationship

As discussed in the findings, the Administrator explained the philosophy dogmatically and the consumers and ILAs’ responses supported the idea that IL philosophy is amended in the day-to-day context of support provision. Indeed, Watson et al (2004) found that despite the IL ideal of professional relationships, “there is already some evidence that disabled people and their assistants do not experience personal assistants in purely contractual, unemotional and instrumental terms” (p.338). Thus, the research in this paper supports two trends in the wider body of Independent Living literature: there is a theoretical stream that espouses a stringent version of IL philosophy (i.e. the version portrayed by the IL Administrator) and a more flexible version that exists in the daily reality of support provision.

In the L’Arche data, the interviews with the Administrator and assistants yielded similar results to the literature review findings. However, the participants did not directly reference some key ideas, most notably the idea of “interdependence.” Indeed, the members in particular did not directly mention many of the ideas that occur in the literature review; however, the participants’ responses to other questions indicate that the values behind the literature are consistent in the community. For instance, although the term “interdependence” was not referenced by any of the L’Arche participants, the group clearly lives out this value by voluntarily living in community and supporting each other. This is the first indication of many that elements of L’Arche philosophy are built into the community milieu and occur without the articulation of all community members.

It is also interesting to note that the L’Arche participants thoroughly conveyed the relationship component of the philosophy as it is depicted in the literature review. This demonstrates that this element of L’Arche literature is an accurate portrayal of life in L’Arche communities. Overall, the L’Arche findings support the existing literature sometimes directly through the participants’ quotes and sometimes indirectly through descriptions of their actions.

General Comments on the Philosophies

As demonstrated in the findings section, the two participant groups have a general awareness of the philosophies of their respective organizations, although some of the participants had more complete understandings than others. The findings also demonstrate that the philosophies are very different from one another in many ways, which supports the distinctions noted in the literature review.

The next section discusses the relevance of the type of philosophy and ways of learning, and the intended audience and purpose of each philosophy. It is important to note the similarities and differences between the philosophies since they help explain how the philosophies shape support provision interactions.

Type of Philosophy and Learning

The findings indicate that the IL philosophy is concrete and succinct. The participants identify it as a single document on the wall at the local Independent Living Resource Centre. Although the IL participants use the term “philosophy,” their description is closer to a “mandate,” that is a formal, foundational document that outlines the ILRC’s general approach to disability and support provision. For the ILAs, the mandate is taught during the 5-week PACE program, before they start supporting consumers through the ILRC. As for the consumers, they said that they did not learn the philosophy formally but intuitively knew and/or had “lived it” for most of their lives. However, the Administrator pointed out that all ILRC volunteers undergo a brief, formal training session where IL philosophy is taught; the consumers in this study were all ILRC volunteers. For both the ILAs and consumers, the ILRC provides time-limited training, reflecting the concrete nature of the philosophy. The possibility of knowing the philosophy intuitively also supports the idea that it is a logical and simple philosophy.

According to the participants in this study, the IL philosophy is simple and accessible to most people. However, similar to criticisms of the social model (Shakespeare & Watson, 2002), it may be argued that the IL philosophy is too simple; the findings show that there are more examples of selective application or "amending" the philosophy on the ground among the IL participants than among the L'Arche participants. The analysis of the ways of interacting (below) explores examples of "amending."

The need to amend the philosophy suggests that it is not altogether practical for the IL participants. The idea that the philosophy might be too simple reflects the findings of Wong and Millard (1992) who found that although ILAs[11] may be trained in IL philosophy, the training does not necessarily equip them to deal with ethical dilemmas within support provision relationships, particularly dilemmas which challenge IL philosophy. Further, in Yamaki and Yamazaki's (2004) study, the consumer participants "had been exposed to and, to varying degrees, accepted IL ideals" (p.43). However, accepting IL ideals did not help the participants' in their study with the complex task of how to best relate to their ILAs (Yamaki & Yamazaki, 2004). These studies suggest that the simplicity of the philosophy limits its potential as a support provision tool as it does not address many common challenges.

---

[11] Wong and Millard (1992) use the term "ILSPs" or "Independent Living Service Providers" instead of "ILAs."

Secondly, ILAs are formally taught the philosophy over five weeks while the consumers simply “know it” (aside from a brief training session); this is an interesting element as it also appears in the L’Arche findings. In this case, it could be related to the social model link in IL philosophy. The Administrator described the type of people accepted into the PACE program: “I mean we accept everybody from every walk of life. Every race, from various religions…we don’t have any criteria set that way.” The IL Administrator further explained that people are not accepted if they do not meet language requirements, cannot commit to the entire duration of the program, or if they are not *physically able* to meet the demands of the program. Thus, the ILAs are typically physically able-bodied. This is why it is important to train them thoroughly in IL philosophy since, like the social model, one of its purposes is to change mainstream attitudes and it is assumed that ILAs are representatives of this population (Linton, 1998; Oliver, 1983, 1999; Rioux, 1997; Titchkosky, 2003). Unfortunately, this assumption does not consider the possibility that some ILAs will also be people with disabilities.

The idea that the consumers intuitively know the philosophy also reflects the social model assumption that there is a common disabled identity; the IL philosophy stems from simply being a person with a disability. However, the consumers did not consistently express the philosophy despite the volunteer training session provided by the ILRC, which challenges the idea of a shared disabled identity that includes an ingrained IL philosophy. The purposes of IL philosophy were expressed clearly (see below), but the philosophy itself was not explained consistently, raising the possibility that the participants know it but adjust it to suit their individual situations.

In contrast, L’Arche philosophy is vast and layered. Although the primary research question sought to explore the significance of organizational mandates, through the interviews it quickly became apparent that the idea of a “mandate” does not accurately reflect the participants’ understanding of L’Arche philosophy. The participants did not reference a specific document that embodies the philosophy, but more generally spoke of an overarching set of concepts. This may be attributed to the method of learning, as L’Arche assistants learn the philosophy through a variety of methods. The L’Arche data was analyzed in light of this difference rather than trying to force the findings to fit the concept of a “mandate.”

The vast nature of the philosophy and intensive, ongoing training have implications for how it is applied. The assistants knew the philosophy very well, and incorporated into their daily interactions and worldview. The intensive training and the controlled context of the L’Arche community also makes the philosophy more enforceable, that is, if it is not being applied the assistants may be asked to leave. As such, the L’Arche philosophy is very different from the IL mandate, since it is not really “amended” on the ground the way IL philosophy is.

Similar to the IL data, the L’Arche assistants are taught the philosophy whereas the members with disabilities are not. The participants implied that the members naturally embody the philosophy while the assistants need to learn it, supporting the literature on the highly valued role of people with disabilities in L’Arche (Cushing, 2003; Nouwen, 2000; Vanier, 1998). This concept in L’Arche is different from the PACE program because according to the L’Arche Administrator, L’Arche is careful about who becomes an assistant; people with certain subjective qualities and/or personalities are selected. Indeed, Cushing (2003) identifies common motives for why people come to live in L’Arche communities. She notes:

> [Most assistants] indicated being motivated by altruistic or socially responsible concerns. These latter concerns can generally be traced to three sources: a history of involvement in volunteer and social service activities, experience with people with intellectual disabilities, or religion. (Cushing, 2003).

The existence of common motives suggests shared personality traits and subjective qualities among assistants who come to live in L'Arche. Here, although the philosophy implicitly aims to change the assumptions and behaviours of L'Arche assistants, the social model idea of trying to change the "mainstream" perspective does not apply since the assistants represent a specific sub-group of the mainstream population. However, the home environment (Duncan & Lambert, 2004) of L'Arche becomes relevant as certain people are consciously incorporated into the community, thus increasing the likelihood of the application of L'Arche philosophy.

Intended Audience and Purpose of the Philosophies

The IL philosophy is a consumer philosophy that must be openly taught in order to subvert disabling societal norms and power imbalances. IL philosophy is an encompassing (inclusive) philosophy that everyone can understand. According to the findings, the purpose of the IL philosophy is to change attitudes and to support the consumers' role as "employer." The overarching goal is to change greater society, which then influences the more specific goal of structuring the support provision interaction. It is interesting that the consumers present IL philosophy more in terms of a "lifestyle" (e.g. comments like "living the philosophy"), which the ILAs did not express.

At L'Arche, the philosophy also implicitly intends to change the assistants' worldview and more explicitly provides guidelines for interacting with the members. In this context, the philosophy purpose is also intended to help hire and filter out assistants deemed unsuitable, and to justify the L'Arche lifestyle. The filtering aspect of L'Arche philosophy makes it an exclusive philosophy to a certain degree as it includes the idea that only some people can understand it and implement it.

Although not the explicit purpose of the philosophies, they both end up justifying the potential mistreatment of the support providers. In IL contexts, the potential mistreatment of support providers is a concern of some feminist writers (Heron, 1998; Kittay, 1999, 2002), who argue that support providers represent a vulnerable group. Titchkosky's (2003) idea that representations have real consequences for real people is apparent in the way the support providers are treated. The philosophy justifies complete consumer control, and thus limits the opportunities for the ILAs to make decisions. How the ILAs react to this vulnerability is further explained in the analysis of the ways of interacting (below). In addition, although the consumers in this study believe in consumer control, they also believe in treating their ILAs with respect as was seen in their response to Scenario Two. Thus, the philosophy justifies consumer control of the relationship and the consumers must then independently decide how to treat the ILAs, as the philosophy leaves this element open to interpretation.

In L'Arche, the material employment conditions (such as low relative wage and long working hours) are indirectly supported by the philosophy and directly supported by community literature, which commends frugal lifestyles. For instance, Vanier (1998) says,

> History is filled with examples of free men and women who refused personal advancement, wealth, and power because they wanted to live in truth and in justice, according to their consciences, following ethical principles. (p. 108).

L'Arche communities create environments where certain values and behaviours are encouraged, while others are discouraged. Assistants may avoid challenging the material conditions at L'Arche because they want to fit into the community milieu. This supports Cushing (2003) who found:

> Among themselves, assistants regularly discuss the strains, conflicts, time and human resource shortages, lack of sleep, and other difficulties of their vocation, eliciting empathy and needed support from each other. In public however, there is a clear reluctance to concede that sometimes, some parts are simply tough, not growthful.

In addition, L'Arche communities are careful to tend to the emotional and spiritual needs of the assistants through mentoring, opportunities for personal growth, and prayer (Cushing, 2003; Vanier, 1998). This creates a duality that reflects the Biblical foundation of L'Arche. A division is made between body and spirit; the needs of the spirit (i.e. emotional support) are very important and carefully tended to, while any bodily needs (i.e. material needs) are seen as less important and even unwarranted.

This research demonstrates that support providers do in fact represent a vulnerable group. Both philosophies subtly justify taking advantage of support providers, although whether or not this actually takes place is a point of contention. In theory, the IL philosophy justifies limited decision-making opportunities for ILAs and gives consumers permission to decide how to treat ILAs, while L'Arche philosophy stresses the importance of emotional support for assistants but discourages material wealth.

While in many ways the ILRC and L'Arche partake in similar activities, the philosophies are very different from each other; IL philosophy is concrete and taught once while L'Arche philosophy is vast and taught many times. Both philosophies intend to redress the societal position of people with disabilities. IL philosophy is intended as a tool for consumers to change mainstream society and support their roles, while L'Arche philosophy is intended to provide guidelines to a specific audience (the assistants). However, both philosophies include elements that justify potential mistreatment of support providers. The differences in the philosophy are considered throughout the analysis of the ways of interacting (below) and the final conclusions.

Comparison of Ways of Interacting

In this study, the differences in organizational philosophies manifest on the ground. This is most clearly seen in the variance between how the L'Arche participants speak of interacting with each other compared to how the IL participants define their interactions (see Figure 1 and 2). The following section addresses the primary research question, "In what ways do the mandates (philosophies) of support provision organizations shape the interactions between people with disabilities and their support providers?"

The overall categories identified by the participants are a significant point to start from. The interactions can be mapped on a continuum ranging from formal and/or practical interactions to informal and/or emotional interactions. The formal/practical interactions are largely action-based and relate to the "work" side of support provision. The informal/emotional interactions are more abstract and relate to the "care" side of support provision. Figure 1 and 2 help to demonstrate the different interactions between IL contexts and L'Arche. In both figures, the horizontal

Figure 1: IL Range of Interactions

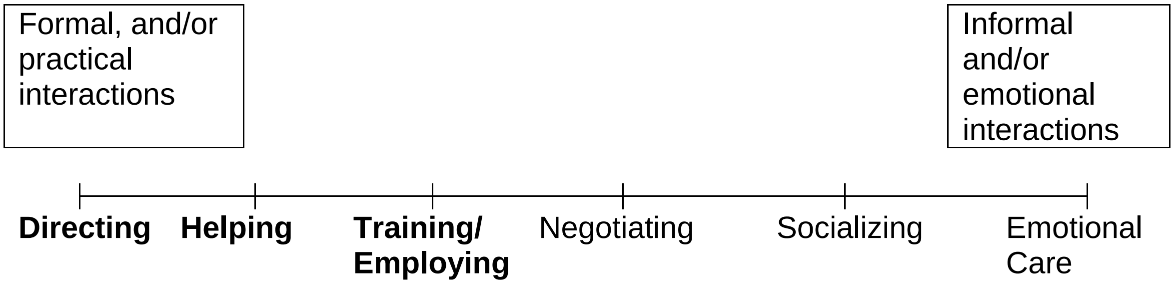
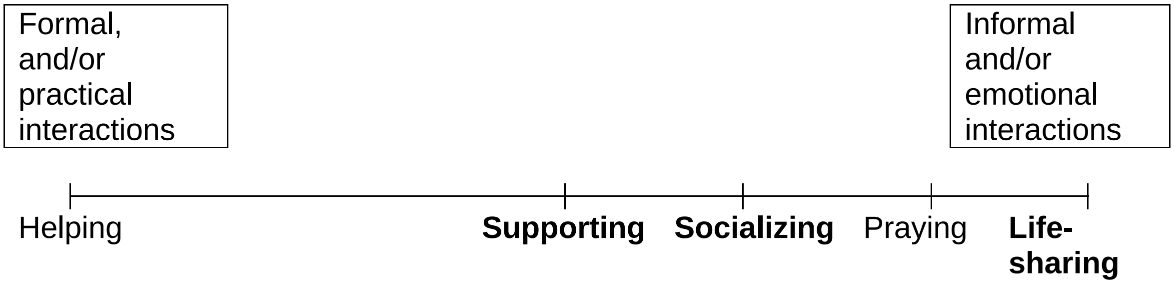


Figure 2: L'Arche Range of Interactions



line represents the range of interactions identified by the participants. The bold terms represent what interactions were emphasized by the participants. For instance, in Figure 1, the three bold categories on the formal, practical end were emphasized by the participants. This contrasts with Figure 2, which has fewer types of interactions on the left side overall, and does not emphasize “helping,” the one category on the formal end. The interactions identified demonstrate that the IL participants and the L’Arche participants conceptualize and perform support provision differently from one another, and these differences may be attributed to the organizational mandate.

This section argues that IL philosophy influences three of the interactions described by the participants, while the other interactions create tension with the philosophy (see Table 10). Earlier, the idea that IL philosophy may be amended by the participants was introduced in the discussion of the general nature of the philosophy. Indeed, some of the interactions described by the IL participants do not seem to extend from IL philosophy. As mentioned in Chapter Four: Independent Living Findings, the IL Administrator suggested that this is because some interactions are left up to the discretion of the consumer. As such, “amending” could be seen as a manifestation of the consumer control element of IL philosophy; that is, consumers are encouraged to decide the degree and frequency of socializing, emotional care and negotiating. However, this section argues that these interactions do not demonstrate IL philosophy but actually contest some of the main principles of it. For the L’Arche data, this section demonstrates that all of the interactions described by the participants are influenced by L’Arche philosophy (see Table 10). In addition, the above general discussion of the philosophy alluded to occasions where the philosophy manifests itself in L’Arche communities without the awareness of all

Table 10: Comparison of Interactions to Philosophies

ILRC	L'Arche
1. Directing/following instructions *This type of interaction is characterized by the consumer directing the ILA in various tasks*. Philosophy links: Consumer control, making choices and political change.	No parallel in L'Arche data Philosophy links: L'Arche philosophy promotes mutual relationships with no dominant figure between member and assistant.
2. Helping interactions *Helping interactions are when the ILAs do specific personal care tasks for the consumer.* Philosophy links: Making choices and decision-based independence.	**1. Helping interactions** *Helping interactions are when the assistants do things for the members.* Philosophy links: L'Arche literature relates helping interactions to relationship building.
3. Negotiating activities *Negotiating activities are when the ILA attempts to convince the consumer to do things, which in the ILA's opinion, are in the best interest of the consumer.* Philosophy links: No link to IL philosophy. Creates tension with the consumer control element of the philosophy.	**2. Supporting activities** *Supporting activities include all household maintenance that the members and assistants intentionally do together, even though the assistant might be able to complete same tasks more efficiently independently.* Philosophy links: Community building.
4. Training/employing interactions *This refers to interactions where the consumer intentionally teaches the ILA, and/or acting as a employer by doing activities such as scheduling and payroll.* Philosophy links: Consumer control and decision-based independence.	**3. Praying/Spiritual activities** *This refers to formal prayer and reflection as a group.* Philosophy links: Faith and religion, community.

(Table continued…)

5. Socializing interactions *Socializing interactions are any fun or extracurricular activities done between consumer and ILA.* Philosophy links: No clear link to IL philosophy.	**4. Socializing interactions** *Socializing interactions are any fun or extracurricular activities done between a member with a disability and an assistant, community member, or friend of L'Arche.* Philosophy links: Community and relationships of mutuality.
6. Emotional care activities *These activities include sharing personal information, providing advice and support through day-to-day life and major decision-making.* Philosophy links: No link to IL philosophy. Contests the formal relationships promoted in IL philosophy.	**5. Life sharing interactions** *Life-sharing interactions are characterized by "relational" or "Family like" activities. These activities are abstract, and include sharing personal information, providing advice and emotional support through day-to-day life and major decision-making.* Philosophy links: Origin story and relationships of mutuality.
Summary: Three of the interactions identified by the IL participants can be linked back to IL philosophy.	**Summary: All interactions identified by the L'Arche participants can be linked back to L'Arche philosophy.**

community members. The interactions in Table 10 present many more examples of this happening.

Directing activities in IL context

The IL participants all mentioned directing activities as a type of interaction, which is particularly significant since it does not appear in the L’Arche data. “Directing” does not fit with L’Arche philosophy, which emphasizes mutual relationships where there is no dominant individual. However, directing interactions can be linked to IL philosophy’s promotion of consumer control, making choices, and the political goal of challenging stereotypes about people with disabilities.

As mentioned in the literature review, the IL literature promotes “direct payment” as a mechanism to implement the consumer control element of the IL philosophy (Shakespeare, 2000). None of the participants in this study utilized the Manitoba version of direct payment, that is, the ‘self-managed homecare program;’ however, in IL philosophy it is possible to see the principle of consumer control in practice through the directing interactions that take place. The ILAs accepted that the consumer is in control of the relationship. For instance, the Long-Term ILA said, “if that’s what he wanted me to do, then that’s what I’ve gotta do.”

The sense that the ILA has to follow the directions of the consumer is strong throughout all the scenario responses. In the first scenario, the ILAs would not force medication against the consumer’s request, and although they would try to convince the consumer to take it (or negotiate, see below), they ultimately would follow the direction of the consumer. The directing interaction reinforces the concept of the ILA as an “extension” of the consumer’s body, with the responsibility and power resting with the consumer (Earle, 2001; Shakespeare, 2000).

In the second scenario, with the exception of Consumer I, even though the participants were uncomfortable with some of Roger’s rules, they felt that the consumer must define the roles in the relationship and the ILA must follow the parameters. Finally, in the third scenario, all participants agreed that the ILA ultimately has a responsibility to follow the direction to “roll over Joyce” despite his own discomfort and health concerns. As indicated by the scenario responses, following directions is an integral element to IL support provision interactions.

The directing interaction between consumers and ILAs is clearly linked to the consumer control element of IL philosophy, as well as to “making choices” and even the political element since it is an empowering action for people with disabilities. When the consumer consistently directs the ILA it results in an emphasis on formal business-like relationships with the defined roles of “employer” and “employee.” These implications are reinforced and challenged in some of the other interactions, which is discussed later.

The social model and Titchkosky’s (2003) work are helpful to explain the significance of directing interactions within support provision relationships. By directing support providers, the consumers are resisting a societal aspect of their disability – the representation of disability as “dependent” (Kestenbaum, 1996). As Titchkosky (2003) notes, the representation of people with disabilities as “dependent” has real consequences in the lives of real people. As the social model suggests, consciously or unconsciously resisting barriers that create disability (such as negative representations) is a method of challenging the dominant ideology. In sum, directing interactions are shaped by IL philosophy and are a powerful political statement; in order to make this statement, the interaction creates specific roles for the consumer and ILA.

Emotional Care Activities and Life-sharing

The directing interactions in the IL findings starkly contrast the emotional care activities, which are paralleled in the L'Arche findings with life-sharing interactions (see Table 10). The ILAs and consumers alluded to emotional care activities, but never directly mentioned any. The lack of emphasis on emotional care activities in the IL data is striking since similar "life-sharing interactions" are the primary emphasis in the L'Arche data. IL philosophy does not have an emotional element built in. In fact, the ILM criticizes the Carers' Movement and the feminist ethic of care, both of which focus on this aspect of support provision (Morris, 1993). Thus, the under-emphasis fits with the literature and engaging in emotional care can actually be seen to contest IL literature and philosophy. However, in this study the IL participants appear to be grappling with how to reconcile IL philosophy with the emotional care that inevitably takes place in support provision relationships. The participants distinguished between knowing and living the philosophy. Consumer II said,

> I have respect for people who practice it, and I don't have respect for people who just pay lip service to it. I can make a philosophy about how you have to treat your dog, doesn't mean that you're going to do it.

The participants want to be publicly seen as "living" Independent Living philosophy, and discussing the emotional care interactions that take place between consumer and ILA may be seen to contradict to this.

Indeed, the observed "grappling" around the nature of relationships is consistent with the findings of Yamaki and Yamazaki's (2004) study of Japanese consumers who struggled with the very same issue; they also found that consumers had to make "efforts to keep their relationships in check" since they were concerned that allowing them to develop naturally may lead to problems (p. 39). Secondly, the idea that emotional care is an inevitable aspect of support provision relationships is supported by Piercy (2000) who found that friendship-like relationships commonly occur between people with disabilities and their support providers (regardless of organizational philosophy). Between these two studies and the findings of this research, it appears as though emotional care is a part of IL support provision interactions (although it is not addressed by the philosophy), and both parties must consciously work to achieve healthy relationships.

According to human geography, the home is a highly emotional space (Duncan & Lambert, 2003). Since support provision takes place within the homes of people with disabilities, and many of the interactions are very personal, it is understandable that the context leads to the development of emotional care interactions. The context of support provision is laden with emotions and thus shapes the interactions between ILA and consumer; however, since this interaction diverges from IL philosophy, the participants are left to deal with the conflicted roles.

At L'Arche, life-sharing interactions were the focus of the assistants' interviews and reflect the "mutuality and relationship" element of L'Arche philosophy and literature. The findings show that long-term assistants and House Leaders become relationship-experts and assistants who do not engage in life-sharing "don't get it" and may be asked to leave the community; these findings underline the importance attributed to life-sharing activities in L'Arche.

Life-sharing interactions were further promoted by the participants' responses to Scenario Two. As mentioned in the findings, the L'Arche assistants were offended at this scenario, as out of respect for one another they felt there should not be a dominate person in support provision relationships. Although less clearly, the members with disabilities agreed with this sentiment (e.g. that would be “bossy”). This is an example of the philosophy shaping support provision interactions. IL philosophy promotes the very different ideal of consumer control, resulting in attempts for business-like ways of interacting. In contrast, at L’Arche, the philosophy promotes relationships of mutuality, resulting in close, family-like ways of interacting.

Life-sharing can be interpreted in light of the social model; life-sharing breaks down the well-documented barrier of stigma and social exclusion that people with intellectual disabilities face (Bogdan & Taylor, 1992; Pottie & Sumarah, 2004; Taylor & Bogdan, 1989; Wolfensberger, 2000). Life-sharing is directly tied to the L’Arche notion of mutual relationships, and crosses over with many of the sentiments expressed in the feminist ethic of care literature, such as the concept that caring is innate and emotion-based (Manning, 1992). With the social model, L’Arche philosophy and the feminist ethic of care in mind, emotional care interactions are natural and expected to occur in support provision relationships In addition, this form of interaction actually breaks down social barriers for people with intellectual disabilities. In addition, the human geography of L’Arche creates a context where certain interactions, which may be seen as unacceptable in other support provision contexts, are promoted and encouraged. This is one of many examples where L’Arche philosophy is built into the structure of the community.

Helping Interactions in Both Contexts

Both participant groups described some helping interactions, although the importance of this type of interaction varied between the groups. Among the IL participants, helping interactions were the most commonly mentioned category. This ties in well with the directing activities, as it is an example of the consumer instructing ILA what to do, and the ILA following the instructions. Secondly, this type of activity reflects on the participants' understanding of independence. At some points, it is clear that it is not important for the consumers to physically do the tasks themselves but only important for the ILAs to follow their instructions, reflecting a decision-based understanding of independence. Helgoy et al (2003) explain this type of independence: "[it means] being able to make decision about one's own life, to be in charge in daily life, regardless of how this is being accomplished" (p. 473). Decision-based independence is the foundation of IL philosophy. However, there were occasions in the interviews where decision-based independence was contradicted. Consumer II spoke about why he does his own cooking, "I could sit there and instruct people to do the things that I do, they could do in one quarter of the time, but to me there's no self-satisfaction in it." Also, the Long-Term ILA gave an example where he might try to convince a consumer to do his/her own dishes "You know, because if you do it yourself you'll feel a little more better about yourself that you're able to do more. You know, than sit back and you know, and have somebody else do it for you." Both of these quotes reflect an action-based understanding of independence based on being "able to perform practical tasks alone or without direct help" (Helgoy et al, 2003, p.473).

The contradiction between the understandings of independence held by the IL participants indicate that, like the participants in Helgoy et al's study (2003), the IL participants in this study have a multifaceted definition of independence that encompasses both decisions and actions. A twofold definition of independence is in conflict with IL philosophy, as IL philosophy attempts to redefine independence solely in decision-based terms. This is a situation where the support provision interactions are only partially shaped by the IL philosophy; the participants have adopted the decision-based understanding to a certain extent since the consumers direct the ILAs in helping activities, but they also maintain the mainstream understanding of independence in terms of action.

Titchkosky (2003) advocates the idea that impairment and disability can “illuminate society” and the social model urges researchers to listen to the voices of people with disabilities (p. 6; Linton, 1998). By listening to some of the consumers in this study, it is clear that the IL definition of independence is not sufficient. IL philosophy argues that defining independence only in action-based terms contributes to the social construction of disability, as there are some tasks that some bodies simply cannot perform (Morris, 1993). However, some of the participants in this study value the traditional action-based definition in some situations. They feel there are subjective benefits to physically doing things for oneself, such as bolstering self-image and personal satisfaction. Thus, the IL philosophy does not always reflect the reality of the consumers’ lives, which corresponds with the criticisms of the social model made by Shakespeare and Watson (2002). The idea that there are benefits to action-based independence is also reflected in L’Arche literature, where members with disabilities are encouraged to help around the house as much as possible, and is also evident in the supporting interactions in L’Arche (below). By defining independence in multiple ways, the participants are amending IL philosophy in order to more accurately reflect their daily reality and perhaps are still challenging societal assumptions in a more complex way.

At L’Arche, helping activities were mentioned, but were not the focus of the data.

Having to “do things” for the members was downplayed by the assistants and the Administrator. Interestingly, L’Arche literature presents the idea of forming close, spiritual relationships through seemingly mundane day-to-day tasks such as bathing and helping someone eat. For instance, Nouwen (1998) explains his relationship with Adam, a core member at L’Arche Daybreak in Ontario:

> My daily time [helping Adam bath, dress and eat] had created a bond between us that was much deeper than I had originally realized. … My closeness to him and to his body was bringing me closer to myself and to my own body. It was as if Adam kept pulling me back to earth, the ground of being, to the source of life. My many words, spoken or written, always tempted me to go up into lofty ideas and perspectives without keeping in touch the dailiness and beauty of ordinary life. (p. 48-49).

The idea that “helping” has deeper ramifications is also reflected in the feminist ethic of care (Watson et al, 2004). The assistants do not articulate this connection, suggesting that in this situation, the philosophy may be shaping support provision interactions without the awareness of the assistants and members. This is possible because of the L’Arche context: its structure and daily functioning are rooted in the writings of Jean Vanier and others. Although assistants are strongly encouraged to learn about the underlying philosophy, a certain structure exists regardless of their awareness of it. This explains why the assistants and the L’Arche Administrator were not concerned with the fact that the members with disabilities may not be aware of the philosophy. The geography of the community includes a structure that functions according to the main aspects of L’Arche philosophy; part of this structure is the understanding that assistants will do things for the members in a “helping” way in order to generate close relationships (which are encouraged). The participants were aware of the relationships, but did not focus on the actions that generate them.

Negotiating Interactions and Supporting Interactions

Among the IL participants, only one consumer and both ILAs referred to “negotiating activities.” The concept that the ILA may try to influence the consumer’s decisions and actions shows the ILA attempting to assert some power in the relationship. This finding supports the work of Wong and Millard (1992), who found that ILA perceptions of what is “best” for a consumer may differ from the consumer’s choices. However, in all the examples in this study, the participants concluded that final decisions are left to the consumers. As such, on some level the participants are aware that negotiating conflicts with IL philosophy as they are careful to point out that negotiating is limited since the consumer ultimately holds the power.

The fact that both ILAs mentioned this type of interaction and only one consumer did implies that negotiating is more important to the ILAs than it is to the consumers. As indicated by the overall responses to Scenario Two, negotiating interactions can only flow in a particular way. In Scenario Two, the participants felt that the ILA can be offended by the rules, but cannot negotiate them. ILAs cannot negotiate on behalf of themselves, but only in what they perceive as the best interest of the consumer. This is a subtle “tug-of-war” over power – the consumer is intentionally in control of the ILA, which reflects IL philosophy, but the ILAs nevertheless attempt to regain some of that power through negotiating with the consumer.

The IL Administrator had a complex understanding of IL philosophy but did not mention negotiating interactions. Thus, since the IL Administrator does not engage in support provision, it appears that the IL philosophy is amended in daily life by the ILAs. The ILAs know that the consumers are the ultimate decision makers in the relationship, yet they still try to negotiate and influence the decisions made by consumers. This notion supports Shakespeare and Watson (2002) who argue that the social model of disability (which is linked to IL philosophy) is not as simple as it is in theory when it is applied in the daily lives of people with disabilities.

The social model of disability can actually be applied to the support providers in this situation. Many authors and this study have pointed out that, like people with disabilities, support providers represent a vulnerable group (Kittay, 1999, Kittay, 2002; Noddings, 1984). In addition, some support providers may be people with disabilities themselves. Part of their vulnerability is socially constructed, and part of it is built into the environment. For instance, societal assumptions about the nature of support provision and the skills (or presumed lack thereof) needed to be a support provider influence the social value attributed to this role (Hugman, 1991). In addition, the geography of support provision can contribute to the vulnerability of support providers, as it can often take place in unregulated systems (Ungerson, 2004). Thus, by engaging in negotiating interactions, the ILAs in this study are resisting (consciously or unconsciously) the label of “powerless,” which is inadvertently a resistance against IL philosophy.

The supporting interactions that occur in L’Arche are somewhat similar to the negotiating interactions identified by some of the IL participants; however, supporting activities are linked to L’Arche philosophy and are not limited to certain roles. The assistants can support the members and vice versa in L’Arche. For instance, the L’Arche Administrator said,

> I remember when I first moved [here], I didn’t know where things were. And one of the people I was supporting in an apartment, she would walk with me and show me where things were. Or while I was driving, she would direct me.

> And she was competent to do this because she knew [this place] inside out and I was very confused. …. So that that tells me that they, they feel like they have something to offer. They are not just receiving from me, they're giving. That it's mutual.

Similarly, the scenario responses reflected the notion of mutual support, particularly Scenario Two where the participants felt that the member has a responsibility to support the assistants just as the assistants support them.

Supporting interactions were not emphasized by the members with disabilities; however, as indicated by the assistants and Administrator's responses, the members do engage in this type of interaction. This strengthens the human geography notion of a community structure (influenced by philosophy) that generates certain interactions with or without the knowledge of the people living there (Duncan & Lambert, 2004).

Socializing Interactions

As mentioned in the findings, the IL participants sometimes socialize together, but attempt to keep this activity separate from their work interactions. The separation of working and socializing resonates with way the IL participants handle emotional care interactions, although socializing does not create the same degree of tension with the philosophy as emotional care does. While socializing interactions may take place, they are downplayed by the participants possibly because they are not dealt with by IL philosophy, or possibly because the participants are attempting to maintain "professional" relationships with each other. The distinction between a work relationship and a social relationship indicates that the participants fill many roles for each other, supporting the findings of Yamaki and Yamazaki (2004). In their study of Japanese consumers, they identified three significant dimensions to the support provision relationships: functional, interpersonal and collective (Yamaki &

Yamazaki, 2004). The findings of Yamaki and Yamazaki (2004) and of this study demonstrate that only certain roles are appropriate within support provision interactions in an IL context, and any other roles that do not fit must be kept separate. Thus, the consumers and support providers alike must juggle their roles carefully, and be cautious about boundaries while providing support.

Human geography calls for reflection on the home environment (Blunt, 2005; Domosh, 1998; Duncan & Lambert, 2004; Imrie, 2004a). According to IL philosophy, living independently in the community empowers people with disabilities. Indeed, IL interactions in this study take place in the consumers' private apartments. These interactions often occur just between the ILA and the consumer, unfortunately making both parties vulnerable (Beatty et al, 1998). The ILA is entering the consumers' home, and the consumer needs to protect his or her personal space and comfort level by feeling in control. It is clear that for these participants, this happens through setting fairly clear boundaries and roles within the home, but allowing for alternative roles in other contexts. This may be the one case where IL philosophy does leave the boundaries up to the consumer, since some would argue that socializing does not conflict with business-like relationships.

At L'Arche, members with disabilities and assistants often interact in shared spaces. The home space is still a personal space for members, but it is also a personal space for the assistants, making L'Arche homes 'communal-personal' spaces. The community structure provides support and protection for members and assistants alike. Thus, in the L'Arche context, socializing interactions are commonplace (Mosteller, 1996; Nouwen, 2000; Pottie & Sumarah, 2004). Socializing is linked to the community element of L'Arche philosophy, as well as is a part of mutual relationships. In the focus group, the members with disabilities emphasized social interactions the most. There is not as much of a need for clear role boundaries in the home since the space is shared and the members are less vulnerable by having other people around.

The final two ways of interacting did not overlap between the two groups, since they are closely linked to the contexts and philosophies. Since they do not overlap, the following interactions are good examples of the influence of the philosophy in daily life. In addition, the nature of these interactions supports the ongoing themes throughout the other interactions and is expanded below.

Training and Employing Interactions in the IL Context

In the IL findings, the consumers were proud to be PACE trainers while the ILAs did not recognize this way of interacting. The ILAs knew that some consumers are trainers since they were trained by consumers in the PACE program. However, outside of the classroom, the ILAs did not identify the consumers that they work with as trainers. Similarly, the consumers only identified themselves as trainers in relation to PACE and not in day-to-day terms. This may be partially attributed to the time-limited nature of the IL training, as discussed earlier. Since the formal training takes place at a set time and is not ongoing, the ILAs assume they are “done” learning, and the consumers see the role of “trainer” as contained in the formal context of the PACE classroom.

Training and employing interactions clearly reflect the consumer control element of IL philosophy. The context (or geography) of the PACE program serves to limit the trainer role to the classroom, however, as Titchkosky (2003) would argue, this trainer role creates a new representation of the consumer, which lingers in support provision interactions in the form of directing interactions.

Praying/spiritual Interactions

Praying and spiritual interactions are common components of daily life in a L'Arche community and faith and religion are major components of L'Arche philosophy (Mosteller, 1996; Nouwen, 2000; Vanier, 1995, 1998). The L'Arche Administrator emphasized that "[L'Arche] is a Christian community that we are living in but you don't have to be Christian to be a part of it, you just have to be respectful and open" and indeed, the Short Term Assistant did not mention any praying interactions. This is another example of how the philosophy is built into the community structure. Whether or not a member or assistant is religious, religious activities take place in the community and even in the home. Again, the philosophy influences daily life with or without the conscious participation of people who live in the community.

Discussion Summary

This chapter pulled together the literature review, general comments on the two philosophies and engaged in an analysis of the ways of interacting as linked to the philosophies. In sum, the IL findings from this research fall between the traditional IL literature and the new body of research on the flexibility of the philosophy. The L'Arche findings are in line with the majority of L'Arche literature.

Secondly, this chapter explored the general nature of the philosophies. The simplicity of IL philosophy and the variety in contexts may lead to amending it in daily life. L'Arche philosophy on the other hand is vast and is implemented fairly consistently because of the controlled community context. The purposes of the IL philosophy were clearly expressed by the participants, despite the fact that the details of it were not, furthering the argument that the philosophy is adjusted in day-to-day life. L'Arche philosophy is geared towards assistants, but unfortunately, both philosophies implicitly justify the potential mistreatment of support providers.

Finally, Chapter Six explored the difference in the overall ways of interaction identified by the two groups. The IL participants focused on formal/practical interactions while the L'Arche participants expressed more informal/emotional interactions. Three of the IL interactions can be linked back to the philosophy, while the other three contest it. All of the L'Arche interactions link back to the philosophy. The main conclusions drawn from the discussion are reiterated in the following chapter.

Chapter Seven: Conclusions

This study demonstrates that organizational mandates and philosophies shape interactions between support providers and people with disabilities in multiple ways, and aspects of this process reinforce and challenge the existing literature. This chapter summarizes the key points emerging from the research for both the ILRC and L'Arche. A key conclusion drawn from the research is that both organizations in this study are examples of ”operationalized mandates/philosophies,” that is, philosophies that “come to life” in practice. The IL philosophy shapes three types of support provision interactions: directing, helping, and employing/training. It is contested or questioned by the three other interactions: emotional care, negotiating, and socializing. In L'Arche, the participants interact through life-sharing, helping, supporting, socializing and praying. L'Arche philosophy, as embedded in the community context, strongly shapes the interactions of the people living and working there.

Independent Living Resource Centre

Upon comparison to the findings of the literature review (Chapter Two) the findings from the Independent Living data in this research support the trends in the wider body of literature. The Administrator's interview reflects the more theoretical stream in the literature, while the consumers' and ILAs' interviews fall in line with the new stream of studies that demonstrate that IL philosophy is adjusted on the frontlines of support provision. Thus, to answer one of the secondary research questions, the theoretical support provision perspectives do in fact manifest in organizational mandates; however, for the IL data, the major tensions in the literature are not clarified in this form.

Overall, the participants in this research see IL philosophy as simple and concrete. The philosophy is inclusive and can be taught to most people. It is taught over a limited period of time to the ILAs. As for the consumers, they said that they “knew” the philosophy by being a person with a disability. In addition, if the consumers volunteer at the ILRC, they are taught the philosophy in a brief training session. Although the participants agreed on the purposes of the philosophy, they did not consistently mention all aspects of it, which challenges the concept of a shared disabled identity that includes understanding the Independent Living philosophy. In addition, the variations in the participants’ understanding of the philosophy suggests that is it amended in daily life.

One of the secondary research questions is: “Do the mandates challenge disabling societal assumptions?” According to the IL participants, the purpose of the IL philosophy is to change societal assumptions about people with disabilities by giving the consumers the role of decision-maker within the support provision relationship. Unfortunately, while these goals may challenge disabling societal assumptions about consumers they also justify potential mistreatment of the support providers, some of whom may be people with disabilities themselves. In some IL literature, support providers are represented as servants and the literature review questioned whether they are actually treated as such. This study found that the responsibility to treat ILAs fairly is left in the hands of the consumer. The Independent Living philosophy may lead to exploitation of support providers since the philosophy justifies limiting their decision-making opportunities within support provision interactions.

Significance of the IL Interactions

Among the participants in this study, the IL philosophy shapes support provision interactions in three main ways and is contested or questioned by the three others. To summarize:

1. Directing interactions: Directing interactions are connected to the consumer control element of IL philosophy, as well as "making choices" and the political goal of challenging stereotypes. Directing interactions create clear roles of "employer" and "employee." The consumers endorse the roles in order to resist the negative representation of people with disabilities as "dependent."

2. Emotional care interactions: The context of support provision is laden with emotions, however this type of interaction is not endorsed by IL philosophy. In fact, the ILM criticizes the Carers' Movement who promote this element of support provision. The participants are left to negotiate support provision roles. In this case, the IL philosophy creates guidelines for what is/is not an appropriate support provision relationship and possibly causes ILAs and consumers to avoid or hide "inappropriate" interactions such as emotional care.

3. Helping interactions: IL philosophy defines independence specifically in terms of decision-making. Some of the participants in this study have a different definition of independence than what is outlined in the philosophy, demonstrating that the philosophy is amended on the ground to reflect the reality of support provision.

4. Negotiating interactions: The IL philosophy does not link to negotiating interactions. The philosophy does argue for a certain power distribution in order

to challenge the typical power imbalance. ILAs, who also represent a vulnerable group, subtly react against this by trying to influence the consumers’ actions and decisions, although the ILAs do not try to improve their own situation. Here, the philosophy again creates certain roles for the participants to which they accept/reject to varying degrees.

5. Socializing interactions: Similar to emotional care activities, socializing interactions occur but the IL participants keep them separate from work, as it is unclear whether it fits within the roles defined by IL philosophy. Part of the emphasis on “role negotiation” can be attributed to the consumers’ efforts to maintain control in their personal spaces.

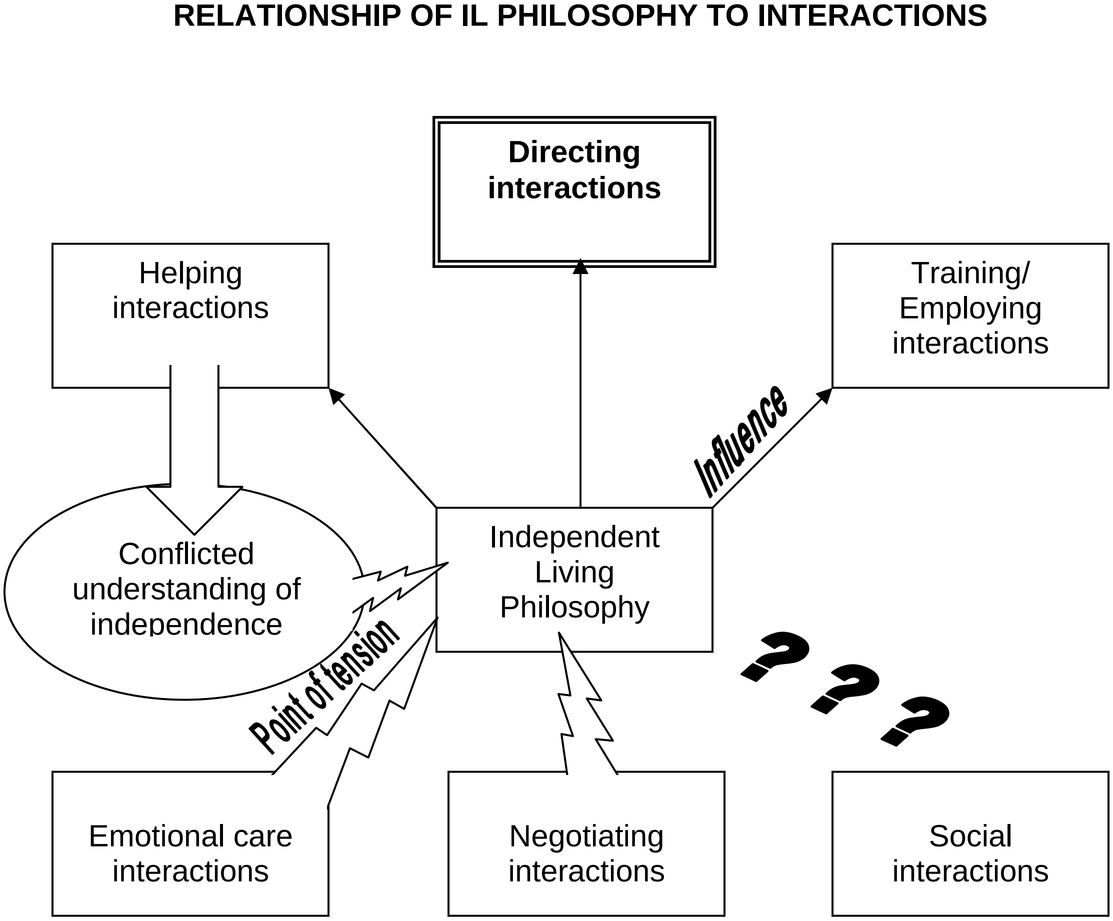
6. Training/employing interactions: Although under-recognized by the ILAs, the training/employer interactions are linked to IL philosophy through the consumer control element and decision-based independence.

Overall, IL philosophy clearly shapes three interactions: directing, training/employing, and helping (although helping is only partial because of the conflicted understanding of independence). The idea of amending as it appears throughout many of the main conclusions of the IL research creates tension with the philosophy. Thus, two interactions serve to directly contest IL philosophy: emotional care and negotiating. It is unclear whether or not socializing is considered appropriate by IL philosophy, leaving this element up to the consumers to determine. In response to one of the secondary research questions, the IL participants adjust the philosophy to a large extent to suit their contexts. In addition, this conclusion ties into one of the literature gaps that suggested the need for organizational philosophies to present flexible understandings of complex support provision concepts. Unfortunately in this case, the simplicity of the IL philosophy leaves the participants to create this flexibility outside of the IL tenets. The IL philosophy is strained by ardent support for the political ideals on one hand and subtle resistance through amending on the other (See Figure 3).

Figure 3 depicts the main findings of the IL data. The figure is in an open space to represent the inclusive nature of the model. The Independent Living philosophy is in the centre. The arrows point outward to the three types of interactions which are clearly shaped by IL philosophy. The emphasis is on directing interactions (bold box), which was the focus of the data. The interactions that IL philosophy shapes are very important since these three hold the potential to change societal assumptions about people with disabilities; however the IL philosophy inadvertently creates a negative representation of support providers as servants and does not challenge their societal position as a vulnerable group. The remaining ways of interacting (on the bottom of Figure 3) represent an amendment of the theoretical version of IL philosophy, and these amendments actually contest some elements of the philosophy. The exceptions are helping interactions, which due to the participants' two-fold definition of independence, serve to both support and challenge IL philosophy, and socializing, which is unclear whether it contests the philosophy.

There are a few reasons that may explain the amendment of the philosophy. A primary reason is that, even in this study, the IL contexts are varied, possibly contributing to the different interpretations and applications of the philosophy. In

Figure 3: Independent Living Conclusions



addition, the people who become ILAs and the people who consider themselves consumers comprise a very diverse group. However, in this study, it appears that when certain interactions are sanctioned by the IL philosophy, those are the interactions that are more likely to occur openly. When alternative interactions take place on the ground, they may be halted before they go “too far” since on some level, the participants know that the alternative actions contest IL philosophy.

L’Arche

In light of the findings of the literature review (Chapter Two), the L’Arche Winnipeg data in this research reflects the trends of the literature. Thus, to respond to one of the secondary research questions, the L’Arche literature does manifest in organizational mandates. However, the participants in the Winnipeg community did not directly reference some of the key notions, such as interdependence, although the notions were demonstrated by their actions and lifestyles. This is one of the first indications that L’Arche philosophy is applied in daily life regardless of the knowledge of the community members.

At L’Arche the participants see the philosophy as an overarching set of concepts rather than a “mandate.” The philosophy is taught to the assistants on many occasions in many ways. The methods of training and the controlled context (including who is accepted into L’Arche communities) make the philosophy more enforceable. The members with disabilities in the L’Arche Winnipeg community are not taught the philosophy in the same way as the assistants are (i.e. in a formal classroom setting); however, the philosophy seems to be implemented regardless of whether all community members possess in-depth knowledge of it. The literature review questioned if and how L’Arche is successful at conveying its philosophy to support providers. This research shows that the L'Arche model is successful at conveying its philosophy to the assistants in the community through intensive training and a controlled context. This method also transfers flexible understandings of complex support provision concepts (another concern of the literature review).

According to the participants, the philosophy is designed as a tool for assistants at L'Arche. To a certain extent, the philosophy is exclusive since it acts as a filter to help hire and weed out assistants. It also outlines acceptable ways the assistants should interact with the members. Finally, it justifies the lifestyle and working conditions at L'Arche. Like the IL mandate, the L'Arche philosophy reinforces the assistants' vulnerability by justifying the material conditions in the communities.

Significance of the L'Arche Interactions

The ways of interacting are the clearest examples of how L'Arche philosophy shapes interactions between people with disabilities and support providers. L'Arche philosophy noticeably shapes all five interactions. This partially results from the community element of L'Arche. Briefly, the five interactions identified by the L'Arche participants are:

1. Life-sharing interactions: At L'Arche the mutual relationship aspect of the philosophy helps to create an environment that supports and promotes rich relational interactions. Unlike the IL participants, this type of interaction occurs often and openly. Life-sharing breaks social barriers for people with intellectual disabilities who often face stigma and exclusion. To respond to a secondary research question, the L'Arche philosophy challenges disabling societal assumptions.

2. Helping interactions: Although not all community members may be aware of the connection, L’Arche literature suggests that helping interactions can generate the close relationships, which are highly valued. The community accepts and encourages these interactions.

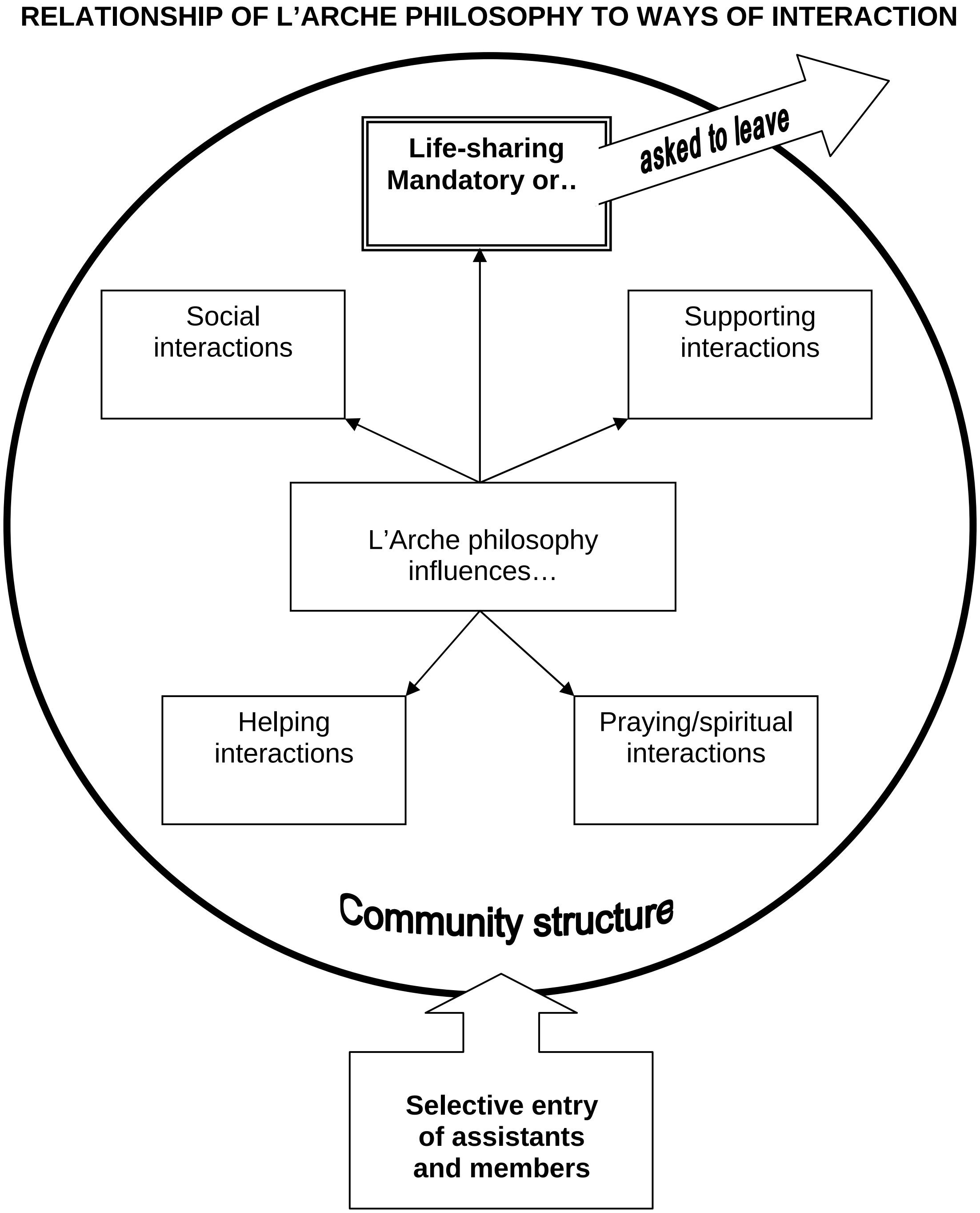
3. Supporting interactions: The community element of L’Arche philosophy is linked to the supporting interactions.

4. Socializing interactions: L’Arche philosophy promotes community and mutual relationships leading to the creation of flexible support provision roles and a relatively “safe” environment. Socializing interactions are commonplace and not considered to be risky in terms of blurring boundaries.

5. Praying/spiritual interactions: The fifth interaction is interesting as it clearly demonstrates a case where the faith and religion aspect of L’Arche philosophy influences day-to-day interactions. Religious interactions will take place at L’Arche, whether or not every community member is interested.

Thus, in L’Arche the organizational philosophy is quite strong, as it can be seen in all identified interactions (see Figure 4). However, all community members do not necessarily have to be active in the implementation of every aspect of the philosophy. To a certain extent, the community is designed in a way that generates the application of the philosophy. In Figure 4, the community structure is represented by the enclosing circle. Two secondary research questions asked: “To what extent do people adjust the mandate to suit their own goals and contexts?” and “What is the

Figure 4: L'Arche Conclusions



role of the L’Arche environment in shaping the interactions?” The L’Arche context almost dictates the ways of interacting, and seems to prevent adjustment to a certain extent considering that assistants may be asked to leave they do not engage in life-sharing interactions (top right of Figure 4). In addition, the community is selective in who comes to L’Arche (bottom box of Figure 4). This extends beyond assistants to members with disabilities, as only people with developmental disabilities are welcome to live at L’Arche and these people must not have violent tendencies (Cushing, 2003; Vanier, 1995). Although this may seem exclusive, it is part of the human geography of L’Arche and also part of why L’Arche is successful at perpetuating its philosophy fairly consistently (Duncan & Lambert, 2004).

Final Thoughts

The findings of this research demonstrate that organizational philosophies are very powerful tools for shaping the interactions between people with disabilities and support providers. However, other factors come into play, particularly context, the historical background of the philosophy, the method of learning, and whether or not the support provider is also disabled. Further research is needed to explore the importance of these factors in order to lead to concrete recommendations that will help support provision organizations create or revise organizational philosophies in ways that will equitably support people with disabilities and support providers.

It is important for all support provision organizations to realize the power of mandates and philosophies. Both participant groups clearly differentiated their organizations from institutions and traditional group homes. L’Arche Winnipeg and the Independent Living Resource Centre consciously attempt to challenge societal norms, which does not necessarily happen in the average group home. This research, and further research in this area, has the potential to continue the important cause of deinstitutionalization through working with organizations that create negative environments for people with disabilities and support providers. The goal of such work would be to use organizational philosophies to improve ground-level interactions. Best practice lessons can already be learned from this project. The findings demonstrate that compelling operationalized mandates must redress the societal position of people with disabilities, set out clear roles for both the disabled person and support provider, operate under a set of common values and finally, exist within a context that supports the actualization of the philosophy. In addition, to move a step beyond the organizations in this study, new models must be conceived that heed the material and emotional needs of support providers. Undoubtedly support provision relationships are complicated; this research shows that organizational philosophies/mandates are practical tools that, if carefully conceptualized, can help people with disabilities and their support providers work though many of the common dilemmas that arise on a daily basis.

Appendix A: Glossary of Terms

Support provision:	Assistance available for all aspects of daily life including: personal care and grooming, finances, transportation and travel, cooking, cleaning, shopping and other errands, communication, facilitated sexuality, socializing, and work. Support provision may be paid or unpaid work; support providers may be relatives, friends, trained or untrained individuals who are selected and hired by the person with a disability, and/or trained or untrained individuals who are assigned to the person with a disability by a support provision organization. This project looks at assigned support providers trained in a L'Arche setting, and ILAs trained in the PACE program at the ILRC.
Philosophy/model:	In this paper, both terms refer to a loose grouping of ideas which explain a concept such as "disability" or "support provision," and are formed with practical application in mind. Philosophies as such are perpetuated through academic and community literature.
Mandate:	A formal, foundational statement or document outlining a support provision organization's general approach to disability and support provision.
Core members/ members:	The people with intellectual disabilities who live in L'Arche communities; they are considered the "core" of the community. Recently, some communities, including the one in this study, chose not to use this term, and refer to people with developmental disabilities as "community members," "members with disabilities," or "members."
Assistants:	The people who support core members. The majority of L'Arche assistants live in the same community and often the same houses as the core members.
PACE:	Personal Attendant Community Education. PACE is a unique five week training program offered by the Independent Living Resource Centre in Winnipeg, Manitoba. The program is "developed, designed and delivered by people with disabilities to promote consumer choice and control in daily decisions that impact the lives of people with disabilities" (ILRC Winnipeg, n.d.).
Consumers:	The people with disabilities who "consume" the services provided through Independent Living Resource Centre, including access to Independent Living Attendants. This term was chosen to emphasize user-control.

Independent Living Attendants (ILAs)	The PACE program term for the people who provide support for consumers. This term was chosen deliberately over "caregiver" in order to reflect that the consumer should be the employer and the decision-maker.

.

Appendix B: Independent Living Philosophy Summary

There are four main tenets of the Independent Living Movement that are consistently referenced throughout the literature:

(1) All human life is of value

(2) Anyone, whatever their impairment, is capable of exerting choices

(3) People who are disabled by society have a right to assert control over their lives

(4) Disabled people have the right to participate fully in society

(Morris, 1993, p. 17).

The ILRC-Winnipeg interprets these tenants into five principles that are taught to PACE students: 1.Taking risks; 2. Making choices; 3. Promoting integration; 4. Accepting responsibility; and 5. Promoting consumer control (ILRC Winnipeg, n.d.)

Independence: Independence is an important concept in the IL literature, and in this context independence is defined in terms of decision-making. As such, although the movement encourages independence, it does not mean physically doing everything for oneself. It does mean that consumers should make decisions about when, where and how support is provided.

Political element: Independent living philosophy is closely tied to the Independent Living Movement. The emphasis on “asserting control” over one’s life ties into the political efforts to empower people with disabilities and challenge prevailing stereotypes of people with disabilities as dependent burdens. The political aspect pushes for a role reversal in terms of who holds the power in support provision relationships, which is embodied in the endorsement of direct payment schemes.

Appendix C: L’Arche Philosophy Summary

Origin story: The origin story of L’Arche is very significant in L’Arche literature. Indeed, almost all books and documents published by L’Arche communities reference the founding of L’Arche (e.g. Vanier 1995, 1998; Mosteller, 1996; Nouwen, 1997).

Relationships of mutuality*:* According to L’Arche literature, mutually beneficial relationships are foundational to L’Arche communities (Vanier, 1998; Cushing, 2003; Pottie & Sumarah, 2004). These relationships take place through “life-sharing” (L’Arche Canada, 1993) and the goal of the relationships is to reveal the gifts of both the core members and assistants. According to the literature, this concept is integral to the daily functioning of L’Arche communities.

Faith and religion*:* The spiritual aspect of L’Arche is significant in L’Arche literature. The Charter of L’Arche says, “each person needs to have the opportunity of being rooted and nourished in a religious tradition” (L’Arche Canada, 1993). Historically, L’Arche is linked to Roman Catholicism, but over time has cultivated a unique “L’Arche spirituality” that includes acceptance and tolerance of other faiths (Cushing, 2003). L’Arche spirituality is derived from the Christian gospel with a special emphasis on the Beatitudes and the gospel of John.

Community*:* Fostering a sense of community through “community building” is another important element of L’Arche. Community building includes celebrating, welcoming and forgiving. Community is recognized on multiple levels, but the literature emphasizes the homes and the communities as key sites for “community building.”

Societal change*:* Finally, the literature subtly recognizes that L’Arche is a medium of social change as its alternative caregiving philosophy acts as a “sign for hope” (L’Arche Winnipeg; Angrosino, 2003). In addition to L’Arche standing out as a unique support provision organization, many assistants who come to live there are “transformed” by the experience (L’Arche Canada, 2005).

Appendix D: Consent Form

The Role of Mandates in Shaping Interactions between People with Disabilities and their Support Providers

A research project by Christine Kelly, a student in the Interdisciplinary Master's Program in Disability Studies at the University of Manitoba.

You have been invited to participate in a qualitative research project. The purpose of this study is to answer the question: In what ways do the mandates of support provision organizations shape the interactions between people with disabilities and their support providers?

What will I have to do?

Participation in this study will involve completing a 30-45 minute semi-structured interview in-person, at your home. The first part of the interview will ask you questions about the philosophy and mandate of the organization you are affiliated with. The second part will present scenarios to you which you will be asked to respond to. The interviews will be tape-recorded and transcribed at a later date by the researcher. The researcher will also take notes during the interviews. Later in the year, the researcher will contact you via phone or email to explain some of the initial findings of the research. At this time, you can make additional comments or suggestions.

What are the risks and benefits of participating in this study?

There is a minimal emotional risk to participants. Since the interviews will discuss the support you either give or receive, this may bring up feelings of frustration. This could make the interview slightly uncomfortable. However, during the interview, you can stop at any time or choose not to answer some questions.

There are important benefits to this research. You may become more aware of the role of the mandate in your support provision interactions. You may discover that the mandates and philosophies of the support provision organizations are a valuable tool for daily decision-making. An enhanced awareness of the mandate could help you build stronger assistant-consumer relationships and increase ownership of the organizations you are affiliated with

Will my identity be kept confidential?

Your identity will be kept confidential by the researcher. The final report and any subsequent papers will not use your name or any identifying characteristics. Your name will not be associated with your responses. The audiotapes, videotapes, and notes will be kept at the researchers' place of residence in a locked drawer and destroyed six months after the final report has been completed. However, please note that the law requires me to report any sign of abuse of specific groups, including people with disabilities in care.

What will you do with my answers?

The answers to all the interviews will be analyzed and compiled into a thesis, which a requirement of the Interdisciplinary Master's Program in Disability Studies at the

University of Manitoba. A version of the thesis may be submitted for publication in an academic journal at some point. This research will also add to the body of knowledge in the field and may contribute to policy development.

Can I see the final results?

The final paper will be completed by September 2007. If you would like a copy of the full report and/or the executive summary, you can obtain one by emailing the researcher.

If you have questions, please contact Christine Kelly (contact information below). This research has been approved by the Joint-Faculty Research Ethics Board. Any ethical concerns about the research can be reported to the Human Ethics Secretariat.

Thank you for your interest.

I ____ (print name) understand what the study is about and what I will have to do. My signature below indicates that I consent to participate in this study:

____

Participant's signature Date

____

Email address

____

Phone number

____

Researcher's signature Date

The consent form for administration will have these variations:

What will I have to do?

Participation in this study will involve completing a 20-30 minute interview in-person. The interview can take place at your place of work. The interview will ask you questions about the philosophy and mandate of the organization you are affiliated with. The interview will also ask about the role of the mandate in hiring and training staff. Later in the year, the researcher will contact you via phone or email to explain some of the initial findings of the research. At this time, you can make additional comments or suggestions.

What are the risks and benefits of participating in this study?

There are no risks associated with participating in this study. There are important benefits to this research. You may become more aware of the role of the mandate in your support provision interactions. You may discover that the mandates and philosophies of the support provision organizations are a valuable tool for daily decision-making. An enhanced awareness of the mandate could help in the hiring and training staff.

Consent form script:

At the beginning:

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

At the end:

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Appendix E: Assent and Consent Form

The role of the Mandate at L'Arche

A research project by Christine Kelly, a Master's student in Disability Studies at the University of Manitoba.

You have been invited to participate in a research project. The purpose of this study is to answer the question: In what ways does the L'Arche mandate shape core member/assistant interactions? A "mandate" is a summary of what Jean Vanier says about L'Arche.

What will I have to do?

Participation in this study will involve coming to a focus group that will take an hour or so. A focus group is like a conversation with a small group of people, in this case, the other people will be core members. First, I will ask you questions about the ideas behind L'Arche. Second, I will read short stories to which you will be asked to give your thoughts on. The conversation will be videotaped and written out at a later date by me. The video will only be seen by me. Friends of mine will help out during the conversation. Later in the year, I will phone or email you to explain what I learned during the conversation. At this time, you can make additional comments or suggestions.

What are the risks and benefits of participating in this study?

There is a minimal risk to participants. Since the conversation will discuss the help you receive from the assistants, this may bring up feelings of frustration. This could make you slightly uncomfortable. However, during the focus group, you can stop at any time or choose not to answer some questions.

There are important benefits to this research. You may become more aware of the role of the mandate in L'Arche. Knowing more about the L'Arche mandate could help build stronger relationships with your assistants and make you feel proud about living at L'Arche.

Will my identity be kept secret?

Your identity will be kept confidential by the researcher. Confidential means I will not tell anyone your name, or anything about you. You may share and hear private information during the conversation. Signing this form means you will not share other people's stories outside of the focus group and they will not share yours. I won't include your personal information in the final report or any other papers I write. Your name will not be attached to your answers. The videotapes and notes will be kept at my house in a locked drawer and destroyed once the final report has been completed. However, please note that the law requires me to report any sign of abuse of specific groups, including people with disabilities in care.

W*hat will you do with my answers?*

The answers to all the interviews will help me write a master's thesis, which is a long paper that I have to do for school. I go to the University of Manitoba. I may try to submit a version of the thesis for publication. This research will also add to the body of knowledge in the field and may help develop policies.

Can I see the final results?

The final paper will be finished by September 2007. If you would like a copy of the full report and/or a short form, you can get one by emailing me.

If you have questions, please contact me, Christine Kelly. My email and phone number are listed at the bottom of the page. This research has been approved by the Joint-Faculty Research Ethics Board at the University of Manitoba. Any ethical concerns about the research can be reported to the Human Ethics Secretariat.

Thank you for your interest.

I ____ (print name) understand what the study is about and what I will have to do. My signature below indicates that I assent/consent (circle whichever is applicable) to participating in this study:

____

Participant's signature Date

____

Email address

____

Phone number

Confirmation from a supportive decision maker

I _____________________________ (print name) helped _________________________ (participant's name) to make the decision to assent/consent to this research. As a close affiliate with this person, to the best of my knowledge I feel he/she understands what the research is about and what he/she will have to do to participate. My signature below endorses this statement.

____

Signature Date

If you are a substitute decision maker:

As the substitute decision maker for _________________________ (participant's name), I consent to him/her participating in this research.

____

Signature Date

____

Relationship to participant

____

Email address

____

Phone number

____

Researcher's signature Date

Bibliography

Anderson, K., Domosh, M., Pile, S., & Thrift, N. (2003). *Handbook of cultural geography.* London: Sage.

Angrosino, M. V. (2003). L'Arche: The phenomenology of Christian counterculturalism. *Qualitative Inquiry, 9* (6), 934-954.

Askheim, O.P. (1999). Personal assistance for disabled people: The Norwegian experience. *International Journal of Social Welfare, 8*, 111-119.

Bach, M. & Rock, M. (1996). *Seeking consent to participate in research from people whose ability to make an informed decision could be questioned: The supported decision-making model.* Toronto: The Roeher Institute.

Beatty, P.W., Richmond, G.W., Tepper, S., & DeJong, G. (1998). Personal assistance for people with physical disabilities: Consumer-direction and satisfaction with services. *Archives of Physical Medical Rehabilitation, 79*, 674-7.

Berkowitz, S. (1997). Analyzing qualitative data. In J. Frechtling & L. Sharpe (Eds.), *User-friendly handbook for mixed method evaluations.* Retrieved April 22, 2007 from http://www.her.nsf.gov/HER/REC/pubs/NSF97-153/START.HTM - TOC.

Blunt, A. (2005). Cultural geography: Cultural geographies of home. *Progress in Human Geography, 29* (4)*,* 505-515.

Bogdan, R. & Taylor, S. J. (1992). The social construction of humanness: Relationships with severely disabled people. In P.M. Ferguson, D.L. Ferguson & S.J. Taylor (Eds.), *Interpreting disability: A qualitative reader* (pp. 275-294). New York: Teacher's College Press.

Botes, A. (2000). A comparison between the ethics of justice and the ethics of care. *Journal of Advanced Nursing*, *32* (5), 1071-1075

Briggs, A. & Oliver, J. (Eds.) (1985). *Caring: Experience looking after disabled relatives*. Boston: Routledge and Keagan Paul.

CAILC (2003).*The Canadian Association of Independent Living Centres.* Retrieved September 15, 2006, from http://www.cailc.ca/CAILC/text/home_e.html.

Corker, M. (1998). *Deaf and disabled, or deafness disabled?* Philadelphia: Open University Press.

Covington, H. (2005). Caring presence: Providing a safe space for patients. *Holistic Nursing Practice*, *July/August*, 169-172.

Cribb, A., Bignold, S., & Ball, S.J. (1994). Linking the parts: an exemplar of philosophical and practical issues in holistic nursing. *Journal of Advanced Nursing*, *20* (2), 233-238.

Cumberbatch, G. & Negrine, R. (1992). *Images of disability on television*. London: Routledge.

Cushing, P. & Lewis, T. (2002). Negotiating mutuality and agency in care-giving relationships with women with intellectual disabilities. *Hypatia, 17* (3), 173-193.

Cushing, P. (2003). *Shaping the moral imagination of caregivers: Disability, difference & inequality in L'Arche.* Retrieved August 14, 2006 from http://www.pamelacushing.com.

Davies, S., Laker, S., & Ellis, L. (1997). Promoting autonomy and independence for older people within nursing practice: A literature review. *Journal of Advanced Nursing, 26,* 408-417.

Davis, L. J. (1997). Constructing normalcy: The Bell curve, the novel, and the intention of the disabled body in the nineteenth century. In L. J. Davis (Ed.) *The disability studies reader* (pp.9-28). New York: Routledge.

Deal, M. (2003). Disabled people’s attitudes toward other impairment groups: A hierarchy of impairments. *Disability & Society*, *18* (7), 897-910.

Domosh, M. (1998). Geography and gender: Home, again? *Progress in Human Geography*, *22* (2), 276-282.

Duncan, J.S., Johnson, N.C. & Schein, R.H. (2004). *A companion to cultural geography.* Malden, MA: Blackwell, Ltd.

Duncan, J. S. & Lambert, D. (2004). Landscapes of home. In J. S. Duncan, N.C. Johnson, & R.H. Schein (Eds.), *A companion to cultural geography* (pp. 382-403). Malden, MA: Blackwell, Ltd.

Earle, S. (1999). Facilitated sex and the concept of sexual need: Disabled students and their personal assistants. *Disability & Society*, *14* (3), 309-323.

Earle, S. (2001). Disability, facilitated sex and the role of the nurse. *Journal of Advanced Nursing*, *36* (3), 433-440.

Eustis, N. N. (2000). Consumer-directed long-term-care services: Evolving perspectives and alliances. *Generations*, *Fall*, 9-15.

Finkelstein, V. (1980). *Attitudes and disabled people*. New York: World Rehabilitation Fund.

Finkelstein, V. (1981). Disability and the helper/helped relationship: An historical view. In A. Brechin, P. Liddiard, & J. Swain. (Eds.), *Handicap in a social world* (pp. 1-5). London: Hodder and Stoughton.

French, S. (1994a). Disabled people and professional practice. In S. French (Ed.), *On equal terms: Working with disabled people* (pp. 103-118). Toronto: Butterworth-Heinemann Ltd.

French, S. (1994b). Institutional and community living. In S. French (Ed.), *On equal terms: Working with disabled people* (pp. 119-135). Toronto: Butterworth-Heinemann Ltd.

Gabel, S. & Peters, S. (2004). Presage of a paradigm shift? Beyond the social model of disability toward resistance theories of disability. *Disability & Society*, *19* (6), 585-600.

Gardner, J. & Glanville, L. (2005). New forms of institutionalization in the community. In K. Johnson & R. Travstadottir (Eds.), *Deinstitutionalization and people with intellectual disability: In and out of institutions* (pp. 222-230). Vancouver: University of British Columbia Press.

Gilligan, C. (1982). *In a different voice: Psychological theory and women's development*. Cambridge, Mass: Harvard University Press.

Gleeson, B. (1999). *Geographies of disability*. New York: Routledge.

Green, J. & Thorogood, N. (2004). *Qualitative methods for health research.* London: Sage.

Helgoy, I., Ravneberg, B., & Solvang, P. (2003). Service provision for an independent life. *Disability and Society*, *18* (4), 471-487.

Heron, C. (1998). *Working with carers.* Pennsylvania: Jessica Kingsley.

Hewison, A. (1995). Nurse's power in interactions with patients. *Journal of Advanced Nursing*, *21,* 75-82.

Hughes, B., McKie, L., Hopkins, D. & Watson, N. (2005). Love's labours lost? Feminism, the disabled people's movement, and an ethic of care. *Sociology*, *39* (2), 259-275.

Hugman, R. (1991). *Power in caring professions*. London: MacMillan Press.

ILRC (2006). *Independent living resource centre.* Retrieved September 15, 2006, from http://www.ilrc.mb.ca/index.htm.

ILRC Winnipeg (n.d.) *PACE handout*. Unpublished. Hard copy available upon request.

Imrie, R. (1996). *Disability and the city: International perspectives.* London: Paul Chapman Publishing.

Imrie, R. (2004a). Disability, embodiment and the meaning of the home. *Housing Studies*, *19* (5), 745-763

Imrie, R. (2004b). Demystifying disability: A review of the *International Classification of Functioning, Disability and Health*. *Sociology of Health & Illness, 26*, 287-305.

Kestenbaum, A. (1996). *Independent living: A review*. York: Joseph Rowntree Foundation.

Kittay, E. F. (1999). *Love's labour: Essays on women, equality & dependency.* New York: Routledge.

Kittay, E. F. (2002). When caring is just and justice is caring: Justice and mental retardation. In E. F. Kittay & E. K. Feder (Eds.), *The subject of care: Feminist perspectives on dependency* (pp. 257-276). New York: Roman & Littlefield.

Kohlberg, L. (1981). The philosophy of moral development: Moral stages and the idea of justice. *Essays on moral development*. New York: Harper & Row.

Kriegel, L. (1987). The cripple in literature. In A. Gartner & T. Joe (Eds.), *Images of the disabled, disabling images* (pp. 31-46). New York: Praeger.

L'Arche Canada (1993). *Charter of L'Arche*. Retrieved September 12, 2006 from http://www.larche.ca/en/members/vision_future/larche_charter/.

L'Arche Canada (1996). *Key elements of a L'Arche community and evaluation guide*. L'Arche Canada.

L'Arche Canada (2003). *Strategic plan for the zone.* Retrieved July 9, 2007 from http://www.larche.ca/en/members/vision_future/strategic_plan/strategic_plan_2003_2009.pdf.

L'Arche Canada (2005). *More than inclusion: Honoring the contributions of people with developmental disabilities.* Richmond Hill, Ontario: L'Arche Canada.

L'Arche Canada (2007). *Final identity and mission statement*. Unpublished. Hard copy available upon request.

L'Arche Daybreak (2003). *L'Arche spirituality*. Unpublished. Hard copy available upon request.

Linton, S. (1998). *Claiming disability: Knowledge and identity.* New York University Press: New York.

Mactavish, J.B., Lutfiyya, Z.M., & Mahon, M.J. (2000). ‘I can speak for myself’: Involving individuals with intellectual disabilities as research participants. *Mental Retardation*, *38* (3), 216-227.

Mactavish, J.B., Lutfiyya, Z.M., & Blais, C. (2004). *Perspectives in change: Issues in community support for adults with intellectual disabilities* (Phase I: Final Report). Retrieved September 20, 2006 from http://www.lifeworks.mb.ca/general.html.

Manitoba Government (1992). *The vulnerable persons living with a mental disability act.* Retrieved September 21, 2006 from http://www.gov.mb.ca/fs/index.html.

Manning, R. (1992). *Speaking from the heart: A feminist perspective on ethics*. Maryland: Rowman & Littlefield.

Marouis, R. & Jackson, R. (2000). Quality of life and quality of service relationships: Experience of people with disabilities. *Disability & Society 15* (3), 411-425.

Maxwell, J.A. (2005). *Qualitative research design: An interactive approach*. Thousand Oaks, CA: Sage.

May, C. (1991). Affective neutrality and involvement in nurse-patient relationships: Perceptions of appropriate behaviour among nurses in acute medical and surgical wards. *Journal of Advanced Nursing, 19*, 552-558.

Miles, M.B, & Huberman, A.M. (1994). *Qualitative Data Analysis* (2nd ed.). Newbury Park, CA: Sage.

Morris, J. (1993). *Independent lives? Community care and disabled people.* London: McMillan Press.

Mosteller, S. (1996). *Body broken, body blessed: Reflections from life in community.* Toronto: Novalis.

Newell, C. (2000). Biomedicine, genetics and disability: Reflections on nursing and a philosophy of holism*. Nursing Ethics, 7* (3), 227-236.

Nicki, A. (2002). Feminist philosophy of disability, care ethics and mental illness. *Nursing Philosophy*, *3*, 270-272.

Noddings, N. (1984) *Caring: A feminine approach to ethics and moral education.* Berkeley, CA: University of California Press.

Northway, R. (1997). Disability and oppression: Some implications for nurses and nursing. *Journal of Advanced Nursing*, *26* (4), 736-744.

Nouwen, H. J.M. (2000). *Adam: God’s Beloved*. Maryknoll, New York: Orbis Books.

Oliver, M. (1983). *Social work with disabled people*. Basingstoke, UK: McMillan Press.

Oliver, M. (1990). *The politics of disablement*. Basingstoke, UK: McMillan Press.

Oliver, M. (2004). The social model in action: If I had a hammer. In C. Barnes & G. Mercer (Eds.), *Implementing the social model of disability: Theory and research* (pp. 18-31). Leeds: The Disability Press.

Park, D.C., Radford, J.P., & Vickers, M.H. (1998). Disability studies in human geography. *Progress in Human Geography, 22* (2), 208-233.

Piercy, K. W. (2000). When it is more than a job: Close relationship between home health aides and older clients. *Journal of Aging and Health 12* (3), 362-387.

Playle, J.F. & Keeley, P. (1997). Non-compliance and professional power. *Journal of Advanced Nursing*, *27,* 304-311.

Pottie, C. & Sumarah, J. (2004). Friendships between persons with and without developmental disabilities. *Mental Retardation, 42* (1), 55-66.

Ramos, M.C. (1992). The nurse-patient relationship: Theme and variations. *Journal of Advanced Nursing, 7,* 496-506.

Rest, J. R. (1994). *Moral development in the professions: Psychology and applied ethics.* (C. Narvaez, Ed.). Hillsdale, New Jersey: Lawrence Erlbaum Associates.

Rioux, M. (1997). When myths masquerade as science: Disability rights from an equality-rights perspective. In L. Barton & M. Oliver. (Eds.), *Disability studies: Past, present and future*. Leeds: The Disability Press.

Rioux, M. & Valentine, F. (2005). “Does theory matter? Exploring the nexus between disability, human rights, and public policy. In D. Potheir & R. Devlin (Eds.), *Critical disability theory: Essays in philosophy, politics, policy and law.* (pp.47-69). Vancouver: University of British Columbia Press.

Scott-Hill, M. (2004). Collectivising experience and rules of engagement: Close(d) encounters in disability research In C. Barnes & G. Mercer (Eds.), *Implementing the social model of disability: Theory and research* (pp. 157-171). Leeds: The Disability Press.

Shakespeare, T., Gillespie-Sells, K., & Davis, D. (1996). *The sexual politics of disability: Untold desires.* London: Cassell.

Shakespeare, T. (2000). *Help: Imagining welfare*. Birmingham: Venture Press.

Shakespeare, T. & Waston, N. (2002). The social model of disability: An outdated ideology? *Research in Social Science and Disability, 2*, 9-28.

Sibley, D. (1995). *Geographies of exclusion.* New York: Routledge.

Singleton, R.A. & Straits, B.C. (2005). *Approaches to social research* (4th ed.). New York: Oxford University Press.

Sourial, S. (1997). An analysis of caring. *Journal of Advanced Nursing*, *26* (6), 1189-1193.

SteinhoffSmith, R.H. (1999). *The mutuality of care.* St. Louis: Chalice Press.

Strauss, A.L. (1987). *Qualitative analysis for social scientists.* New York: Cambridge University Press.

Stroman, D. F. (2003). *The disability rights movement: From deinstitutionalization to self-determination*. Lanham, Maryland: University Press of America.

Sultana, R. G. (1989). Transition education, student contestation and the production of meaning: Possibilities and limitations of resistance theories. *British Journal of Sociology of Education, 10* (3), 287-309.

Taylor, S.J. & Bogdan, R. (1989). On accepting relationships between people with mental retardation and non-disabled people: Towards an understanding of acceptance. *Disability, Handicap, & Society, 4* (1), 21-36.

Thomas, R. M. (1997). *Moral development theories – secular and religious: A comparative study*. Westport, Connecticut: Greenwood Press.

Titchkosky, T. (2003) *Disability, self and society*. Toronto: University of Toronto Press.

Ungerson, C. (1997). Give them the money: Is cash a route to empowerment? *Social Policy & Administration, 31* (1), 45-53.

Ungerson, C. (1999). Personal assistants and disabled people: An examination of a hybrid form of work and care. *Work, Employment & Society, 13* (4), 583-600.

Ungerson, C. (2004). Whose empowerment and independence? A cross-national perspective on ‘cash for care’ schemes. *Ageing & Society, 24,* 189-212.

U of C, Berkeley (2004). *Disability rights and Independent Living Movement.* Retrieved September 15, 2006 from http://bancroft.berkeley.edu/collections/drilm/index.html.

Vanier, J. (1995). *An ark for the poor: The story of L'Arche.* Toronto: Novalis

Vanier, J. (1998). *Becoming human*. Toronto: Anansi Press.

Walker, J. C. (1985). Rebels with our applause? A critique of resistance theory in Paul Willis's ethnography of schooling. *Journal of Education, 167* (2), 63-84.

Watson, N., McKie, L., Hughes, B., Hopkins, D., & Gregory, S. (2004). (Inter)Dependence, needs and care: The potential for disability and feminist theorists to develop an emancipatory model. *Sociology, 38* (2), 331-350.

Wolfensberger, W. (2000). A brief overview of social role valorization. *Mental Retardation, 38* (2), 105-123.

Wong, H.D. & Millard, R.P. (1992). Ethical dilemmas encountered by independent living service providers. *Journal of Rehabilitation, 58* (4), 10-15.

Woodward, V. M. (1997). Professional caring: a contradiction in terms? *Journal of Advanced Nursing*, *26* (5), 999-1004.

Wynne N., Brand, S. & Smith, R. (1997). Incomplete holism in preregistration nurse education: The position of the biological sciences. *Journal of Advanced Nursing, 26* (3), 470–474.

Yamaki, C.K. & Yamazaki, Y. (2004). 'Instruments', 'employees', 'companions', 'social assets': Understanding relationships between people with disabilities and their assistants in Japan. *Disability & Society, 19* (1), 31-46.