

SHAPING THE MORAL IMAGINATION OF CAREGIVERS:
DISABILITY, DIFFERENCE & INEQUALITY IN L'ARCHE

By

PAMELA J. CUSHING, B. Comm, M.A.

A Thesis

Submitted to the School of Graduate Studies

In Partial Fulfillment of the Requirements

For the Degree

Doctorate of Philosophy

McMaster University

© Copyright by P. J. Cushing, January 2003

CUSHING

SHAPING THE MORAL IMAGINATION OF L'ARCHE CAREGIVERS

Ph.D.

DOCTORATE OF PHILOSOPHY (2003)
(Anthropology)

McMaster University
Hamilton, ON

TITLE: Shaping the Moral Imagination of Caregivers:

Disability, Difference & Inequality in L'Arche

AUTHOR: Pamela J. Cushing, B. Comm (Queen's University), M.A. (McMaster University)

SUPERVISOR: Professor Matthew Cooper

NUMBER OF PAGES: iv, 329 (+ 34 pages of appendixes)

Shaping the Moral Imagination of Caregivers: Disability, Difference & Inequality in L'Arche

This ethnography explores moral dimensions of the motives and experiences of L'Arche caregivers in Canada. L'Arche is an intentional faith community, whose mission is to be a sign of hope and love to the world through creating homes and relationships with people with intellectual disability. I historicize the evolution of L'Arche by identifying the confluence of socio-political, economic, and religious factors through which it emerged. Related to this is how the founders reframed the negative overtones of difference and disability, and developed a radical ethic and model of caregiving. To illuminate how radical that model was, and still is, I situate it in relation to mainstream histories of care based on a deficit model of disability. I also illustrate the cultural construction of disability historically.

The narratives of L'Arche caregivers point to what it means for them to live and work in L'Arche. These narratives reveal a blend of self-interest and altruism, tied to identity, morality, spirituality, and community. While some of their motives reflect their desire to contribute to broader socio-political change, I show that in the end these aspirations are not finding sufficient outlets in today's inward-focused communities.

The caregivers learn this radical approach through a process of enculturation into the local moral world of L'Arche. This transforms their moral perspective on difference, disability, and care, and makes them suitable reproductive agents. I deconstruct this process into key strategies and illustrate with ethnographic data. The constructive and negative potential of each aspect of the cultural system is dealt with from assistants' perspectives. I analyse the key fruits of L'Arche; the mutual relationships between caregivers and people with intellectual disabilities. I discuss traditional barriers against such relationships and present fieldwork examples of negotiating relations in practice, across the capacity and power imbalances inherent in them.

Acknowledgments

I am grateful for the support and patience that my McMaster committee has given me throughout the doctoral process – patience that I regularly tested. Matthew Cooper has helped me to grow through his willingness to hear me out on an endless range of shady and serious scholarly arguments. He helped guide my initial insights through his fine erudition, insightful vision and quiet insistence that I stay close to central strengths of anthropological theory. Wayne Warry delivered timely doses of encouragement and respect, along with thought-provoking challenges. He inspired me to see how the ethnography could be more polemical and broadly relevant by engaging the context and history more rigorously. Petra Rethmann's perceptive interpretations of anthropological theory in classes and discussions galvanized my interest in the discipline and provided inspiration and direction for analysis and writing. Thank you to Wayne and Petra for stretching outside their study areas with me. Finally, Rosita, Janis, Cookie, Luce and Rabia have been a dream team of staff, making tasks and trips to the department both enjoyable and efficient.

My heartfelt thanks to the people in Daybreak, and especially those who shared a home with me for the better part of a year. Looking back, I am struck by your generosity and trust in welcoming a researcher to live with you. Thank you also to assistants in other L'Arche communities across Canada for your welcome, and for sharing your history(s) and hopes with me in interviews. I hope that you find that this ethnography does justice to your precious, precious stories. Namaste to those core members I go to know for your brilliant individuality, humour, and gentle lessons; Porter, David x 3, Bill, Carol, Jan, Smeltz, Eddie, and Harry. Carl MacMillan, my L'Arche liaison and friend, has encouraged and assisted me above and beyond what any anthropologist could dream of, from our first negotiations, through times when I was lost in the netherworld of analysis, and right to the end with insight, wit and class. My appreciation of the daily simplicity and ultimate complexity of L'Arche was strengthened especially by regular guidance from Warren, Matthew, Lydia, Clara, Jay, Joe E, Sr. Brenda, Marni, Joe V and Gerard. For everything that you taught me about L'Arche and about being a decent person, thank you.

Thank you also to those scholars who helped me to work through conceptual challenges at various stages, and who have also been good friends: Cory Silverstein, Colin Pottie, Michel Desjardins, Michael Hymniuk, and Harvey Feit. Similarly thanks to Patricia Smith, Maria Patriquin and Ruthie Edelstein. I thank again Bill Rodman, Bob Henderson and Peggy Cunningham for earlier support. In addition, the critiques of several additional people at L'Arche on sections of the thesis were instrumental in strengthening the analysis: Carl, Jay, Warren, Cheryl, Tanya, Sister Sue M, Joe E, Marni, Beth, Lydia, Matthew, Clara, Tim G, Eric B, and Liska. Thank you for editing assistance to David Hoyt, Tracy T, Shannon C, and Dorothy P.

I thank my parents for their ongoing support, and especially for raising me to look for the beauty in people, to do my best at whatever I choose to do, and to think for myself. My brother and sister have also encouraged me to stick with this dream in various ways. Finally, sharing the excitement of getting to know anthropology and L'Arche with good friends like Judi, Simone, Adrienne, Paul, Greg, Susan, Suzanne, Tracy P and Sareena made discoveries that much sweeter.

Jay, I treasure your humour, steady companionship, original insights and strength so much. I can't thank you enough for enthusiastically sharing the journey of this project with me and keeping me balanced. Thanks for believing in me. Meet you where the road is turning.

Thank you to SSHRC, the Scottish Rite Mission, The Roeher Institute, PBC, L'Arche, my parents, and McMaster University for financial support of this ethnography.

TABLE OF CONTENTS

1.0 INTRODUCTION	1
1.1 The challenges of full inclusion	2
1.2 Failure to account for and deal with the challenges	4
1.3 Research questions and themes	7
1.4 Approach to the research problem	10
1.5 Chapter Summaries	13
1.6 Endnotes.....	18
2.0 A STATEMENT ON METHOD	19
2.1 A protean project.....	19
2.1.1 A brief theoretical orientation.....	20
2.2 Negotiating the topic and field site.....	22
2.3 Orienting themes and method	27
2.3.1 Participant observation in the field.....	28
2.3.2 Representation and multiple, partial, situated perspectives	31
Cultures or particulars? Difference or similarity?.....	31
Partial and co-constructed truths	33
2.3.3 Openness and engagement in the field	35
2.4 Research plan and discussion of fieldwork methods.....	37
2.4.1 Fieldwork chronology	38
2.4.2 Distribution of time at principal research site	40
2.4.3 Formal interviews	44
Table 2.1 Interview distribution.....	46
2.5 Problematic aspects of fieldwork.....	48
2.5.1 Research at home	48
2.5.2 Ethics of consent	51
Background.....	54
Key issues	58
a) Conflicting notions of what is ethical.....	58
b) Right to privacy	59
c) Potential risk of harm	60
d) Appropriateness of representation.....	60
Potential solutions and their issues	61
L'Arche negotiation and agreement	65
2.6 Conclusion.....	67
2.7 Endnotes.....	68

3.0 HISTORICAL REVIEW OF INTELLECTUAL DISABILITY..... 70

3.1 Background.....	70
3.2 Current definitions of developmental disability.....	71
3.2.1 Reasons behind the proliferation of terms and definitions.....	71
3.2.2 Definitions of Intellectual Disability.....	74
3.2.3 Defining Developmental Disability.....	76
3.2.4 Key changes in definitions: 1941-2002.....	78
3.3 A critical history of the concept of intellectual disability.....	81
3.3.1 Competition for control of the definition.....	82
3.3.2 Dominant approaches in different historical periods.....	84
3.3.3 Normalization and deinstitutionalization.....	88
3.3.4 Problems with deinstitutionalization and normalization.....	90
Lack of funding.....	91
Persistent negative social attitudes.....	92
Lack of support, training, and rationale for caregivers in the new models.....	94
3.4 Contemporary approaches to intellectual disability.....	95
Living arrangements.....	96
Disability movements.....	97
Approaches to understanding developmental disabilities.....	98
a) Bio-medical approach.....	99
b) Functional/Adaptive approach.....	102
c) Environmental approach.....	102
d) The Rights-Outcome approach.....	103
3.5 Conclusion.....	105
3.6 Endnotes.....	106

4.0 EMERGING AND CONVERGING FORCES IN THE HISTORY OF L'ARCHE..... 108

4.1 Introduction.....	108
4.2 The Roots of L'Arche.....	110
4.2.1 Setting the scene: L'Arche and Jean Vanier's pre-L'Arche years.....	110
Particular vocabulary.....	111
Chronology of Jean Vanier's life.....	112
4.2.2 Influential people's worldviews.....	114
Georges Vanier, Jean's father.....	114
Père Thomas Philippe, Dominican priest.....	116
Aristotle, moral philosopher.....	118
4.2.3 Environmental conditions.....	119
Religious changes.....	119
Social changes—Intentional communities.....	120
Changes in the field of disability care.....	123

4.3 The founding of L'Arche	125
4.3.1 Fragments of the charism.....	127
4.3.2 Start-up and identity formation	130
4.3.3 The early steps of growth	132
4.3.4 Translation to Canada and beyond	133
4.4 L'Arche in Canada today: mandate and issues	137
4.4.1 L'Arche today	137
Aims and strategies documents.....	138
Community or agency.....	141
Table 4.1 Comparing L'Arche and Regular Care Agencies	142
4.4.2 Staff today: role, importance and issues.....	143
Recruiting.....	144
Formation and foyer lifestyle.....	145
Paradox of care	146
Mental health	147
4.5 Conclusion	147
4.6 Endnotes.....	148

5.0 ASSISTANTS' INITIAL MOTIVES AND EXPECTATIONS..... 150

5.1 Introduction	150
5.1.1 Relevance and Outline.....	152
5.2 Internal L'Arche perspective.....	153
5.2.1 Barriers to internal analytical clarity on the issues.....	153
5.2.2 Whom L'Arche wants, and whom they get	156
Whom L'Arche gets	159
5.2.3 L'Arche research on why people want to live and work there.....	160
5.3 Background and circumstance.....	162
5.3.1 Circumstance: opportunity and impetus	165
5.3.2 Personal history and predispositions	168
Humanitarian, helping orientation	168
Religion	170
Desire to work with people with intellectual disabilities	173
5.4 Authenticity and resolving moral tension.....	175
5.5 The twin dimensions of meaningful fulfillment.....	179
5.5.1 Work-related concerns.....	180
5.5.2 Adventure, becoming and growth	181
5.5.3 Belonging & home	182
5.6 Conclusion.....	185
5.7 Endnotes.....	185

6.0 THE ENCULTURATION PROCESS OF A LOCAL, MORAL WORLD 187

6.1 Introduction	187
6.2 Tactics that support the enculturation strategies	189
6.2.1 Spatio-temporal layout	190
Shared space and decisions	190
Symbolism in décor and scheduling	192
Dynamics of personal hygiene routines	194
Meetings and decision processes	196
Issues of sustained liminality	197
6.2.2 Narrative: informal storytelling	199
Narrative theory, intended aims and roles of stories	201
Functions of informal narratives	202
a) The use of narratives as a didactic mechanism	203
b) Identity production	211
6.3 Strategies	214
6.3.1 Productivity redefined as fecundity/generativity	215
6.3.2 Revalorizing difference	219
Different forms of the case for diversity	220
Shifting roles in the regime of recognition	223
Side-effect issue	225
6.3.3 Caring for caregivers	227
Establishing the need for support	228
Particular scenarios of support	229
The ethics of care and the deferral of needs	232
The need and challenge of limits with an ideology of diversity	234
The side-effects of a supportive community	235
6.4 Conclusion	237
6.5 Endnotes	238

7.0 NEGOTIATING MUTUALITY ACROSS DIFFERENCE AND INEQUALITY 240

7.1 Introduction	240
7.1.1 Themes	242
7.1.2 Ethics and interpretations	243
7.2 Defining mutuality in caregiving relations	244
7.2.1 Caregivers' motives for mutual relations	251
Humanitarian	252
Pleasure	253
Experience	254
Just what we do	255
7.3 Historical attitudes to relationships and caregiving	255
7.3.1 Impersonal but fair: a paradigm shift in caregiving models	256

7.3.2 The structural privileging of technique over disposition: competence vs. caring	258
7.3.3 Persistent negative attitudes towards difference and disability	260
7.3.4 Intrinsic difficulty of relations across difference and inequality	261
7.4 Journey of discovery	262
7.4.1 Learning to “be with”	265
Straight and on the left	269
7.4.2 Lessons for life.....	271
7.5 Negotiating power in caregiving relations	277
7.5.1 Pro-active sharing of power.....	279
7.5.2 Being forced to share or use power	283
7.6 Conclusion: The limits of mutuality at L’Arche.....	288
7.7 Endnotes.....	291
8.0 CONCLUSION	293
8.1 Research questions.....	294
8.2 Chapter summaries.....	294
8.2.1 Contributions to knowledge / anthropology.....	299
8.2.2 Contributions to the disability field	301
8.2.3 Contributions to L’Arche specifically	303
8.3 Directions for future research.....	308
8.4 Endnotes.....	312
BIBLIOGRAPHY.....	313
APPENDICES.....	330
2.0 List of appendices for Chapter Two	330
2.1 Diagram of L’Arche Daybreak community layout.....	330
2.2 Growing in the Mission survey	330
2.3 Summer Intern survey at Daybreak.....	330
2.4 Research participants’ evaluation of anthropologist (questionnaire).....	330
2.5 Terms and conditions agreement for research ethics.....	330

1.0 INTRODUCTION

*“It is not a question of doing extraordinary things,
but rather of doing ordinary things with love.”*
(Jean Vanier)

In an important but controversial discussion of the liberal democratic ideal, Habermas argues for the social value of full inclusion of all citizens and its potential realization in what he calls the bourgeois public sphere (1962). Ideally, this public sphere is the discursive arena in which differences among citizens are bracketed, so that the contributions of all actors are accepted and valued without them having to conform to dominant norms (Fraser 1994:74-7). Historians of sub-dominant groups like women, blacks, or the working class, however, show that in practice this ideal was rarely actualized. This is evident in the degree of conformity to normative styles that has been required of “others” if they wished to be heard or included (Fraser 1994:77; Tannen 1994; Cushing 1996). This expectation to conform is perhaps most evident in the case of colonized, indigenous people who, as a condition of their acceptance and even existence, have been pressured and coerced into “performing normal” as per the colonizers’ definitions (Povinelli 2001). While competition for power and resources is obviously at play in issues of inclusion and recognition, it has also been argued that cultural relativism, or a non-judgemental appreciation for people who are different from us, is neither natural nor easy for humans to achieve (Geertz 1994). Indeed, the beliefs and behaviours of others often partially conflict with our own or even call ours into question, creating discomfort, uncertainty, and sometimes hostility.

As an example, last year I took my seven-year-old cousin Vera to the cinema. As we headed in with our super-size popcorn, I noticed a man with significant physical impairments

using a wheelchair manoeuvred by the breath of the user. Having seen this marvellous invention recently demonstrated elsewhere, I was excited to see someone making use of it and I wanted to share this discovery with Vera. Vera and I have a light-hearted friendship but when I suggested that we go over and ask the gentleman to show us how the chair worked, she balked: "I don't want to," she said. Undeterred, I started to move in that direction while assuring her that she would find the chair interesting. At this point she was visibly distressed. Her grip on my hand tightened, her body went stiff, and she pleaded, "Noooo- please – I don't want to meet *him!*"

Whether you agree with my desire to ask this stranger about his wheelchair or not¹, the point is that I was struck by the degree of aversion, and even fear, expressed by this otherwise friendly and inquisitive child. This was perhaps not an ideal setting for an educational experience but there was more going on. Robert Murphy, an anthropologist who himself became profoundly impaired mid-career, vividly described similarly awkward and tense encounters in *familiar* settings with able-bodied adults, colleagues, and even old friends (1990:86). Murphy wrote candidly and bravely of the shame and embarrassment that even well-intentioned people can perpetuate by inadvertently reproducing pity and condescension in what they say, or do not say, to people with disabilities. Often, people simply do not know what to say or do.

1.1 The challenges of full inclusion

Biological, cognitive differences obviously limit the capacity of people with intellectual or developmental disabilities to participate in society. Such limits, however, are, in effect, exacerbated by the social rejection and stigma attached to the particular ways in which they are different; many of people with intellectual disabilities ways of being in the world transgress some of our culture's core value ideals such as intelligence, independence, productivity, and beauty (Goffman 1963; Murphy 1990; Vanier 1995; Wolfensberger 1975). How we experience and interpret people who are different from us is, by and large, culturally mediated and not natural;

experience is pre-conditioned by how we have been socialized to understand certain categories of people (J. Scott 1992a). Vera's reaction can, I think, be fairly said to reflect a socially-learned predisposition. Contemporary socio-political movements and laws effectively advocate for the rights of people with intellectual disabilities to decent caregiving, equal opportunity, and physical inclusion in society. And yet, as Ignatieff writes, people cannot be legislated to care *about* others (1984). Without inspiring that caring or interest, however, genuine inclusion and integration can hardly be achieved. How might public interest and understanding of people who are different in devalued ways be encouraged?

L'Arche takes this question seriously. L'Arche was formed in the 1960s as an apostolic, intentional, faith community to create small group homes with people with intellectual disabilities, who would otherwise not have a home. L'Arche now has 131 affiliated communities with an average of three homes each, in 29 countries. One of the founders, Jean Vanier, believed that in order to work against the prevalent negative and dehumanizing stereotypes of people with intellectual disabilities, non-disabled people² needed to have a chance to get to know them as individuals; thereby recognizing their shared humanity. In particular, he felt that in the safety of an accepting environment, the unconventional gifts³ of people with intellectual disabilities could be called forth. This would create a basis for mutually growthful relationships between them and those non-disabled people who came to live with, and care for them. But, as Vanier and others in the communities soon learned, it takes more than just putting people together to create a sense of commonality and engagement and a desire to understand one another (Vanier 95: 61). In order to facilitate these mutually growthful relationships, L'Arche evolved into a local moral community in which an alternative set of values and priorities came to prevail.

Recently, Vera and her family came with me to a large interfaith social gathering at L'Arche. Vera's parents wanted her to have a positive experience among people with intellectual

disabilities. Initially, Vera was somewhat overwhelmed by the diversity of this animated group and spent some time watching, wide-eyed, quiet, and nervous, as some of the people with disabilities spoke, gestured or behaved in ways that were quite unfamiliar to her. By the end of the night, however, she was visibly more at ease; less awed by the people around her, and had even spoken with a few people. Her family's supportive presence was undoubtedly reassuring but her sense of comfort was likely also assisted by the normalizing effect of the L'Arche cultural environment where disability is treated as normal and unremarkable.

Many L'Arche assistants and volunteers shared similar stories with me about their own awkward transition when learning to be comfortable with people with disabilities. For some people, it was simply a matter of becoming accustomed to how people looked, or to their often unusual manners or behaviours. For others, there was something deeper that required a shift. In one community, an assistant named Lea told me that while she had always considered herself a caring, liberal-minded person, for years she felt extremely uncomfortable around the people with intellectual disabilities in two agencies at which she worked. She insisted that it was only once she got to L'Arche that she learned a new way of "seeing" and being with people with intellectual disabilities and was able to move past her negative feelings towards them. Lea attributed her shift in attitude to the atmosphere of normalcy in the L'Arche milieu in which people with intellectual disabilities, staff and volunteers interacted for work, social and spiritual activities. She said that this allowed her to see them as people who laugh and cry and who have needs similar to her own.

1.2 Failure to account for and deal with the challenges

Stories like these, of the awkwardness and tension that difference and disability occasion, are not uncommon. And yet, what is striking in the history of policies and programs for people with intellectual disabilities in the latter half of the twentieth century is the seeming refusal of

scholars or leaders to design programs which recognize and deal with this reality. Since the late 1960s, there has been a liberalization of professionals' attitudes towards people with intellectual disabilities. Bureaucrats and directors have executed the deinstitutionalization of residents with an apparent assumption that the residents' physical placement in urban community environments would somehow transform the public attitude from fear and moral condescension into interest and welcome⁴. In other words, they believed that if the residents are *in* society, they will become *part of* society. Most assessment research, however, flatly refutes this assumption. The impoverished social networks of people with intellectual disabilities are a strong indicator of lack of change in public attitudes towards them, and the failure to achieve full integration (Pottie 2001, Brown et al. 1997, O'Brien & O'Brien 1993, Desjardins 1998). In spite of important progress in formal procedural and contractual rights, people with intellectual disabilities remain misunderstood and under-appreciated by the public. In Chapter Three I assert the contingency of these stigmatized images by reviewing the stages of their cultural construction by directors, politicians and state planners who advocated moral hygiene and eugenics policies.

Canadian employees or volunteers, who want to work overseas, are often given cross-cultural training to familiarize them with the cultural values of the people at their destination. Similar training is also available to teach men and women how to co-operate across their broadly gendered approaches to problem-solving (Tannen 1994). This kind of orientation provides a framework within which the different beliefs and behaviours of "the other" are given meaning and logic, to help avoid negative responses to difference. People with intellectual disabilities constitute in some ways a particularized "cultural" group. Their cultural differences are also exacerbated by the inequality of capacity and regular asymmetry of power between them and non-disabled people. And yet, directors and direct caregivers are not given much formal orientation in the common ways and characteristics of people with intellectual disabilities and

even less likely to be provided with a positive framework in which to appreciate the *value* of their differences in order to counter the default deficit model of disability (Taylor and Bogdan 1989).

At best, ideologies of normalization and rights theories suggest that people with intellectual disabilities are worthy of respect because they are on a continuum with us (i.e. almost normal) or simply because of the sanctity of all human life (i.e. in spite of abnormalities). But neither of these ideas, which dominate the contemporary disability field, offers caregivers, much less the public, a rationale for accepting or liking people with intellectual disabilities as they are; *with* their differences, not *in spite of* them. People are therefore left to learn from their direct experiences of people with intellectual disabilities. Since experience is culturally mediated, however, our interpretation of our experience tends simply to confirm and reproduce existing negative stereotypes. Thus, while new social movements for people with disabilities advocate for treating and thinking about them in new ways, they do not necessarily provide caregivers with the tools or training they need to genuinely adopt a new perspective and carry out these goals.

This is an important oversight given that caregivers are not merely executing the same care in different physical locations; they are also being asked to engage with people with intellectual disabilities more as human clients and not as objects of care, and to cede significant power and decision-making authority to them (Roher 1996, Phillips and Benner 1994, Bogdan and Taylor 1992, Rioux 1994a). In other words, caregivers stand to *lose* power and status in the new models of care. This fact alone suggests that articulating some rationale for why this is the best overall solution could greatly facilitate their acceptance of the shift in care ideologies. Since caregivers are themselves a vulnerable, underpaid economic group, they have not been effective in voicing these concerns but research on the issues in the caregiving systems indicates the caregivers' dissatisfaction and how that impacts the quality of care they are able to provide (Ungerson 1999, Braddock and Mitchell 1992, Bauman 2001, Amado 1993b, c).

1.3 Research questions and themes

The preceding discussion of inclusion, difference, and caregivers provides the broad context for the questions I examine in this thesis. In Chapter Three and elsewhere, I point to issues in the disability care field generally because these issues are part of what makes L'Arche worth discussing. My ethnographic focus, however, is centred on what L'Arche is doing. I indicate what they do well, how some of their strategies are transferable outside L'Arche, and what can be learned from the unintentional issues that have developed for them with this unusual approach. Although the L'Arche philosophy is clearly religious in origin and spirit, assistants often talked about it as a radical *moral* alternative and this ethnography reflects that emphasis.

The fundamental question that I address in this ethnography is: **How does L'Arche motivate and enable people to become the kind of caregivers it needs in order to carry out its radical ethic of care with people with intellectual disabilities?** *Motivate* denotes how to attract and interest people in the philosophy; *enable* indicates how to support them to enact and sustain that interest. Fieldwork enabled me to develop several subsidiary lines of inquiry that were salient to the overall research question. Below, I list the three component areas of inquiry which in the end made the most fruitful contributions to the purposes of this ethnography:

- How does the cultural environment of L'Arche encourage “the unique value and vocation” of people with intellectual disabilities to be called forth and nourished?
- How does L'Arche bring about a revised and revalorized ideology of disability, difference, and inequality in practice?
- How does the L'Arche philosophy imbue the basic labour of caregiving with greater moral and political meaning for the caregivers?

The main thrust of my analysis examines the manner in which L'Arche has developed a local moral sub-culture with which, by stimulating *moral imagination*, it is able to enculturate caregivers into its alternative approach to disability and its ethic of care. L'Arche stimulates their

imagination by combining its compelling moral perspective on disability and care with extensive practice and opportunities for direct experience with people with intellectual disabilities in both work and social settings. The actual daily practices and relations are central in L'Arche and it should be clear in this ethnography that it is in the practice of care that caregivers grow and change – not in simply learning the philosophy intellectually.

The daily practices, however, are transformative precisely because L'Arche has succeeded in imbuing them with greater meaning and moral-spiritual purposes. As Geertz stated: “It is in placing proximate acts in ultimate contexts that makes religion, frequently at least, socially so powerful. It alters, often radically, the whole landscape presented to common sense” (1973c:122). Geertz also argued that anthropology needed closer attention to the *processes*, not just the outcomes, of religion; to study *how* symbols, especially sacred symbols, actually accomplish the mediation of meaning in daily life that allows religion to achieve “an aura of factuality” for its particular ethos and worldview⁵ (Geertz 1973c:89-90). The interpretive analysis of this thesis follows that line of thinking, although with greater emphasis on the moral dimension than on the spiritual.

Although most readers, after reading the ethnographic stories herein, will likely conclude that L'Arche provides a high quality of care for people with intellectual disabilities, I do not attempt to evaluate the outcomes or quality of care specifically. I focus on identifying and explicating the processes that L'Arche has constructed to achieve those ends and on evoking assistants' experiences of them. A direct evaluation of the quality of care in L'Arche would be a worthy project but would require extensive research with the people with intellectual disabilities themselves, which I did not do here.

I deal with several questions and issues in the ethnography and they operate at different levels of complexity and generalization. At the most general level, this ethnography attempts to

contribute to various theoretical areas of concern as alluded to in the prior discussion: the development and evolution of a social movement, the contingency and cultural-construction of medical knowledge, representations of disability, the management of difference and inequality, processes of (re-) enculturation of adults, the meaning of work, and the ethics of care. At the middle-theory level, my principal aim is to name and elaborate on those ideas, practices, and structures in L'Arche which seem most effective and most transferable to outside organizations. Some of the key strategies that I describe and analyse are: a strong case for inclusion and revalorizing difference, the emphasis on mutuality in caregiving relations, the use of story-telling to humanize the caregivers' understanding of people with intellectual disabilities, the ideologically-informed use of space and time in the homes to facilitate interaction, and the L'Arche attempt to care for the caregivers.

Finally, the ethnography works at the local or site-specific level. I use the analysis to name, and pull back, some of the veils which currently prevent the organization's attempts to understand the causes of the strain and confusion that some of their caregivers feel. In particular, I address questions related to the recruiting and retention of caregivers (assistants) and the connection of these questions to the mission of L'Arche. The two-fold L'Arche mission is to create homes and live in solidarity with people with intellectual disabilities and to thereby be a sign to the world that diversity is possible and desirable, implying that socio-political change is necessary. Both aims of the mission are radical in the field but as I will show, the first aim has, over time, come to dominate the time, energy, and resources of the communities. There are good reasons for why the emphasis worked out in this way and it has had many fruitful effects. In the end, however, I conclude that this imbalance in attention ignores the fundamental interdependence of the two goals; how they inform and fuel each other.

My interpretation of the tone and concerns of the assistants in Canadian communities today is that, as a whole, many assistants feel that the communities are too inward-looking, too politically conservative, and not connected enough with the developments and issues in social justice generally or in the field of disability in particular. These themes were most common among assistants with 1-5 years experience, but were also present among a sizeable share of the long-term assistant group. Restlessness, and eventually dissatisfaction with the limits of the role, and their potential to grow and make a difference (within the current inward-direction), was a commonly noted precursor for leaving L'Arche; much more common in fact, than any intrinsic issue with the community or role per se. Generally, assistants did not want to give up the important home life and L'Arche relations, but they expressed a need for a greater sense of connection with the broader field and community *as well*. This is notable given that L'Arche could not survive if all assistants saw the home role as a mere stepping stone. Instead, they wanted to learn to do both. A number of assistants expressed a desire for ways and means, however small or simple, to work *from within L'Arche* to effect greater change in the general social conditions affecting the lives of people with intellectual disabilities.

1.4 Approach to the research problem

This ethnography is based on a year of fieldwork in L'Arche communities across Canada. The principal component of the fieldwork was active participation and observation in the communities. In these communities, I divided my time between being a live-in L'Arche assistant (caregiver), initiating other research activities such as interviews and observations, and participation in community events. I interviewed and spent time with a wide range of L'Arche assistants who differed in age, location, experience, and roles in the community as well as some who were no longer with the community. This breadth of research was an advantage because it exposed me to the manner in which assistants' perspectives can deepen and shift over time; in

particular, as they learn from and experience new ways of dealing with the inherent challenges of community living. I elaborate on the details of the methodology in Chapter Two but I provide some reflections on the process here.

In a thoughtful reflection on research, Foucault questions the value of knowledge that does not also result in “the knower’s straying afield of himself” (1990:8). The experience of simply being part of the world of L’Arche was powerful for me personally; it awakened me to new ways of understanding and dealing with people and issues that had bothered me for years. To give just one example, I found that lessons that I had heard for years about the value of forgiveness came alive for me in that context through the observation of many examples of both the people with intellectual disabilities (core members) and the assistants. Again, the combination of ideas and practice and the chance to observe other people in practice made the experience especially potent. The research process itself also yielded to me many insights that helped me in ways that reached far beyond the project. Various assumptions I held about human nature and motivation were questioned and proven wrong by the assistants and core members.

These lessons often came through most clearly during formal interviews in which I was struck by the questions and challenges that I shared in common with the people who volunteered to share their stories with me. I was particularly moved by the complexity of individuals’ struggles with religion and the generous acts to which it had often moved people. The similarities I shared with the people I was attempting to research sometimes made achieving distance difficult (see Chapter Two). Nevertheless, similarities also helped me to avoid a common pitfall in self-narrative research: taking too literally what people *say they are*. Having some shared background, I was well-positioned to “go beyond the words” as Wikan put it, to attend to “the intent they are trying to convey,” and who they are trying to be in the world (1992:466).

Ethnographic methodologies were especially fruitful in this research for a number of reasons. Participant observation produces an unusually wide variety of data types and helps a researcher develop an intuitive understanding of a culture as well (Bernard 1994:140-3). The grounded and engaged nature of fieldwork provides anthropologists with unique insights into the daily reality of people and how that often differs from their official accounts of life and their stated ideals. This was useful in L'Arche where the ideals are respected and aspired to by most assistants. As such, there is much pressure on them not to question the standards which are called for, even when the expectations seem unrealistically high and lead them to feel inadequate. In official discussions of L'Arche, the sacrifice and hardship borne by assistants in fulfilling the aims of the mission are usually *off-camera*. This is a result of the organization's desire to show the positive side of interacting with people with intellectual disabilities. While that desire is admirable, it creates umbral areas for the leaders when they try to understand the roots of assistant-related issues. For example, since stories of *positive* relations with people with intellectual disabilities are vastly more common than negative ones at L'Arche, assistants who are having normal difficulty with the transition can mistakenly feel that they must not be *cut out* for the position. They should be helped to see that others before them have faced the same issues and learning curve in dealing with people with intellectual disabilities.

Sherry Ortner suggests that good ethnography should examine both the "meanings and the mystifications" which form the basis for people's decisions and actions (1995:188). *Meanings* refers to people's official accounts of why they believe or do what they do. *Mystifications* refers to those reasons which are at a less conscious level for people or even intuitions and beliefs which are not "reasons" at all but still exert a powerful influence on choices. Ortner further notes the danger when anthropologists fail to put all of the pieces of an ethnographic puzzle together, either because they want to protect the subjects' reputation, protect their own relations with the subjects,

or to present the subjects in the best light for advocacy-related reasons (e.g. land claims, reparations, rights negotiations, social assistance benefits, and so on). While these are not bad motives, she insists that the resulting “interpretive refusal” is ultimately illogical because basically, it makes for poor analysis, which can only lead to poor solutions (Ortner 1995: 176-79). In other words, she argues that in the long-run, our interpretive refusal is an avoidance of our professional responsibility to do analyses which strive to provide vulnerable subject groups (and others who can assist them) with as accurate an understanding of their history, situation, and issues as we can (Ortner 1995)⁶. While this ethnography presents many positive aspects of L’Arche, I strive to name and illuminate some of the unintentional shadow sides and detrimental effects of the L’Arche approach to caregiving and community.

1.5 Chapter Summaries

I begin the thesis with a thorough discussion in Chapter Two of the evolution of my research questions, the theoretical framework for the research, and the methodology and research plan. I outline why the methods, plan, and theories that I employed were appropriate to the problems I wished to explore and to the site where I wished to explore them. In the interest of making the qualitative research process and, in particular, participant observation more transparent to the reader, I also outline errors in my research design and the ways in which I executed the methods less effectively than I could have. Identification of such weaknesses helped me to recognize various inaccurate assumptions I had made about the beliefs of the assistants and to base my analysis on the more thorough aspects of the research data. Finally, I outline key ethical and methodological issues that I faced in the field related to conducting research in one’s own country, with caregivers, and with people with intellectual disabilities.

Although this thesis is focused on the L’Arche assistants, it is essential, for context, to lay out a general history of people with intellectual and developmental disabilities and how they have

been cared for. In Chapter Three, I explain how this category of person and medical classification emerged as well as the culturally-constructed stigma associated with the label. I outline the history of changes to the official definitions of intellectual and developmental disabilities over time, the known causes of the impairments, the existing treatments, and estimates regarding the size of this group. I discuss at length the different forms and ideologies of care for people with intellectual disabilities over time as well as the issues which each of them present or, at least, fail to resolve. Chief among these are deinstitutionalization, the theory of normalization, the biomedical model, independent living and the disability rights movement. I argue that while contemporary movements have achieved progress in procedural inclusion and the material conditions of life for people with intellectual disabilities, these movements have not been able to achieve much change in public attitudes towards these people. This is partly because most models do not radically, or credibly, challenge the deficit model of disability. Generally, the continuing existence of issues in the field of disability is what makes L'Arche, and its alternative approach, worth discussing.

I build on that broad history by re-constructing an extensive analysis of the story of L'Arche in Chapter Four. L'Arche developed at the confluence of several important changes in society, religion, and public beliefs about the utility, efficacy, and humanity of large, congregate care facilities in the late 1960s. I discuss the evolution of the origins, philosophy, and radical mission of L'Arche communities in France and later in Canada and abroad. I attempt to show that "History is not simply something that happens *to* people, but something *they make*" (Ortner 1984:159; *my emphasis*). I begin by outlining the lives of the founders and, later, how their personal aims are distinct from the organization's aims today. I situate the L'Arche philosophy in the context of the field of disability care in order to highlight how it differs philosophically *and in*

practice from dominant models. L'Arche offers stimulating alternative ideas to the field, particularly in its strong case for the social value of greater inclusion of people with disabilities.

L'Arche shares many beliefs and practices with mainstream care organizations in Canada but also offers a distinct vision of care and well-being (quality of life) through its inversion of various conventional therapeutic aims. This does not mean that L'Arche is a universal solution that meets the diverse needs and desires of all people with intellectual disabilities. L'Arche does offer, however, a potentially unifying ideological rationale for helping to shift mainstream public and caregiver attitudes about people with intellectual disabilities. Historicizing the emergence and development of L'Arche also illuminates some early structural and philosophical origins of current L'Arche-specific concerns.

In Chapter Five I tackle the question of why people want to live and work in L'Arche as assistants, in Canada today. I begin with a review of whom L'Arche would like to have as assistants, what *they* think about whom they get, and ways in which the L'Arche culture has prevented a better understanding of the serious recruiting and retention issues that they face. My focus is on what it *means* to these young people to choose this line of work, especially in a moral sense, and what this tells us about who they are trying to be in the world. I examine what assistants expect from their time in L'Arche and I analyse the *blend* of self-interest and altruism, or social concern in their motives and how people mediate the tension between them through both talk (discourse) and action. Being an assistant is a multi-faceted choice, but many people have political or social justice motives for engaging in this type of work, fuelled by a desire to make a difference in the world. Consequently, a certain feeling of moral authenticity seemed to be imparted to their identity through this sort of work and lifestyle. Nonetheless, I also show how the socio-political goals, which many assistants enter with, are not given sufficient opportunity to blossom in L'Arche; this is an important, but heretofore unidentified, reason for people, who

otherwise like L'Arche, to leave. I believe this is tied to an overemphasis in daily practice on the "homes" part of the mission (i.e. being, belonging) to the detriment of the symbolic, political, "hope" (i.e. becoming) aspect and a subsequent ethos of personalism, anti-politicism, and inward focus in the communities.

Chapter Six is an extensive description of the structure and process of enculturation that L'Arche provides for all assistants. Enculturation at L'Arche blends spiritual and moral ideology with practice, or experience. Enculturation creates a moral environment in which L'Arche's alternative model of disability and ethic of care can thrive as well as creating caregivers who can reproduce that environment. L'Arche believes that good execution of their model of relational, mutual care requires a new kind of caregiver. What L'Arche asks of assistants is radical so most people need the combination of learning the philosophy *and* practicing it daily in order to grasp fully its ramifications. This transition in moral imagination takes time and requires significant supports to bring about and sustain because it is difficult and can be emotionally draining.

I discuss how L'Arche attempts to support and care for its caregivers in various ways and also how it provides them with a spiritual-moral explanation to give ultimate meaning to their proximate, daily hardship and sacrifices (Geertz 1973c:122). I outline how the communities attempt to revalorize difference and disability as well as to redefine what productivity means in this caregiving context. I also detail community tactics, such as the use of informal narrative and unconventional use of space and time to produce its ethic of care in practice. While these ideas powerfully reshape caregivers' moral imaginations in positive ways, they have also had certain unintended unhealthy side-effects for some assistants. Discussing the side-effects of these sacred, and sometimes mystified, values in L'Arche should help to clarify the issues.

Chapter Seven provides an extensive analysis of perhaps the key reason for the credibility of the L'Arche philosophy and model: the common, and surprisingly mutual, relationships

between assistants and people with intellectual disabilities in their communities. I discuss the cultural and systemic barriers that have historically worked against the possibility of such relations in the public and mainstream health care agencies, in order to show how unusual such relations are. Research shows that the lack of relationships is still a major issue for most people with intellectual disabilities in Canada and the USA. I provide a detailed definition of what L'Arche leaders and assistants seem to mean by *mutuality* and *relationships* using data from fieldwork and interviews as well as formal community documents. Defining these terms is essential in helping new assistants see the degree to which mutuality is a regulative ideal and long-term process and not, as they sometimes feel and are intimidated by, something that is expected of them immediately. I discuss how assistants mediate between mutuality as a regulative ideal and mutuality as it is possible to live in the homes. Further, I show how they are aided in this project by enculturation, which teaches them to learn the value of simply being present and to recognize the unconventional gifts which people who are different have to offer.

I discuss how both assistants and people with intellectual disabilities must actively negotiate the terms and conditions of mutuality across the unavoidable power imbalance inherent in the relations, an imbalance caused by structural inequality and actual difference. The success of these negotiations is predicated on whether L'Arche has successfully created a sense of solidarity, commonality, and appreciation of difference between caregivers and core members. Stories about particular relationships (successful and failed) between particular people are provided throughout the chapter in order to move this idea from the realm of liberal cliché to that of radical practice.

In Chapter Eight, the conclusion, I pull together the various pieces of this case of enculturation and radical caregiving. I offer thoughts on what lessons the experience of L'Arche provides for mainstream care providers and on implications of my analysis for the future of L'Arche itself. A secularized version of the L'Arche philosophy could provide a strong foundation

for uniting several contemporary movements and heightening their effectiveness. This could be accomplished by helping them to speak more convincingly to the sociological imagination of the public regarding the social value of people with intellectual disabilities. It is already clear that this will require more than physical relocation of people with intellectual disabilities. This means actively encouraging a cultural shift in the understanding of disability.

I summarize the implications of my research for L'Arche questions around retention, the mission, and revitalizing its early dynamism. The latter two are particularly urgent issues given the anticipated diminution of direction and energy from their charismatic leader, Jean Vanier, as he ages. In the conclusion, I extend an argument which I build subtly throughout the thesis. This argument deals with what I see as an imbalance in how the communities are currently living out their mission. The dual mission of L'Arche involves the two radical aims of creating homes and relationships with people with impairments, and being a sign of the value of diversity and compassion to the world through their example. A lack of emphasis on the latter, externally-oriented part of the mission, risks allowing the former to lose its radicalism and become merely reformist. I finish by outlining the potential benefits of greater external, grounded political engagement for L'Arche, its assistants, and people with intellectual disabilities in general.

1.6 Endnotes

¹ Some people might argue that I am invading his privacy or highlighting his difference by addressing him. Others might suggest that it was arrogant of me to assume that he wants to take the time to explain such things to an uninformed, able-bodied/minded person.

² There is no widely accepted manner to refer to the group of people who do not have an intellectual or physical disability. Some writers say "the non-disabled" while others use terms like "typical" or "normal." Some people with physical disabilities refer to the rest as "TABS" or the temporarily able-bodied. I discuss at length, in Chapters Two and Three, language issues in the field.

³ An expanded discussion of the notion of "gifts" is provided in Chapter Four. Briefly, it simply refers to a special talent or lesson that someone has to share. It is commonly used in religious discussions.

⁴ I discuss evidence of this extensively in Chapter Three. Trent's (1994) critical history is an excellent source for primary evidence on the public's moral and physical fears towards people with disabilities.

⁵ Ethos—a social group's moral and aesthetic tone; Worldview—their perception of reality, (Geertz 1973c:89).

⁶ See also Footnote 6 on page 209.

2.0 A Statement on Method

*“Simply take yourself, in all your singularity, importance, complexity, and love—
and multiply.”*

Annie Dillard (1999:47)

2.1 A protean project

Describing human experience is a formidable task, and the reflection of novelist Annie Dillard points to the risk of misrepresentation when a writer loses track of the distinctiveness of individuals in the process of generalizing. General accounts and large numbers can lead to a loss of perspective and “compassion fatigue... At what number do other individuals blur for me? Vanish?” (Dillard 1999:131). The ethnographic methods I employed were designed to hold onto both sides of the story: the lives and creative agency of particular caregivers, as well as broad patterns in their collective response to the L’Arche cultural system. I observed and examined how the caregiving services are organized in L’Arche, and how caregivers behave in their natural settings, but also asked the caregivers individually about their perceptions and experiences of daily life in the homes. Eventually, I set this data within a broader operational context using secondary sources from a literature review in chapters 3 and 4.

In this chapter, I discuss the original and eventual research design for the project, and key issues that I encountered in the process. Section 2.2 traces the trajectory of the project from my original inspiration to the early negotiations for a research site and subsequent shifts in my focus. In section 2.3 I discuss my principal method, participant observation, and three key themes that orient my approach to anthropological fieldwork. The discussion in section 2.4 turns towards

defining and evaluating the specific methods I used and their place in the overall research design and chronology. The final section (2.5) addresses two concerns that emerged over the course of my fieldwork: the ethical issue of obtaining informed consent for research from people with intellectual disabilities, and problematic aspects of conducting research in one's own culture. Ethnographic fieldwork is a highly variable research method. My aim in discussing issues I faced at this site is to make the strengths and weaknesses of the process transparent.

2.1.1 A brief theoretical orientation

My primary theoretical approach in this ethnography is interpretive anthropology, combined with some aspects of symbolic interactionism, and critical ideas from feminist and post-modern theory regarding reflexivity, representation, voice and fieldwork that respects the people being studied, not objectifies them. These latter critical ideas are further elaborated in section 2.3.2.

A straightforward starting point for defining the goal of anthropology is: "to describe and explain the regularities and variations in social behaviour," or cultural description, and this is accomplished primarily through ethnography (Spradley 1980:13). An ethnographer attempts to describe and analyze "the meaning of actions and events to the people we [anthropologists] seek to understand" by studying "what people do, what people know, and the things people make and use;" cultural behaviour, cultural knowledge, and cultural artefacts (Spradley 1980:5). Geertz (1973b) defined culture as a socially established (shared) system of meaning "in terms of which people engage in social action" (Nanda 1994:56). Spradley suggests that culture can be explicit (what people can tell you) or tacit (what they know intuitively but most can not articulate), but either way, "culture is the acquired knowledge that people use to interpret experience and generate behaviour" (1980:6-7). So in this minimal definition, culture is learned and shared.

Many developments in theory since the early 1980s have challenged the definition and usefulness of the concept of culture for building cross-cultural understanding. In the post-colonial period, feminists and post-modernists in particular have challenged anthropologists to reflect critically on issues related to power asymmetry in the ethnographic process: voice, representation, inclusion and exclusion, exoticizing and essentializing difference, and the objectification of research subjects (Clifford and Marcus 1986; Marcus and Fischer 1986; Abu-Lughod 1991). A full review of these issues is beyond the scope of this thesis, but I discuss those arguments that are salient to my project in section 2.3.2 on “partial knowledge.” For now, I briefly outline the main idea of interpretive anthropology.

Symbolic interactionists posit that cultural meanings derive from social interaction and thus they “seek to explain human behavior in terms of meanings” (Spradley 1980:8). Interpretive anthropologists believe that “human behaviour is symbolic: It has meaning—it signifies something—to those who engage in it” (Nanda 1994: 56). To understand these cultural meanings an anthropologist observes people in their natural settings since “it is through the flow of behaviour, as social action, that culture is articulated” (Nanda 1994: 56). Interpretive anthropology moves away from a view of cultures as “abstract systems” and encourages a focus on the often “messier,” but fruitful approach, of examining “the *experience* of being a member of that culture” (Marcus and Fischer 1986) ¹. This approach has helped promote an understanding of culture as multi-dimensional, differentially shared among its members, and as dynamic, not static. In this thesis, I show how the L’Arche cultural environment has undergone many changes and continues to change in response to both internal efforts and externally imposed conditions, and also show intra-group differences in perspective and experience among assistants.

The interpretive paradigm fostered many questions about the effect of inherent human biases on fieldwork and interpretations, power asymmetries in our relations with “the other,” and

what implications these suggest regarding research objectivity (Nanda 1994: 36). In attempting to grapple with these questions, anthropologists' professional self-awareness and reflexivity have been heightened. Reflexivity in ethnography means being aware of and accountable for the effect of your personality, culture and feelings on your research and analysis (ibid:37). Throughout this chapter I use reflexivity to elucidate how I enacted the interpretive approach. This discussion provides an overview within which the rest of the more specific sections below operate.

2.2 Negotiating the topic and field site

The general idea for this ethnography grew out of my previous research and experiences, but changed once I chose a research site and began my fieldwork. In this section, I trace the trajectory of the project from my original inspiration, to the early negotiations for a research site, and finally the proposal and agreement struck with L'Arche. The multi-sited fieldwork lasted just over a year, and in the end comprised many research methods and sites of engagement, under the organizing approach of participant observation. Methods are elaborated in section 2.3.1 on participant observation and in 2.4 on research design.

The topic for this project originally grew out of my interest in questions about how people change themselves, why they want to or think they should, and what cultural beliefs are at play in helping to direct how they think they should or could change. In previous ethnographic research, I examined similar questions about personal change through applying the rites of passage model (Turner 1964) to self-narratives that I co-produced with students, before and after their three-week experiential wilderness courses at a school where I worked, called Outward Bound (Cushing 1997a, b). Since Outward Bound's primary objective was to promote personal development, I was interested in how their local cultural belief system encouraged and supported people towards that end. I examined three dimensions of the efficacy of the program in encouraging personal change: the content or nature of change, intensity or degree, and longevity².

Many students experienced positive short-term effects like greater confidence, empathy and openness, but afterwards, even those who indicated that they were trying, seemed to find sustaining these changes very challenging.

Based on interviews three months post-course, I argued that there were five contributing issues to this problem, and one of those is the most salient to the origins of the present ethnography³. Briefly, one key issue was the lack of a compelling motive to sustain the change(s); their own desire was simply not enough to inspire them to the extra effort required off-course to overcome blocks such as peer pressure and absence of support. One student, Jeremy, who *was* still trying at the time of the post-course interview, disclosed that he was tired of letting his mom down with his delinquent behaviour, how he was desperate not to end up stuck in his hometown, and how much he wanted to do something more with his life than attend house parties. The source of those ambitions is less relevant here than the role they played in bolstering his desire to sustain his changes. These comments represent a set of broader, long-term, and partly other-oriented concerns that seemed to be buoying his spirit and providing him with a meaningful rationale for continuing to make an effort to grow. This insight led me to consider whether Jeremy's situation was common. My initial research problem for this study was the following: *Are personal change projects enhanced or prolonged when interwoven with relational and existential goals, or guiding purposes?*

I wanted a research site where I could delve further into this question. I was particularly interested in whether a person's goals for being involved with *social* change or social good projects could have a spin-off positive effect on their capacity to develop and sustain *personal* changes in everyday life. My personal agenda was the hope that if I could illustrate this relationship, it would provide a compelling motive for people to get more involved in volunteer and community work. L'Arche met my research needs since its philosophy endorses both a

socially progressive approach to caregiving, as well as the importance of caregivers' growth towards maturity. I first learned of L'Arche in 1998 in a fortuitous conversation with a friend, Ann Osler, who is a long-time associate and supporter of the Daybreak community.

After a series of inquiries, I was invited by the community to dinner at one of their eight homes in October 1998. My nervousness was alleviated by Russell, an elderly core member, who gave me a house tour replete with detailed stories of his family tree and his connections within the church! A young assistant included me in dinner preparations, and later one of the long-term assistants shared her thoughts and suggestions about researching personal transformation based on her experience in L'Arche. The casual, comfortable manner and tone of the evening allayed my concern about feeling uncomfortable in a religious community.

Over the next two months, I met and discussed options for the project with two long-term assistants, Matthew Marosszeky (Human Resources) and Carl MacMillan (Development and Outreach). Both men helped me to understand more about the organization, and about being sensitive to protecting the privacy of the people with intellectual disabilities in their homes. Together we developed a mutually beneficial plan by combining my research objectives with questions that were of interest to the community. For example, L'Arche communities nationally were interested to know more about assistants' reasons for working there, in order to assist their incipient recruiting efforts.

Given the research site, I developed other goals, such as understanding the fields of intellectual disability and caregiving, and how L'Arche was situated within them, as well as how their position might influence people's decisions to become a caregiver there. These factors are elaborated in Chapter 3. Carl and Matthew's prime concern was to minimize the disruption my presence would cause to people's home lives, and achieve an acceptable balance between individuals' privacy and my ability to access various people and situations in L'Arche. They

obtained approval for my proposal (see Exhibit 2.2) from community council, which allowed me to be trained as an assistant and to be able to participate actively in the homes in that capacity part-time. I was given a bedroom upstairs in the Big House, which also houses the community's main office. I was officially "connected to" one of the regular community homes, Shalom House,⁴ which means that I was there for most meals, social activities and caregiving tasks. Assistants are always connected to a particular home, which facilitates familiarity with care routines and interpersonal connections. I lived at L'Arche four to five days a week, and at my home for the rest. It was agreed that taking regular days away would help prevent me from becoming overly drawn into the needs of the community at the cost of the research. Initially, the time was split between two days to be scheduled as an assistant, and two to three days for interviews, surveys, observation of meetings, assisting on committees, and field notes.

I was trained as an assistant in how to spend social time with core members, do personal care and health/medical routines, household chores, and other outings like church, shopping or going for coffee. After a few months, I shifted a greater share of my time towards those aspects of the research that involved less active household participation, such as interviews, and so reduced my in-home assistant commitment to roughly one day. Still, since I took all meals with Shalom House, I continued to spend considerable time there in a less active form of participant observation, and simply for fun. I was also involved in committees and meetings outside the home in order to help out, but also to be involved in different aspects of community life for observation purposes. My formal interviews began after a few months once I had established a familiarity with community life. Finally, I was given permission to do short-term, comparative fieldwork in eight other Canadian L'Arche communities that differed from Daybreak in various ways (age, size, region, language, and orienting religion)⁵.

After a short time living in the community, I was aware that some assumptions of my research problem did not jibe with how the assistants understood and acted in their world. Assistants on the Shalom House team were especially helpful in pointing out my assumptions about them, their lives and what was important to them that were inaccurate as far as they were concerned. Although I initially resisted their direction, with greater experience in the community I came to see the relevance of their insights through findings which surprised me. One surprise came around key terms like personal change and social good. Several interviewees for example, insisted (though not in so many words) that the personal change that they were most proud of was learning to “be myself” or getting back to “my old self,” or even learning to be content just “being” or being alone. None of these squared with the typical terms of personal change literature with their additive or developmental notions. Another insight around change was that it seemed to happen almost as a side-effect, or requirement of other goals and practices. Some explanations implied that while in *retrospect* they felt they had grown or changed as an assistant, at the time, the issue and the process of change had been painful and not something that they had sought.

It is not uncommon for anthropological definitions to be derived in an ongoing, inductive manner, as new information from informants and insights arises from fieldwork (Barrett 1996:220) (see for example Pool 1991). For example, assistants resisted my inference that they were sacrificing self-interest to do this socially beneficial work; instead, they insisted that they received as much as they gave up. This is not to say that I took their statements about what they do and why only at face value, which would be naïve. But participant observation and social engagement revealed that these were not merely image-oriented claims; they reflected important aspects of the moral order and theology of L’Arche, and of the processes of everyday life there.

Although I continued to gather information on personal change and the cultural construction of disability, I eventually broadened the scope and nature of my research questions

to include why assistants chose to be in L'Arche, and what their experience there was like. I could access both their reported experience in interviews, as well as observe their conduct and experiences firsthand. Although also concerned with individual assistants' experiences in L'Arche, I became interested in patterns to their collective response to the process of socialization into this new sub-culture: What specifically did people respond to, or resonate with in the messages and daily practices of L'Arche? What did it mean to them to be there, and to live according to the theology of L'Arche?

In his classic discussion of religion as a cultural system, Geertz supports this genre of research on the meanings and symbols that comprise religion, in addition to the common focus on religious behaviour (Geertz 1973c:125). He argues for more detailed, empirically-grounded analyses of *how* sacred symbols actually accomplish the mediation of meaning in people's daily practice, that allows religion to "miraculously" achieve "an aura of factuality" about its particular ethos and worldview⁶ (ibid:89-90). To loosely adapt Geertz's phrase, in retrospect, I wanted to examine how people in L'Arche produced their faith or belief in L'Arche theology and approach to care, *as they practiced it* (ibid:114).

2.3 Orienting themes and method

There are many ways to conduct fieldwork and to construct ethnography. The extended and extensive nature of fieldwork, and participant observation in particular, mean that there are innumerable small decisions and judgements made by the ethnographer every day regarding what kinds of observations to include or exclude and how to interpret differential responses of the subject group towards the ethnographer. In an attempt to make the process more transparent, I define my main methodological approach, participant observation, and outline three themes that animate and orient my personal approach to this method. I conduct fieldwork under the assumption that all knowledge is partial, which implies that a researcher's perspective is but one

among many possible ones. As such, I try to remain consciously open to persuasion by what informants believe and tell me about their worlds and how to make sense of them, albeit with a critical awareness. Through experiential learning I was exposed to a similar process of socialization into the unique L'Arche ethos as the assistants. This facilitated an understanding of how they experience L'Arche as a "moral order," not simply an agency (Kleinman 1995a: 117).

2.3.1 Participant observation in the field

Fieldwork is "the firsthand, systematic exploration of the variety of human cultures by anthropologists" and ethnography is a written account of that exploration, usually about one particular society or group (Nanda 1994:23). Although sometimes used interchangeably, "All participant observation is fieldwork, but not all fieldwork is participant observation" (Bernard 1994:137). In other words, people can be doing fieldwork, that is, going into the field to gather data and observe, without being participants. Fieldwork and participant observation both include a range of data collection methods (interviews, checklists, questionnaires, etc.), and is largely open-ended and inductive. Fieldwork concerns how people act and talk in their natural settings.

Although participant observation is a "foundation of cultural anthropology" (Bernard 1994:136), there are different ways of describing its nuances and key features. Below, I include several variants. Bernard and Spradley specify degrees of participant observation, and evoke a sense of how it differs from regular observation, while Barrett names the analytical elements of the process. They are paraphrased except where there are quotation marks.

A participating observer goes to the field, hangs around, listens and talks to people like nurses, but does not do the work of a nurse. An *observing participant* becomes qualified to do what his or her subjects do, like become a jail guard, then actively does the same things as them, (part-time) while also observing. Subjects should be informed of your research (Bernard 1994:138-9).

The four levels of participation are: passive (spectator), moderate (disengaged role), active (do what they do), and complete (go native, or research where you are already a

native). Non-participative fieldwork could involve observing at a distance, email, or interviews (Spradley 1980:58-62).

The active participant seeks to do what other people are doing, not merely to gain acceptance, but to more fully learn the cultural rules for behaviour. Active participation begins with observations, but as knowledge of what others do grows, the ethnographer tries to learn the same behaviour (Spradley 1980:60-1).

From the time of Malinowski onwards, anthropologists have proceeded in the same rough fashion: gathering data, getting hunches, checking them out, generating tentative hypotheses, rejecting them as contradictory data emerge, arranging their data into categories, searching for themes and patterns, and conducting comparative research (Barrett 1996:215).

My dominant mode in the field was as an active or observing participant, but at different times I was also engaged in the other modes, with the exception of “complete.” In a recruiting meeting, or in the home for example, I was actively participating and had a role and responsibilities to fulfill. When I attended an all-assistants meeting in a new community however, my involvement was moderate, since I usually did a presentation of my project at the meetings, but was otherwise simply observing and remained disengaged from the meeting issues. In all of these modes, a participant observer attempts to become “explicitly aware” of the environmental details and behavioural patterns that people tune out in regular life (Spradley 1980:55).

I also engaged in all of the grounded, analytic activities that Barrett insists need to be an integrated part of the fieldwork. Since this was my first major project as a full-time, long-term, participant observer however, I do not think I used the reflection tools as adequately as I could have to narrow my topic down while still in the field (Barrett 1996:190). I invested substantial time and energy in gathering data about a wide variety of situations, which was fruitful, and also a way for me to give something back to the community. In retrospect, I see that this broad perspective and empirical breadth came at the cost of depth and focus in the latter half of the fieldwork. My notes at the mid-way point of fieldwork reveal that I was considering the change in focus, but I did not *formally* revise my questions, and redesign my methods to ensure adequate

data would be gathered on the new questions. Fortunately my field was not far away and I was able to have several additional interviews and informal conversations with research participants during the writing stage.

Simply asking people for their own account of what they believe and do and why, can also be highly instructive and I did this extensively in interviews as I outline in section 2.4.4. Still, if conducted thoughtfully and ethically, participant observation can yield rich and different kinds of data. Participant observation produces an unusually wide variety of data types and helps a researcher develop an intuitive understanding of a culture and form “sensible” questions (Bernard 1994:140-43). Research shows that 35-50% of what informants report about their behaviour is not true (Bernard 1994:114)! Since people usually try to present their best selves in self-narrative or self-report, methods that track *actual* behaviour provide a different perspective (Wikan 1995:265). Participant observation helps illuminate “the difference between what people say they do, feel, and think, and what kinds of action they take.” (Nanda 1994:29).

My final point about participant observation relates to ethics and privacy. If the description of this method thus far sounds potentially intrusive, that is not inaccurate. All of the authors I have discussed here mention the necessity of subtle deception and obfuscation of aims that many ethnographers engage in, in order to put their subjects at ease and achieve access to “back stage” information. Ethnographers have an ethical responsibility to disclose research intentions to their liaisons and participants, and I did this regularly in homes, interviews and group meetings. When the written report includes elements of analysis that are not explicitly part of the original proposal for the research, as is my case, it seems reasonable to at least discuss the changes with the liaisons. My liaison has read the entire thesis and others in leadership at L’Arche have read different parts during the writing process, including the final draft. All interviewees were given an opportunity to review the thesis and provide feedback generally and

for passages where they have been quoted. Participants were invited to input on both my accuracy and interpretations (see survey⁷ in Exhibit 2.4). Since they have encouraged me to write honestly about their organization, it has been a constructive process so far.

2.3.2 Representation and multiple, partial, situated perspectives

“Ethnographic truths are thus inherently partial—committed and incomplete.”
(Clifford 1986:7)

With that famous dictum, Clifford urged ethnographers to take certain limitations of fieldwork and writing seriously. The crises of representation, realism and difference in the discipline are forcing each anthropologist to consider how they are positioned in the field through personal history and commitments, and how that circumscribes what they see and choose to focus on. An anthropologist “seeks and highlights, notices this but not that” (Peacock 1986:66). Methodologically, I tried to mitigate this mono-perspectival tendency by incorporating different ways to participate and observe in the community, and interviews with a range of people in different L’Arche communities. This is not to imply that I established an all-knowing perspective; I occupied a grounded, partial position along with others, and was implicated in their world through relations and professional commitments⁸. Although having multiple experiences and perspectives does not guarantee better understanding, it does nourish critical insight by bringing to light counter-examples, internal conflicts of interest, and the actors’ interrelations, which can in turn, illuminate “what is at stake for particular participants” (Kleinman 1995a:98).

Cultures or particulars? Difference or similarity?

In this section, I review issues of representation that I tried to mitigate in the field, or which emerged in the field. These issues often begin with questions about how to define, study and represent the cultural. One polemic against the traditional anthropological sense of culture argues that it tends to exaggerate inter-cultural differences and down-play intra-cultural

differences by presenting cultures to have “homogeneity, coherence, and timelessness” (Abu-Lughod 1991:154). Indeed ethnographers have seemed reluctant to show differences, disagreements, and change among members of a cultural group⁹. Instead, Abu-Lughod calls for ethnographers to attend to the equally important project of finding similarities and common ground on which to build cross-cultural understanding (Abu-Lughod 1991:154). I tried to follow this orientation in my writing. For example, in Chapter 5 on assistants’ motives for joining L’Arche, I try to present them as individuals and whole actors, so that parts of their lives and beliefs might resonate with the reader’s own experiences. Further, I try to de-mystify L’Arche in Chapter 4, by dealing with the particulars of Vanier’s journey to founding L’Arche, and revealing the familiarity and universality of his hopes and fears, rather than reifying him and L’Arche.

Abu-Lughod’s solution for how to enhance attention to cross-cultural commonalities instead of differences is “ethnography of the particulars” that takes as its subject the changing lives of particular people and relations, in particular places and times (Abu-Lughod 1991:149). Two factors inhibited my ability to construct the whole thesis as an ethnography of particular people in particular situations within the culture in the evocative way that she did (Abu-Lughod 1993). When my analytical focus shifted away from the self-narratives of change at the writing stage, I found that the data I had gathered on other areas of daily life did not include enough detail on the movements and challenges of one or two assistants in one community to write thick, multi-scenario accounts of the same people. Since there are fewer roles, and varieties or classes of experience in L’Arche than in a full-scale ethnic group such as she studies, I feel that my broader account is not therefore weak. Still, an analysis that more systematically separates out the particular experiences of short-term and long-term assistants, a sort of “class” analysis, could yield interesting insights.

Part of the reason that I did not gather detailed particulars was my perceived conflict between gathering detailed ethnographic particulars about two or three people and respecting their privacy—a privacy, I hasten to add, that they had the power to insist on. I was never unaware that the community could easily ask me to leave if some assistants felt that my inquiries were inappropriate¹⁰ (see also Pool 1991:68). I was thus grateful to my housemates for agreeing to let me partake so intimately in the ups and downs of their home life, even though this compromised their privacy—a sensitive concern in L'Arche¹¹. Barrett's research suggests that this feeling of vulnerability among subjects of qualitative research is not uncommon or unfounded (1996:197). I thus made a conscious effort *not* to track all daily movements and challenges of my housemates while still attending to patterns in use of time, core member-assistant interactions and decision-making processes¹².

Partial and co-constructed truths

Anthropologists' privileged role as representatives of "the truth" about those they study has been robustly challenged. Criticism has been levelled at the "culture as text" metaphor and the inference that anthropologists are better positioned to "read" that local text, than the locals themselves. Post-modern and feminist theorists point out how the textual metaphor obscures the fact that power asymmetries mean that cultural knowledge is differentially shared and understood within the cultural group, and that therefore anyone in it, including the anthropologist, can only ever speak from their own positioned, and thus inevitably partial perspective (Clifford 1986; Narayan 1993:678). New metaphors emerged to "reconceptualize cultures as fields of overlapping and juxtaposed discourses" which emphasize that anthropological discourse is one among many possible partial truths, and is not *superior* to a particular native's angle (Lambek 1991:47). Proponents of this more modest role for ethnography insist that it be "self-conscious, serious partiality" not relativistic (Clifford 1986:7). The ethnographic voice can contribute to the

polyphony through the fresh perspective and different, if equally resilient, commitments and interests it brings to bear on issues than locals hold.

These partial truths were also revealed to be co-constructed *with* informants, rather than “discovered” solo by the anthropologists’ cleverness. Notions of accuracy and a single truth are misleading because they ignore diversity of locals’ and informants’ perspectives. They also falsely assume that segments of cultural knowledge are “there, ready in the natives’ head to be called up and expressed in discursive statements” and “collected” (Pool 1991:70, 75-6) (see also Tyler 1986). Instead, some have suggested ways to be clearer about how ethnography results from an ongoing co-production of cultural knowledge about how a particular group of people makes sense of themselves and others (Fabian 1990; Pool 1991:75-6). Dialogical anthropology and multi-vocality have been proposed as ways to redistribute authorial power and improve ethnographic texts’ capacity to convey cross-cultural understanding. While such formats are not perfect, they do evoke a sense of the fieldworker’s position, her native concepts, confusion, relationships, and management of conflicting data (Pool 1991:72-3).

I am drawn to the rich possibilities of multi-vocal projects. It is worth noting that doing so is not always solely up to the anthropologist. I tried to share power in my fieldwork, and it was often fruitful, but a few factors worked against realizing it as fully as I had hoped. Most assistants were very busy and it would have been impossible for one of them to spend extensive hours with me, answering questions and co-interpreting interviews, like a typical “key informant.” While there were about three people with whom I did have extended discussions informally about the community and my research during and after fieldwork, they did not have access to the interview material. In addition, while most assistants were highly amiable, co-operative and informative, they are not members of an oppressed group, yearning to have their voice or their story heard. They thus had less at stake to motivate them to be highly involved in my project than perhaps an

indigenous person whose rainforest is being destroyed, or a psychiatric patient who wants to explain the iatrogenic effects of institutionalization. I therefore tried to spread out discussions of my many questions and theories among a handful of assistants whom I considered insightful and honest, so as not to overwhelm any one person.

I did initiate a collaborative writing project with six women assistants and four core members that began with a jointly-conceived format that would minimize my mediation of their voices to produce a polyphony of experiences in one article. I would provide the necessary background and weave their independently-conceived and written sections together at the end¹³. While the assistants were enthusiastic and encouraging, it became clear that they did not want to actually *write* their own sections. Competence was not the issue; they were all university-educated. They simply wanted to share their stories, and have me write them up with any necessary context and interpretations. They seemed genuinely unconcerned about giving up control to me (when I mentioned it), since they knew me, we had agreed on the theme, and they could edit the written product. Informants are not necessarily interested in, or ready to commit time to such collaboration (Barrett 1996:195). Other researchers (Acker et al. 1983:429) found that “they could not avoid assuming the privileged position of experts. In fact, the women in the project” insisted on it (Barrett 1996:196). The article was published with explicit reference to assistants’ contribution but no pretence to multiple authorship (Cushing and Lewis 2002).

2.3.3 Openness and engagement in the field

“After all, what would be the value of the passion for knowledge if it resulted only in a certain amount of knowledgeableness and not, in one way or another and to the extent possible, of the knower’s straying afield of himself?”
(Foucault 1990:8)

The choice of participant observation for this research was not an accident; it was a way to get underneath a superficial understanding of the life of assistants in L’Arche. I felt that

fieldwork and interviews alone would not allow for that. I also wanted to experiment with what I perceived to be key advantages of participant observation over other forms of research: its iterative, or open-ended nature, and its attempt to translate deep, experiential understanding of a cultural system into analytically useful insights. Jackson proposes that ethnography is unique because it involves the “turbulent merger” of different kinds of knowledge: rational inquiry and intense, engaged experience¹⁴ (Jackson 1995:170).

Initially, I hoped that participating would improve my analysis, but I did not imagine how it could *connect* me to the people I was interviewing (Mohanty 1989). Nor did I consider how I might grow (other than in professional skill), or learn from people in the field. Once at L’Arche however, I did become close to a few people there, and certainly grew, and became personally invested in the overall project of the communities. When I cried in a meeting where I learned that three of my housemates would be leaving the house, I felt that perhaps I had become *too* involved and might lose perspective. Other researchers, however, suggest that forgoing objective distance and becoming engaged, vulnerable and open to personal change in the field is vital. It moves an anthropologist beyond relativism and “sentimental charity” to genuine understanding (Mohanty 1989:10-16; Jackson 1995; Scheper-Hughes 1992:24; Narayan 1993:680).

The surrender to engagement and experience did not necessarily feel more comfortable or safe, especially as I still had to negotiate multiple identities in the field such as researcher, caregiver, consultant, critic, and friend. Remaining in character as a “researcher” does afford one a certain safe distance from questions that one does not want to answer, relationships that entail responsibilities and challenges to one’s credibility. Becoming a participant in community life opens you up to all of these. One assistant from another house who had a rudimentary sociology background, came to our house for dinner more than once, insisting that I explain my hypotheses and methods in detail, only to (supposedly playfully) suggest that I *must* have other hidden

agendas about “stereotyping” them. Being open to changing both my research ideas, and in some ways, myself, was at times also arduous, exhausting and disorienting.

This disorientation followed by re-orientation was important to ensure that I didn’t overlook things that seemed familiar to me given that I was doing anthropology “at home.” It pushed me to become aware of at least some of my false assumptions. One such example arose in an informal conversation about personal change with Raoul, a short-term assistant. To summarize, I had assumed that all assistants came to L’Arche with an idea about one or more ways in which they might like to grow. Raoul disagreed based on his own experience; he insisted that he could not have planned to work on particular things at L’Arche because he did not know enough about it. It was only after living there that he could seriously assess how this environment and work could assist him to grow. While this did not necessarily apply to every assistant, his thoughts certainly problematized my assumptions around personal change and motives.

2.4 Research plan and discussion of fieldwork methods

“Life in the field is itself fragmentary, not at all organized around familiar ethnological categories such as kinship, economy, and religion.”
(Tyler 1986:131)

This ethnography is the fruit of a myriad of research settings and tools. As was described through section 2.3, I hoped to experience, observe and listen to people talk about different types of activities in the communities, and the diverse ways that people choose to engage in them, and the meanings they associate with them. In this section, I outline those elements and tactics of the research design that were planned, as well as unanticipated opportunities for particular sorts of inquiries that emerged in the field. The elements were designed to achieve a balance between assistants’ explanations of their experiences and their (diverse) perceptions of the meanings of symbols and processes in L’Arche, and what I could observe was actually happening on a day-to-

day basis. Below, I outline the main elements of this multi-sited, polyvalent approach and their chronology. I begin with a chronology of the entire fieldwork period for perspective, followed by two sections on participant observation in and outside of the home. I close with a discussion of the formal interviews conducted with assistants in all communities.

2.4.1 Fieldwork chronology

The principal component of this ethnography was an extended period of participant observation with one L'Arche community, Daybreak. This time was complemented, however, by shorter stays in eight other communities across Canada with the main aim being to test some of the insights gained in one community to see if they were applicable to various L'Arche settings. The latter component was strongly endorsed by my liaisons at L'Arche given their awareness of regional variations as well as other axes of difference among the communities.

The total fieldwork time stretched just over a year beginning in February 1999. My primary research site and home base was at the original and largest L'Arche community in Canada, Daybreak, which has a section in Toronto, Ontario with four homes and the original section north of Toronto with eight homes. I lived in the northern section of Daybreak for almost nine months in total, with visits and interviews in the southern section (see Exhibit 2.1). The balance of fieldwork time was spent organizing and travelling to seven other L'Arche communities across Canada for approximately one week each. In them, I observed the diverse ways that the L'Arche mission can be enacted and lived, which helped to strengthen the research relevance. I was also able to test and re-work certain insights that I had developed at Daybreak. These communities varied in size, (from three to eight homes, with two to six core members in each home), in age of community (10 to 30 years), and in regional ways (government regulations and funding, language, cultural and religious differences). The particular flavour of each

community is also strongly influenced by the individuals that comprise them, from core members and assistants to the leader.

The eight communities that I visited in addition to Daybreak included: Ottawa, and Toronto, Ontario; Trois Rivières and Hull, Quebec; Wycocomagh (Cape Breton) and Antigonish, Nova Scotia; Burnaby, British Columbia; and Calgary, Alberta. These short-term visits occurred after I had lived at Daybreak and were opportunities to refine my theories and test their relevance in different L'Arche settings. Prior to the visits, I worked with the directors and their assistants to arrange interviews with a variety of people and to set up a schedule of attending different meetings, prayer services, social events and also house visits during my time there. I lived in the communities and took most meals in the homes, including socializing, cooking and clean-up afterwards. I attended their all-assistants or community meetings in order to introduce the research, solicit feedback, and openly signal myself as a researcher, not just a guest. I also attended a sample of house and team meetings, and community events in each community depending on their schedules. The core components of these visits were the formal interviews that I conducted with people whom the community leaders worked with me to choose and invite. The five categories of people I wanted to interview were: the community leader, one to two long-term assistants, a short-term assistant (one to two years), a board member and a former assistant.

These shorter periods of fieldwork were highly useful for various reasons. Although the trust built up in extended fieldwork is often discussed, less has been said about the advantages of short-term visits for someone already familiar with a culture. My limited time in the other seven communities meant that in some ways, I had neither a history nor a future with them. This served two purposes. First, I was not seen to be aligned with any one group, person, or attitude in the community and this "neutral" status meant reduced barriers for people to engage openly with me in discussions and interviews. I was struck by the richness of these interviews given that the

interviewees had often only met me moments before. In extended research, one often forms alliances (intentionally or by default due to gender, class, etc.) that hinder or restrict one's access to other people within the sub-group, who dislike or differ from your allies or sponsors (see for example Abu-Lughod 1993; Duncier 1999). Second, since my time was limited, my impression was that people had a greater sense of urgency about conveying their thoughts to me. On these visits, several people sought me out to share stories about L'Arche, positive and critical, or to teach me about things that they felt I needed to understand better. Certain others were highly candid in interviews about their experiences and concerns with L'Arche, in spite of their overall admiration for the organization. There could be a range of reasons for the urgency and openness, but one seemed to be that people felt greater freedom to be candid knowing that I was not going to be there every day for another year.

2.4.2 Distribution of time at principal research site

"Ethnography ... holds the possibility of a way of knowing more valid to the dialectical structure and contingent flow of lived experience than reductionistic forms of knowing that by definition distort the existential conditions of life."
(Kleinman 1995a:99)

The largest part of the ethnography was conducted while living at the northern part of the Daybreak community. In this section, I outline the ways in which my time was spent there, divided between participant observation inside the homes, and in other settings in the community. Interviews are discussed in section 2.4.3. I discuss becoming familiar with the community and learning to listen to their suggestions about what was important to them.

On my first night sleeping at the Big House, I found a hand-drawn welcome sign hung on my door as is the L'Arche tradition. Over the next several months, the two other assistants living there posted various other signs, playful and serious about rules of the house, requests of me, and welcomes. A later tongue-in-cheek sign for example read: "Big House Rules: No smoking * No

sex * No long phone calls.” I painted and decorated the room and many people from the office downstairs dropped by to welcome me and see the colours. Although I did presentations to various configurations of community members to explain who I was, and what I was doing there, I think that small things like casual conversations, painting the room, or cooking a nice meal were in the end what really positioned me in people’s minds. I suppose research can seem distant and curious to what people live. When I concluded my presentation by saying, “So I guess I’d just like to understand better what L’Arche is all about,” one long-time core member, Frank, got up and teased “Oh good, Pamela, because I’d like to understand it too!”

Originally, I wanted to use the first few months to familiarize myself with the cultural norms of the community through participant observation in the home and community. As it turned out, I was also involved with other projects, as I discuss in the next section. Still, I spent most of my time in Shalom House. After roughly two and a half months I began to conduct my formal interviews, and spent slightly less time in practice of care at Shalom House. My participant observation mainly took place at Shalom House where I became a part-time house assistant for two days a week. This meant being scheduled to do the direct labour of care or tasks component of this occupation. As one of the primary caregivers in the house, I had to undertake chores as well as take time to simply be with the core members socially. I was also involved in the latter during many non-scheduled times, and this kind of hanging out is both enjoyable and a skill. As Bernard notes, learning to be with people and listen well without jumping into the questions is vital to understanding the processes, norms and meanings of your site (1994:151). The tasks of caring centred on the personal health care and daily routines with core members but also included cooking and serving dinner meals, general house cleaning/laundry, accompanying people to doctors or church, shopping and miscellaneous errands in the house such as making

cards or going for walks or swims with core members for exercise. I was given basic training in areas of core member hygiene, safety and medical care.

Field notes are essential ways to record close observations in the field. I was intentionally obvious about taking field-notes in order to remind people that I was doing research, since I was otherwise indistinguishable from my subjects. I found the note-taking method of quick jottings in the moment to be socially awkward and thus ineffective in informal settings. People seemed to stop doing what they were doing when I started writing. I did still use this method during meetings and group events. I had a mid-size, five-section notebook to record various types of data whenever a comfortable opportunity could be found. I had detailed descriptions of goings on, conversations, interactions, or scheduling of time. If I was just observing a meeting or event, I recorded descriptions in the moment, but otherwise I did this from memory soon after the interaction or conversation. At night and at the end of each week, I recorded some interpretation of those descriptions. I also had sections in the notebooks for general reflections, new hypotheses, stories, and interview notes and reflections.

I learned how helpful it could be to be responsive to feedback from assistants about the method or research focus. Early on, for example, the Shalom House team suggested that if I really wanted to understand how assistants experience L'Arche, then I needed to become more grounded in the daily rhythm of the home. They felt that I was missing things because of external projects at the office that fragmented my attention and energy. At the outset, I was prone to think that the "real action" would be happening in the offices and meetings. Later I understood that certain kinds of action do of course happen in the meetings, but that the home life was without question at the heart of why the experience was powerful for people. Following their suggestion made an immense difference; I found that the quality of my relationships in the home improved and I began to enjoy the experience and people more.

Although being involved in activities outside the home was sometimes distracting, it was also an effective way for me to see how the L'Arche philosophy was or was not lived out in the practice of meetings, committees and decision-making. Others have reported on the personal and professional value of establishing multiple sites of engagement while in the field (Bernard 1994:155). My main external activities were working on committees and research surveys. The three committees I partook in were recruiting, marketing and training. I was able to become involved in them because of my prior work experience in those areas. Although my initial intent was to be quite involved in them, the advice from the Shalom House team directed me not to get too involved there at the expense of deepening my experience in the homes.

In tandem with the recruiting committee, I designed and executed a mail-out research survey to the 12 summer interns for 1999 before they arrived (see Exhibit 2.3). This methodological tool was intended to establish a sense of how assistants would describe why they were coming to L'Arche, and what they hoped to get *before* they actually got there. As I discuss in Chapter 5 below, once assistants have been in L'Arche for a few months, their descriptions of these things often become highly influenced by prevailing L'Arche norms. Nine out of 12 surveys were returned with complete responses. I discuss the results in Chapter 5, but it is of note that their candid, and often practical responses obliged me to rethink my original conceptions of their primary motives as social justice oriented.

I designed, administered and interpreted another, longer qualitative research survey (see Exhibit 2.2) through my collaboration with a group of long-term assistants at Daybreak who were initiating an innovative new extended training project in Ontario called Growing in the Mission. The training was intended to assist three- to five-year assistants in discerning their vocation and learning to live community life well. There were three one-week periods of training and reflection with multiple instructors or guides as per the model from L'Arche France: *Eau de Vie*. The

committee wanted some objective tool for gauging how useful the assistants had found the project and how they felt about their place in their community afterwards. It was immensely instructive for me both to analyze the results, and to discuss my interpretation of the results with the long-term assistants, and hear what they agreed or disagreed with. I was also involved in conducting a few sessions, given my teaching experience.

2.4.3 Formal interviews

The original research questions that motivated my research centred on the intersection of personal change goals and other-oriented goals of relationships and social justice. It was thus important for me to interview individual assistants about the trajectory of their lives to gain a sense of their particular paths. Interviews are a standard part of ethnographic fieldwork and are a better tool for eliciting private information than large group settings. The interviews were intended to gather a number of self-narratives about what different assistants' lives were like before they came to L'Arche, and how that led them there, as well as what their experience in L'Arche had been like. In this section I discuss the interviews, their advantages and disadvantages, and some weaknesses of my interview design and style.

The inclusion of research participants' self-narratives in ethnography is one way to share authority with them. Narayan suggests that the narrative stance is ethical in that it can shift the representation of participants from (mere) informants about cultural data to "subjects with complex lives and a range of opinions" (Narayan 1993:681). This stance reminds the writer and reader that what people tell the researcher is not an unsponsored truth, but a positioned perspective that is usually coloured by their interests and agendas, including what they think the researcher is interested in hearing (see also Pool 1991). I wanted to elicit a sense of the assistants' lives that was organized around the markers and themes that they considered important. As such, I used a formal, semi-structured interview guideline with a set of topic areas.

The advantage of this method of interviewing is its flexibility to be guided by the interviewee's priorities (Spradley 1980:123-7). I think its casual feel also increases interviewee comfort. Indeed, I found it highly effective as I was honoured with hearing incredible details and moving stories about people's families, relationships, hard choices and peak experiences. I was moved to tears and laughter by several informants' stories. Since I have grappled with some of the same issues that many of the assistants talked about, I also grew in my capacity to understand and think about my own experiences through these interviews.

There are three issues with this open-ended style of interview that I discovered upon analyzing my transcripts. First, when I started reading the transcripts out of the field, I realized that my own personal interest in their stories, and in certain issues that they brought up, had led me to allow too much discussion on their pre-L'Arche lives, and on questions of interest to them or me, but which were not salient to the research topic. Because of this, other directly relevant research topics were *not* discussed in sufficient detail in some interviews. In particular, I found that in the end, I had not gathered even basic census data in many of the interviews about factors such as ethnicity, religion, religious changes, age, years in community(s), number of homes lived in, and so on. This made it difficult for me to do useful comparisons on certain points in the analysis. In future, I intend to be more aware of not letting my, or their, extraneous personal interests take up as much time, even though this often adds to both of our comfort levels and trust. In addition, I would have a structured component regarding basic questions at either the beginning or end of each interview to ensure that basic facts are gathered.

People also led full lives prior to L'Arche and many expressed that it was enjoyable to reflect on them. Towards the end, however, I was beginning to realize that I was going to shift my research topic, and that I was perhaps not gathering enough information on the details of their L'Arche experience. As a likely result of this, I found a few places in my interview transcripts

later in the fieldwork, where I was less-than-subtle about trying to redirect the discussion when I (apparently) felt it was getting off-track. In future, I think a better alternative would be to work harder at structuring questions so that the interviewee is clear up front about how much detail I am interested in on each question. In reviewing a few other transcripts, I noted some moments where I challenged an interviewee's claims of adherence to certain L'Arche "party lines" and pressed them to articulate a notion in their own words. This was my way of trying to unsettle, or get underneath the public story or myth. In retrospect however, an open-ended, casual interview format is vulnerable to allowing this kind of pressing to go further than intended, precisely because of the lack of structure.

Once I had established a basic understanding of the community life, I conducted one-on-one interviews with a range of assistants between May 1999 and February 2000. In sum, I conducted 66 interviews about people's self-narratives, of which 26 were with people connected to the north and south Daybreak communities, and 40 were with people from the seven other Canadian L'Arche communities. The discussions ranged from one to seven hours but averaged two hours. All interviews were transcribed and translated for analysis. The interviews were distributed as indicated in the following table:

Table 2.1 Interview distribution

	Daybreak (2)	Other communities (7)	
Community leaders	2	7	
Long-term assistants	9	9	
0 to 3 year assistants	6	6	
Former assistants	3	7	
Board members	2	11	
Administrative staff and volunteers	4	2	
Totals	26	40	= 66

The sample of interviewees was developed in three ways. At Daybreak many people volunteered after hearing my presentation. I also asked some assistants to be interviewed in order to achieve a representative balance of assistants across the categories of age, gender and tenure in L'Arche. Various insightful people contributed greatly to my understanding of L'Arche outside of interviews. In the other communities, the community leaders assigned most people for me to interview, and I reaffirmed each person's willingness when I arrived. Most former assistants that I interviewed were recommended to me by someone in the community. I followed the appropriate research ethics guidelines¹⁵ for research with human subjects. I was as interested in people who seemed to be model assistants as those who were less enthusiastic, competent or well-liked; interviewing people in different positions vis-à-vis the community norm enhances the research by indicating the intra-group diversity, and the kinds of stakes people in different positions have (DeLauretis 1990:139; Barrett 1996:190).

The interviewees were either Canadian or had been living in Canada for a significant period of time (eight to 50 years). Only three interviewees were new to Canada (0 to four years) and I found that they provided helpful perspectives on Canadian priorities and preoccupations. All interviews were voluntary and were unpaid. All interviews were confidential, recorded on audiotapes, and conducted one-on-one in a private location of that person's choosing. Most were completed in one sitting, but fourteen required multiple sittings due either to length or interruptions. In general, people gave the impression that they enjoyed these discussions and the chance to reflect on their lives and their experience in L'Arche.

A final piece of research, which I decided to include at the end, was a personal evaluation of my work. I sent a survey to each community, for the people I interviewed and lived with, asking them to evaluate my fieldwork presence and interview style in order to help me understand ways in which I might have spoken or acted inappropriately and to what degree people felt that

they could trust me with their stories (see Exhibit 2.5). I used their anonymous responses (15) to help discern how I can improve my technique in future research.

Having outlined the main tenets of the research process, it is now important to discuss significant problems and dilemmas that I encountered in the field in order to clarify why certain approaches were necessary, and so that others might benefit from a discussion of the elements at issue and how they were resolved.

2.5 Problematic aspects of fieldwork

Fieldwork is a layered and unpredictable process and invariably presents the anthropologist with problematic procedural, ethical and interpersonal situations that he or she has not considered before, at least in its particular manifestation in that site. In my L'Arche fieldwork, I encountered two central issues that have undoubtedly been raised in other settings and which presented difficulty for me: issues related to doing research "at home" and the problematics of the ethics of consent with people with intellectual disability.

2.5.1 Research at home

Anthropologists working with people in their own country or cultural group face a different set of challenges in the field. "In studying their own culture, anthropologists must try to maintain the social distance of the outsider, because it is all too easy to take for granted what one knows" (Nanda 1994:37-8). Doing research with people with whom I shared many traits and experiences, influenced the research and my experience as a researcher. I discuss some of the effects below.

People doing research in their own culture have a variety of labels applied to them by other anthropologists including insider, native or indigenous anthropologists. Insider anthropologist is "the term applied to anthropologists from dominant ethnic groups who do research at home," while native refers to those studying their own ethnic minority group and

indigenous usually refers to Third World academics studying their own country (Barrett 1996:201). In some ways, you could say that I was an insider since I was studying others, most of whom (although not all) were also Canadian, white, university-educated, middle-class and raised in the church. I shared other less tangible traits with them too, such as an interest in social justice issues, canoeing, soccer and music. On other important axes though, I was quite different; not just in my mind, but in theirs. For example, in a community defined by its attempt to raise the “value of the heart” above the western privileging of intellectual skill, a PhD student is not really seen as being in the same state of mind. In fact, although several assistants had advanced degrees, most of those individuals were not keen to connect with me on this basis, perhaps because of the cultural emphasis on other virtues in L’Arche. Narayan has written about this issue and argues that both anthropologists and our subjects have “many strands of identification available, strands that may be tugged into the open or stuffed out of sight” (1993 :673, 676). Narayan undermines the myth of insider knowledge, arguing that it is based on a misguided assumption of heterogeneity among the group, and it misses the fact that there are always grounds for “sameness and difference” between us and informants (ibid:676-80).

Reports that deal with the methodological concerns of doing research at home commonly claim that familiarity is the source of both advantages and disadvantages—the former being that “they [researchers] have better rapport, greater linguistic competence, and a greater capacity to appreciate the nuances of non-verbal, subjective data. They also are less likely to construct misleading stereotypes of people.” (see also Spradley 1980:161; Barrett 1996:201). On the other hand, this familiarity makes it “harder to recognize cultural patterns that you live every day, and you’re likely to take a lot of things for granted that an outsider would pick up right away” (Bernard 1994:154, 149).

Since most L'Arche assistants are university educated, I found that I did not have any kind of mysterious status or respect just by virtue of my project. Occasionally certain assistants liked to inquire deeply into what philosophical or psychological literature I had used in forming my ideas, often showing me issues with my questions based on their own readings. And in various situations, assistants followed the underlying meaning or assumptions behind my questions closely, and would thereby make their own assessments and judgments of me, and the level of development of my understanding of L'Arche. Their responses would sometimes include not just the content or answer I was interested in, but an additional commentary about the nature of the question, and advice about whether I was on the right track. This contrasts with the reports of some researchers who suggest that the locals or natives take their own cultural assumptions for granted (Spradley 1980:11). In fact, the assistants' comments were often vital catalysts to my critical understanding of L'Arche.

One issue that arose with participant observation was the difficulty of balancing the participating side of things with the more passive, observing aspects of research. This issue is not exclusive to research at home but was exaggerated due to my overt resemblance to the assistants. Hanging out, observing, taking notes, re-reading and adding to one's notes in the evening, and quiet reflection are all essential parts of fieldwork, but they do not always look like "work" to those with whom you are living (Bernard 1994:151; Nanda 1994:29). When I was in the home or office and doing one of these more passive-looking tasks, I was often asked to assist with some project or task related to care or the community, or invited to do something social like go for a swim with Donna, a core member. In the house, especially, I found that I had more requests made of me, and I often *felt* as if I should help more than was probably good for the research. Although the requests were always polite and mostly hesitant, it got so that it was difficult for either them or me to keep up the supposed distinction between when I was officially scheduled to be on or

just observing. The impulse also came from me; I often wanted to help anyway, or do someone a favour, and sometimes being involved put me in a better observational position on decision processes or conflict management than if I had been just observing.

Many anthropologists experience conflicting pulls on their time and need to balance multiple roles of researcher, community participant and friend. At L'Arche though, there is an intensification of that pressure since relationships and serving others is central to L'Arche philosophy. In these moments, I somehow felt as if just saying that I supported what the community was about was not enough; my actions would speak louder than words. It was also often the case that I preferred doing the other social activity more than my research tasks. Although the notes and reflections were sacrificed, it did give me an *experiential* understanding of how caregivers at L'Arche and elsewhere are vulnerable to the pressure to defer their needs in the face of others' more urgent needs (Kittay 1999:48-53) and how hard it is in practice to create boundaries around your time. In this way, it was vital that I did live in that tension to some extent—trying to do both. The assistants' role requires a certain surrender of self in learning to “be for others” and it can be a growthful experience. My involvement also made it clear that many situations require compromises or sub-optimal solutions. This highlighted the fact that what the assistants did was not always what they preferred—resource constraints were also at play.

2.5.2 Ethics of consent

Ethical dilemmas are familiar ground for anthropologists who are being increasingly called to accountability for how they represent others in their writing, and the potential effects of their writing. While many research subjects are now able to exercise a degree of control over their story and its representation, others cannot exert that control, because of intervening factors like distance, resources, language, and intellectual impairments. All plans for research with humans must be approved by governing bodies like university ethics boards, and, especially in health

research, a similar body at the research site. The boards are guided by professional codes such as the Anthropology Guidelines, and can require changes to the research as necessary (AAA 1999). These reviews are especially important in the case of research with people whose ability to exercise control is limited, such as with people with intellectual disabilities. In this section, I review the ethical rationale and written agreement, which ultimately guided how I would represent people with intellectual disabilities in this thesis, and the process of consultations with L'Arche and the literature through which I came to this position. I discuss it here in detail in order to be clear with the reader about the particular resolution that was jointly developed for this project. However, I would argue that these issues are far from resolved generally, and require more urgent attention from researchers and agencies.

Anthropological researchers must expect to encounter ethical dilemmas at every stage of their work, and must make good-faith efforts to identify potential ethical claims and conflicts in advance when preparing proposals and as projects proceed. A section raising and responding to potential ethical issues should be part of every research proposal. (AAA 1999:Sec. B.1)

The preamble to the American Anthropological Association's (AAA) ethical guidelines notes that dilemmas often arise between the competing ethical claims on research from the scholarly community, the people in the study, and the funding bodies (AAA 1999). The AAA rightfully prioritizes the safety and protection of the subjects of the research first, and "informed consent" is the principal tool for ensuring the safety for human subjects. The main ethical concerns in fieldwork should be "acquiring the consent of the people to be studied, protecting them from risk, and respecting their privacy and dignity" (Spradley 1980:20-5; Nanda 1994:41) Matysiak and others note that "The ability to give informed consent is always a concern, but especially with people with intellectual disabilities" (Stalker 1998; Swain, Heyman et al. 1998). (Matysiak 2001:194). AAA insists that its ethics guidelines must also be reconciled with "the ethics of the country or community in which the research is pursued" (1999), in this case L'Arche

in Canada. Still, even after working with a team at L'Arche to combine the AAA and L'Arche guidelines with other professional recommendations on obtaining informed consent from people with intellectual disabilities I was left with some procedural and ethical uncertainty, as the discussion below reveals.

My original proposal to the university ethics review board at McMaster University did not include a discussion of the ethical issues surrounding research with people with intellectual disabilities because my original intention was to restrict the focus of the study to the caregivers. Although my committee, the review board and my liaisons and housemates at L'Arche all raised the question with me of protecting the people with intellectual disabilities' right to privacy, I did not yet understand how the assistants' growth and development were catalyzed primarily in relationships and experiences with *specific* core members (and specific assistants), rather than by the experience as a whole. Lacking experience in the field of disability, I also did not foresee the wide diversity of impairments and etiologies subsumed within the umbrella of "intellectual disability," nor did I grasp how idiosyncratic personalities are often essential elements to the power and meaning of assistants' stories. Lacking this awareness, I proposed to L'Arche and the review board that any information about core members would be conveyed through composites, or their identities would be made unrecognizable. My field notes include information about core members since they are the focus of life there, but I intended to obfuscate the identifiable details at the writing stage. At the writing stage, however, when I began to seriously think about what to include in the ethnography, I began to realize the importance of the particulars just noted, as well as other representational concerns. Before discussing the ensuing process of negotiation with L'Arche, I will provide background on the more general issues.

Background

There are myriad scenarios in which the question of whether to obtain, and how to ask for, “informed consent” directly from people with intellectual disabilities is raised and worked out, including for research, medical procedures and financial or legal decisions. Family or institutional legal guardians have most commonly been asked to give (or withhold) this consent, but there have been increasing efforts to put the decision-making power back in the person’s own hands whenever possible. First, I discuss the various degrees of disability and why this creates confusion or lack of standardization around procedures for consent.

The medical category of “intellectual disability or impairment” varies widely in degree and form. I discuss the medical history and cultural construction of the label in detail in Chapter 3, but I want to give a sense of its vast range. A person can have more than one intellectual impairment as well as one or more physical impairments. In addition, people with intellectual disabilities also have high rates of mental illness—often the iatrogenic consequences of poor conditions and treatment in institutions, and the stigma they face in society today. (Langness and Levine 1986; Edgerton 1993 (1967); Lunsky 2002). Old categorizations such as mild, moderate, profound or severe degrees of retardation are no longer in fashion, particularly in rights and self-advocacy discourses, but an awareness of the grades or degree of impairment, and how that affects what kind of life, activities, independence, consent and health are possible is still useful and in use (Langness and Levine 1986; Ferguson 1994; Kittay 1999). The question of informed consent then, involves different issues depending on the nature or degree of impairment of the individual being asked. In an attempt to formalize the “recognition that impairments in one area of a person’s functioning do not by definition mean that all areas of functioning are affected,” British Columbia has developed new guardianship legislation through Representation Agreements (Matysiak 2002). Instead of the previous blanket agreements where a person was

declared incompetent, "Representation Agreements allow people to identify specific areas in which they would like or need help to make decisions" (ibid).

This discussion is primarily concerned with consent for research, not medical or financial decisions. A general discussion of two core members whose stories are included in this research should help illuminate the range of situations at hand. Alfred has profound intellectual and physical impairments and does not use language to communicate (non-verbal). However, he has lived in the same home in L'Arche for many years and as such, several assistants in his community have known him a long time and a certain base of knowledge has been accumulated about his preferences. The four primary ways that the assistants use to determine how he feels about something include: the tension in his body, his grumbling/vocalizations, his level of excitement expressed in agitated head or body movement or yelling, and his eye movements, where looking up often, though not always, indicates agreement. Information from these sources is gathered, and passing or temporary theories about his preferences are developed, to be tested repeatedly in new situations.

For example, assistants noticed that when the singer Sarah Harmer¹⁶ came on the radio, Alfred often became excited, and when one particular song of Sarah's came on, he almost always got very agitated and excited. The assistants feel fairly certain after years of this kind of behaviour, that Alfred likes Sarah's music, and he likes that song, but they do not know why, or what in particular appeals to him, and it is even possible that he detests the song, although this is considered unlikely since when he has been asked if he wants it played, he usually looks up, indicating yes. But at other times, he did not look up. This generates irresolvable uncertainty over whether he is not looking up because he does not want to hear it, or because some intellectual or physical process is preventing him from responding in that moment. Part of what I am exploring

in this section is what kind of procedure for consent would be the most respectful and realistic with Alfred or others with similar degrees of impairment?¹⁷

There are other people with intellectual disabilities in L'Arche whose impairments are moderate. As with Alfred, though, while assistants are fairly sure about some of these people's preferences, in other domains, the best they can do is develop a working theory about what the person *wants* and balance that with what support workers and family determine is in the person's best interest and possible/affordable. Even this can be vague though—assistants and agencies differ in their personal and organizational biases, such as whether they should turn to pharmaceutical or therapeutic approaches to solving core members' concerns. Other people with intellectual disabilities have only mild cognitive and physical impairments and can have discussions and regularly make choices about what they do and do not want to do, as will be illustrated throughout this thesis. Henry, for example, is talkative and understands what books are, and he knows that he has been included in other writing, as well as in helping to present his life story at retreats for assistants. He likes attention and is happy to be talked about, and to have other people learn from and empathize with what he has lived through. He is very kind and sociable and has given me permission to talk about him and use his picture in my work. But in this thesis, along with saying nice things about him, I include a story about how hard he can be on the assistants who care for him. I am not sure that he would like that, and I wonder about my ethical responsibility to go back and explain to him exactly what the story implies. However, I would not do the same for an assistant since it is standard practice in social science research for the researcher to be willing to make change related to accuracy, but not to interpretations simply because the participant does not like it. Should the protocol be different for people with intellectual disabilities? What kind of ethnography would result then if people were able to remove all trace of their less likable sides¹⁸?

Another factor in this issue is the relationship between the researcher, or a social worker or caregiver who is facilitating the process of requesting consent, and the person with intellectual disability. What is important is not so much the *actual* pressure on the person with intellectual disability to say yes, as the *possibility* or likelihood that they *perceive* pressure or obligation to be wrapped up in the process. Some researchers can ask a person directly for consent, but most research is undertaken in organizational settings and so this process is normally facilitated by a caregiver, social worker, parent, guardian, or friend who knows them better to heighten comprehension of their response, and to help protect them (Stalker 1998). Both of these procedures (direct and assisted requests of the person themselves) have the advantage of including the person in the decision, which can be empowering and respectful. L'Arche assistants are trained in ways to involve core members in decisions that affect them, but how this is accomplished in practice is complex, highly iterative, and often not definitive. Still, it is considered a valuable reminder that people with intellectual disabilities are fully human beings who have rights and preferences and deserve inclusion, even where their ability to understand or respond is ambiguous. Although this procedure can be effective, it is also possible that in some situations the person's response is more an indication of their relationship with the person making the request than their feelings about the research. Vanier has written extensively about how lonely and loving many people with intellectual disabilities often are, and how this habitually leads them to want to help or please people in order to establish a connection (Vanier 1979; Vanier 1998). Many are also very trusting, although, as with any group, there is a range of personalities. With some of the people who gave me consent, I could not say for sure whether they said yes to be pleasing, or because we were friends or acquaintances, or because they approved of the research. They may also assume that as a "friend" (or at least someone their caretakers apparently trust), the researcher would only write good things about them.

Other researchers have addressed directly how these relational concerns, as well as the inherent power asymmetries, leave them uncertain about how *valid* the consent can be considered. Matysiak for example, expressed her concern over “the issue of trained compliance or acquiescence which is a feature that may be present among some people with intellectual disabilities, especially with regard to requests made by non-disabled authority figures (Sigelman, Budd et al. 1981; Biklen and Moseley 1988; Sobsey 1994).” (Matysiak 2001:194). She admits that although all of her participants were legally able to give consent, and seemed to understand the nature of the research, she wonders whether, or how much, they were influenced to participate by the fact that she was an able-bodied staff member working in that agency (Matysiak 2001:196). In his research about sterilization of people with intellectual disabilities in Canada today, Desjardins argues that power and relational factors, such as wanting their parents’ approval, and their perception of medical authority, amount to such pressure on the people with intellectual disabilities to agree that it hardly constitutes voluntary consent (Desjardins 2000).

Key issues

At this juncture, I want to separate out several strands of the question of informed consent generally, and for my research in particular. In order to sort out what concrete procedures are appropriate, the intangible, ethical questions at hand need to be teased out. There are four key elements to the ethical dimension of this dilemma: conflicting notions of what is *ethical*, the right to privacy, potential for harm and appropriateness of representation.

a) Conflicting notions of what is ethical

The moral position one employs to decide what is ethical, and the historical period in which the case transpires, can greatly influence what is considered *ethical*. Deontologists establish principles to be universally applied, whereas a teleological position such as utilitarianism dictates that consequences be taken into account and that therefore, *ethical* means the greatest good for the greatest number. Furthermore, in the field of intellectual disability, the

parents', caretakers' and governmental notions of what constitutes ethical practice and care have varied radically over time, as I discuss in detail in Chapter 3. Notions that many today (although not all) would consider quite unethical, such as involuntary sterilization, were at one time considered ethical from the utilitarian perspective of government-sponsored social and moral hygiene programs that claimed to be preparing disabled adults for parole, and protecting society from further unfit births (Tylor and Bell 1984; Ferguson 1994; Trent Jr. 1994; Smith 1997). Charitable campaigns run in the recent past by well-intentioned supporters, have now been criticized for promoting stigma by reproducing stereotyped images of people with intellectual disabilities as helpless and pitiable, in spite of the funds raised. It is likely that well-intentioned research today will be the target of similar revised understanding ten years from now.

b) Right to privacy

The second key issue is how to define the parameters and pragmatics of a person with intellectual disability's right to privacy in such a situation. Basic research ethics guidelines say that it is the researcher's responsibility to protect the *privacy* of those about whom they write. What is not always specified is *private from whom*, and for what reasons. In research about people who are using and sometimes cheating on welfare, it is clear that the person would want privacy from the state social workers, but not clear that the individuals need to be unrecognizable to their friends, with whom they often talk about claims and loop-holes (Kingfisher 1996). In this research, most of the stories that I use are in circulation in the communities and therefore already not "private" or secret, and if I use pseudonyms so that they are unidentifiable to people outside their community, (as I did for assistants), is this sufficient privacy?

"Anthropological researchers have primary ethical obligations to the people, species, and materials they study and to the people with whom they work ... To avoid harm or wrong ... To respect the well-being of humans ... To consult actively with the affected individuals or group(s)" *and to* "do everything in their power to ensure that their research does not harm the safety, dignity, or privacy of the people with whom they conduct research" (*paraphrased*) (AAA 1999)

c) Potential risk of harm

The third key issue is the potential risk of harm to the participant from being identifiable by strangers or by people who already know them. Possible sources of harm to people with intellectual disabilities in the process of being interviewed have been identified, (Swain, Heyman et al. 1998; Matysiak 2001) but my research with them was only *indirect*, that is, through observation and others' stories. In discussions with L'Arche, we could not determine any risk of harm to the core members from writing stories about their relations and behaviours in the community, excluding their medical and family histories. Although writing something that exposes a weakness or fault arguably taints someone's image, again these stories are generally known inside their communities. In any case, I did not afford the privilege of flawless representations to the assistants either. Duneier insists that accurate portrayals of people and events, even when unattractive, are essential to drawing connections between particular histories and unjust socio-political forces that act on them (1999).¹⁹

d) Appropriateness of representation

The fourth issue is about representation and questions of voice. As discussed in section 2.3.2, anthropologists are working to develop better ways to include the voice of others in their research, as a way to open up authorial control. In this fieldwork, however, I did not interview people with intellectual disabilities directly because this was not my project. My project was to give voice to the experiences of assistants, and in the course of those interviews and daily conversations, the assistants told me many stories about the people with intellectual disabilities with whom they lived and worked, and how that person had affected them. So whose story is it then? If Zoe tells me a story about how powerful it was to work through a difficult relationship with Joe, a raucous core member, is Zoe's consent sufficient for me to proceed? Certainly this is sufficient in most ethnographies of people without intellectual impairments.

Procedurally, there are two central issues: the *quality of understanding* resulting from being informed about the research, and the *quality or meaning of the consent*. In other words, to what degree does someone understand the risks and benefits of what they are agreeing to? Second, who decides what constitutes a valid yes (whether in gestures or verbally), and whether that yes means he likes the research, or that he likes the researcher or assisting caregiver, and is trying to be nice to them? As discussed, in each case there are degrees of quality of understanding and consent. In the case of research like mine that includes people of a wide range of abilities, should a researcher therefore develop a different process and tool for each person?

In the ethnography, there are two further issues: degree of consent and responsibility to revisit consent. If a person with intellectual disability gives consent in the form of a non-verbal expression of *yes*, does that mean I can write anything about her, including medical or abuse histories, or an interpretation that may not be flattering? Alternatively, should a gesture or verbal *no* mean never mentioning her, even if it is flattering or part of someone else's story? Establishing a nuanced or limited consent would be very difficult in most cases, which leaves the decision largely up to the researcher or guardian. Finally, once the work is written, what responsibility does a researcher have to review it with a person with intellectual disability? Although I do not meet individually with the assistants to revisit their consent, they are ostensibly able to read the draft copies I provided for the communities, which core members could not do.

Potential solutions and their issues

A few solutions have been developed in the field but each of them has been critiqued from some perspective, or they are not suitable for this research project. It was difficult to determine what the most common approach in the field is because many articles and reports do not specify what method or ethical principles are followed. Since classifications and labelling are currently considered distasteful, it can also be difficult to assess the degree of intellectual

impairment of people in some studies. My main concern is that it is often not clear to what extent a person with intellectual impairments is able to give *informed* consent even when they are *willing* to consent. The ambiguity of the term “informed” does not make it easier to clarify. How much does the research participant have to be informed of? Does consent to use someone’s story cover its eventual use to illustrate an argument that was entirely unimagined and unanticipated by the participant, and possibly quite undesirable to them? My impression is that this risk is rarely made clear to participants by any researchers at the time of the request for consent.

I outline the range of solutions that have been developed in the field, as background to my negotiations with L’Arche. In trying to develop an appropriate solution for this project at the writing stage, I consulted a range of sources including the AAA’s and the American Association for Mental Retardation’s (AAMR) ethics guidelines, the disability literature for other discussions of consent, conversations with researchers in this field about their approach (where it was not specified in their published work), L’Arche, and people from other agencies. The AAMR’s “Guidelines to Professional Conduct” do not provide any clear *procedure* for how to handle this issue, although it lays out some helpful principles. It urges practitioners and researchers to honour the needs and choices of the person with intellectual disability(s), to respect their “dignity, privacy and confidentiality” and to practice full disclosure so people can “make their own informed decisions to the best of their ability” (AAMR 2001). The AAMR cannot provide specific procedures for ascertaining choice or consent in every case due to the diverse possibilities. Principles like this are good for at least establishing a sensibility around the issue. For example, this principle makes it clear that if a person is judged *capable* to understand this concept and give consent, then the researcher should ask them directly. The ambiguity lies in who makes that judgement about *capability*; the person themselves, their legal guardian, their agency,

or the researcher? The appropriate procedure for establishing consent then, depends on the degree of someone's disability but also on the researcher and agency's politics.

Several researchers in and outside of L'Arche feel that the most respectful approach is to discuss and obtain consent directly from the person with intellectual disability, but they were also all required to have consent from the sponsoring agency or group through which they had access to meet these people (Mosteller 1996; Porter 1998; Stalker 1998; Kittay 1999; Desjardins 2000; Epp 2000; Matysiak 2001; Pottie 2001). Matysiak, for example, wanted to do a focus group with people in the agency where she worked, all of whom, she helpfully specifies, "were legally able to give consent (i.e.) had not been declared incompetent. All of the people in the study were able to clearly indicate their choice as to whether or not they wished to participate" (2001:194). Still, she also sought approval from the agency sponsoring that self-advocacy group, and she worked in that agency herself. Her consent letter was written and read in "plain language,"²⁰ but she reports that even this seemed "inadequate" for certain participants (ibid:195).

The most common legal solution for medical procedures or financial questions, is to get the consent of a person's legal guardian. In research however, this would mean that a guardian (who may or may not be versed in different and new ways of thinking about intellectual disability and how to represent it), would have the power to restrict a researcher from writing anything that *the guardian* considered inappropriate. For example, something that revealed a side of their charge that *they* did not like, or an embarrassing part of how the family treated the person with intellectual disability, could be disallowed. Furthermore, a guardian's decision can be biased towards self-interest, or protection of family history, rather than what might be in their charge's best interest. This kind of veto could block a writer from presenting individuals as whole actors, with strengths and challenges, which is as important for people with intellectual disabilities as it is for others. It is likely even more important given a common tendency for them to be presented

as a homogenous group based on medical diagnosis alone, and labelled with one-dimensional, polarized stereotypes (Trent Jr. 1994).

Composite identities and pseudonyms are another way to protect people's privacy. In discussions with the group of assistants at L'Arche, we considered both of these options. Composites facilitate a great degree of privacy, however they raise other issues. Composites can be objectifying, in that they can imply that anyone with a certain trait, (e.g., native, wealthy, disabled) is the same: generic, interchangeable, and having no relevant individuality. In an article that I co-wrote about relationships between assistants and core members, the Daybreak assistants requested that we limit the particulars provided about the individual core members in it for their privacy. Instead, we discussed general patterns of abuse and hardship that people with disabilities suffer to evoke a sense of what many of them had been through, without revealing their identities. Ironically, one of the three peer reviewers at the major journal it was eventually published in required that this composite approach be changed, or at least more clearly justified, in order to avoid the pitfalls just described (Cushing and Lewis 2002). Obviously the two ethical goals of protecting and humanizing people with disabilities were in conflict here.

The most compelling strike against composites in my mind however, and particularly for research with L'Arche, which promotes the value of individual diversity, is that composite figures can compromise integrity of identity. I need to share at least something of the character and complexity of the people with intellectual disability in this research because *it is precisely their particularities that can transform them from stereotyped caricatures into fully human subjects* for the unfamiliar reader. *It also evokes how assistants experience them: not as a group, but as individuals.* Their unique character or personality is often why they have such a strong influence in the lives of the assistants who live with them. It is also sometimes the frightening details of their history of abuse or neglect that are moving for assistants, (see for example Mosteller 1996;

Vanier 1996; Vanier 1998). In my project however, I chose not to include stories that required personal medical data to be relevant, since it was not essential to make the same points.

L'Arche negotiation and agreement

In this section, I outline the procedure that L'Arche and I followed in developing a solution for this thesis, including additional factors specific to this community. As noted earlier, in my initial proposal and agreement with the community, I had their consent to observe and write about the lives of assistants in L'Arche, which would include general information about core members, but not specifics. Although I did presentations for everyone in each community, I only sought written consent forms from people whom I interviewed formally, and I did not interview any people with intellectual disabilities. Eventually I decided that it would be important, and in my judgement, ethical, for the ethnographic representation of core members to include salient particulars about their personalities and lives, as discussed above. At this point, I discussed the issue with my liaison, who felt the issue needed to be considered from different perspectives. He organized an ad hoc committee of long-term assistants with diverse experience and positions on such matters, and they asked me to write up a discussion of what I thought the key issues were, what I wanted their advice on and permission for, and a written sample. I did not anticipate any concerns given that other people had written about L'Arche core members in more detail than I intended to in books, article and theses, with and, more often without, pseudonyms. However, in raising the issue, I generated a forum for discussing concerns that had been on their minds.

L'Arche communities have a blanket policy that most core members' legal guardians agree to in advance that authorizes L'Arche assistants or approved writers to write and talk about core members for internal and external audiences in line with their mission so long as it is respectful. This is common practice in other agencies as well. Most writers, primarily assistants and journalists, have community permission. They also usually ask the core member for consent

directly or with an assistant as intermediary, but do not typically go to their legal guardians, or use pseudonyms. Many writers feel that using the person's real name is a form of respect. Since most writing is done by L'Arche assistants with long tenures, good relationships with core members, and a commitment to serving them, there is a certain freedom around what they write, and indeed, most core members say they are proud and happy to be named. The writing focuses on the positive message L'Arche has about the value of people with intellectual disabilities, and on a pragmatic level, these spiritual writings are a significant means of attracting assistants and donations²¹. The writing tends to highlight the best sides of the core members, but sometimes what L'Arche, or these writers consider best, does not agree with what guardians consider best. In recent years, L'Arche has had a few cases of guardians being opposed to, and insisting on the removal of, information about their charge from articles and books. As a result of these changes, and the fact that my work is a scholarly work, apt to contain a more balanced, and thus in some cases, critical perspective on life in L'Arche, the ad hoc ethics committee determined to establish more specific guidelines.

After several iterations to my original writing sample and draft statement of terms and conditions, the committee and I agreed on a course of action that we considered was ethically appropriate, and could not lead to harm for the core members. I agreed to use pseudonyms for all core members, as was my approach with assistants. We distinguished between when the recognizable details were about their personality, or their medical and personal histories. I agreed that for most stories, I could include salient details of the core member's idiosyncratic personality, but not *details* about their medical conditions or family and institutional history. For those stories where some detail about the core member's medical history is necessary, or where a person's attitude or behaviour is not flattering, I would change other details about them so that they would not be recognizable to other assistants who likely did not already know about that

condition or behaviour. The exception is with stories that are already written about, or very well-known in L'Arche. We developed a revised general consent form outlining the terms and conditions that I agreed to abide by as listed here (see Exhibit 2.6 *Terms*). Although this agreement would not satisfy every possible criticism, it does better address the specifics of my approach, provides clear protection of privacy and makes the process transparent to the reader. I also committed to providing each community I visited a copy of the thesis to review, and give feedback on. In practice, I have shared several sections with different assistants throughout the writing process to ensure that the work abided by the agreement. My thesis committee at McMaster University also approved this form, agreeing that it dealt appropriately with the various ethical guidelines involved.

2.6 Conclusion

In this chapter, I presented a comprehensive outline of my theoretical orientation to ethnographic field work, my methodological approach and my research design. My aim in being transparent about how my information was obtained is to provide the reader with a firm basis from which to evaluate the quality of the ethnographic data. I also disclosed my reflections on weaknesses in my methodology, errors that I made, and dilemmas that I faced in the field, and how the issue and my approach compare with the experiences of more experienced anthropologists. In each case, my hope is to show how these minor and major problems influenced the quality of data that I gathered, but also to show what degree of self-awareness I had in the field and afterwards regarding the limits of my work. I learned a great deal about ethnography and participant observation by facing such concerns, making mistakes, hearing feedback from my participants and my committee, and in reflecting on the outcomes. My original research questions now seem impossibly broad and vague, and I see how this played out in the field where I cast a wide net, but did not have a clear map to help me narrow down what kind of

information I sought. Fortunately, these issues have not been ruinous, as I was eventually able to discern a narrower writing focus.

What follows in Chapter 3 is the fascinating history of the medical changes, and cultural construction of the category of intellectual disability, and the different solutions to this social question that have emerged over time. Understanding this history provides the necessary grounding for the discussion in Chapter 4 about where L'Arche fits into the overall picture of the field. The basic history is also a necessary background for understanding what draws people to be assistants in L'Arche, which is the central concern of Chapter 5. People who come to L'Arche start off with a perception of people with intellectual disabilities that is at least partially based on common cultural representations of them. Therefore, in a less direct way, the basic history also informs my analysis of how assistants' experience of L'Arche and people with intellectual disabilities is constructed, as I discuss in chapters 6 and 7.

2.7 Endnotes

¹ Later in this thesis I discuss how other writers have problematized the notion of experience (Scott 1992b; Mohanty 1989).

² It was not until the end of the project that I began to problematize the cultural assumptions and norms that make personal change desirable.

³ The other four issues that I identified were: 1) the experience was too short for them to experiment with, and fully integrate the changes into their self-concept; 2) many of the supportive cultural and relational factors on course did not exist in their busy regular lives; 3) the people they went home to, did not have a shared understanding of what the student had been through and were thus ill-prepared to support them in their change; and finally, 4) that Outward Bound's course design failed to enact the necessary elements of a proper 'exit' phase according to the rites of passage model, leaving students unsure of how to reintegrate as their (partially) "changed self" (Cushing 1998; Cushing 1999).

⁴ Not the real name of the house.

⁵ As the oldest and largest Canadian community, Daybreak was not necessarily representative.

⁶ Where ethos is the social group's moral and aesthetic tone, and worldview is their perception of "actual reality" (Geertz 1973c:89).

⁷ Results will be made available later.

⁸ Narayan (1993:676) discusses the importance of acknowledging ways in which the research is connected with and implicated in the worlds of those they study.

⁹ See Ortner (1995) for a compelling discussion of other dangers of omitting internal diversity.

¹⁰ Although L'Arche might be aided by my research, I think the chief reason that I was allowed to be there was their desire to help a student.

¹¹ Intentional community means much of your life is public knowledge, so many assistants seemed protective (reasonably, I think) of their few hours of private time. Before I understood this, I would often

ask assistants what they were doing/did in trying to gather information. Their responses ranged from candid to vague, which subtly indicated my overstep, and one friendly housemate was explicit about her discomfort with my questions about her time off.

¹² I now see that other creative solutions to this dilemma are possible; at the time however, I did not think that the issue was worth pushing.

¹³ Each assistant was to be paired with the female core member whom they felt closest to, and each pair was to work together to construct their joint story. Four of the five core members involved were not able to write or tell an unassisted story. T. Lewis co-wrote this article with me.

¹⁴ Foucault explained that the French distinguish linguistically between the knowledge achieved or embodied in intense, initiatory moments, *l'épreuve*, and knowledge achieved via safe, rational inquiry, *l'enquête* (Miller 1993:269-73).

¹⁵ The ethics guidelines that I consulted were: Social Science and Humanities Research Council (SSHRC), American Anthropological Association (AAA), American Association for Mental Retardation (AAMR), and McMaster University guidelines.

¹⁶ This is not the actual singer that Alfred likes, just a substitute for discussion purposes.

¹⁷ Matysiak notes that traditional medical and rehabilitative researchers usually get consent from sources like the institution or a public trustee. This is thus mainly an issue for *critical* researchers who have tended to simply avoid the issue by not involving people with profound disabilities (Matysiak 2002).

¹⁸ For examples which do *not* remove the negatives sides, see Kingfisher (1996), Duneier (1999)

¹⁹ Similarly, Ortner maintains that to cover up the unflattering aspects of our subjects' lives is a disservice to them, and seriously impairs the quality of the analysis and representation (1995).

²⁰ Plain language is an approach developed to help make requests for consent more accessible to people with intellectual disabilities. It means "a type of writing that is straightforward and jargon free, but is not condescending or simplistic" (CACL 1997). For example, *consent* is replaced by the simpler, *permission*.

²¹ Stories in books by Mosteller, Vanier, and Nouwen are profound statements about the gift that the core members have been in many people's lives (Mosteller 1996; Nouwen 1997; Vanier 1995; Vanier 1998).

3.0 Historical Review of Intellectual Disability

3.1 Background

“By its very presence, the exceptional body seems to compel explanation, inspire representation, and incite regulation.”
(Thomson 1996:1)

This chapter provides a discussion of the history of how people with intellectual disabilities have been understood, labelled, cared for, and, at times, mistreated. It is important to understand this history of disability and care because it is in that history that contemporary attitudes and means of caring for these people have their origins. There are four goals for this chapter. The first goal is to use the literature to show the historically poor treatment of people with intellectual disabilities in state care, and the social rejection and stigma they have been subject to since roughly the 1840s. The second goal is to discuss the many ways in which this stigma has been culturally constructed through false conceptions of intellectual disabilities despite changed understandings among professionals in the caregiving field. Third, I show that the conditions, needs and characters of people who are labelled intellectually or developmentally disabled vary significantly, and I discuss the concomitant importance of offering a variety of forms of care and residential options. Independent living has not, in fact, produced greater well being for *all* people with intellectual disabilities. The final goal is to show that the failure to properly support and retrain front-line caregivers in the new care ideologies has produced unnecessary strain and role confusion for them that ultimately affects the quality of care that they can provide.

I begin with a discussion of *current* definitions of intellectual and developmental disability and the history behind the many changes to the label. I then expand on the complex history of the emergence of intellectual disability as a category and a “problem” that is both biologically based and culturally constructed. Finally, I review the colourful history of changing attitudes towards people with developmental disabilities, and the various mechanisms of caring for and housing them that have emerged from the early 1800’s onwards. For historical accuracy, and to evoke the moral dynamics surrounding disability, I use period-appropriate language throughout this chapter.

3.2 Current definitions of developmental disability

L’Arche communities were formed to serve and to create homes for people with intellectual and developmental disabilities. The term “disability” has changed in meaning and scope many times since the mid-1800’s, and even since the 1960s when L’Arche was formed. The disability and mental health fields have generated a proliferation of terms in the last 150 years. These terms also vary in usage between Canada, the US, Europe, and elsewhere. For example, in the UK, the term “learning disability” is roughly equivalent to the term “mental retardation”, as it is used in the USA, and to “intellectual disability”, as this term is used in Canada. In Canada and the USA, “learning disability” refers to yet another area, including dyslexia or other difficulties which can often be corrected. I restrict this discussion to the Canadian and American terminological developments, which have been mutually-informing. While the meanings of the terms continue to change, this discussion provides an overview of the key elements and issues.

3.2.1 Reasons behind the proliferation of terms and definitions

It is important to address briefly why there have been so many labels for, and definitions of this group of people. The dual, and at times contradictory, goals of the definitions were to help create higher quality and lower cost ways to handle, and care for, people considered

developmentally disabled, or in some way unable to accomplish self-care. Smith notes that since the mid-1900's, changes to the definition have been conceived out of the tension between two somewhat incongruous goals of scientific accuracy and of greater sensitivity towards people labelled as mentally retarded (Smith 1997:11-12). Definitions also proliferated because different groups created typologies for different purposes. A listing of terms used by different professions illustrates this point. In the mid-1800's, doctors created medical terms or "grades" to try to separate out priorities for distribution of care in their increasingly crowded asylums: fools (mild retardation), moron (high-grade mental defectives), imbecile (moderately severe retardation), or idiot (severe retardation) (Simmons 1982; see also Trent Jr. 1994:159-73; Smith 1997:4). Early in the 1900's, psychologists used IQ test performance to grade people for treatment eligibility and financial support, with the levels of mild, moderate, severe, profound, and un-testable mental retardation (See Appendix 3.2) (Smith 1997:4; APA Task Force 2000). In the 1950s, educators developed levels that indicated the declining expectations of development among their charges: educable mentally retarded (could read eventually but learn very slowly), trainable (no reading but does basic tasks), sub-trainable, and custodial (Smith 1997:4).

In his historical account of changing attitudes to "severely retarded people," Ferguson argues forcefully that, while these classifications have led to better supports for people with the least impairment (i.e. mildly retarded and educable), they have, in fact, worsened the life conditions of, and negative attitudes towards, people in the middle-to-low end of impairment because the grades impose a sense of chronic failure, hopelessness, and uselessness onto them (1994:3-4). Further, his research suggests that this so-called *failure* to be rehabilitated is consistently blamed on the impaired individual rather than acknowledging the roles of professional inadequacy (Simmons 1982; Ferguson 1994:43, 161; Trent Jr. 1994).

Problems with labels and grading systems notwithstanding, some form of definitions and classification is necessary given the state medical, economic, and educational intervention that is required and, indeed, demanded by people with disabilities, their families, advocates, and society. Definitions of disability have a role in shaping what is considered to be appropriate support, for whom, and how that support should be delivered to people with disabilities. This relationship becomes apparent when disability is redefined, along with eligibility for funding (Smith 1997:3). For example, in the USA, in 1975, changed definitions dramatically reduced the number of students classified with mental retardation in schools by reclassifying people with “mild” retardation as having a “learning disability” which, while less stigmatizing, also reduced the amount and length of their state financial support (ibid:3).

The definitions interact with and shape public attitudes towards people classified with an intellectual disability. Many activists have argued for a change in public perception and language to recognize that a disability is not necessarily a global or dominant feature of someone’s identity (Simpson 1998:6). Advocates argue for language that better reflects that they are “people first” rather than disabled first (Roehrer Institute 1996:19-24; Epp 2000a; WSDSHS 2002). In Canada, the Roehrer Institute and the Canadian Association for Community Living (CACL) have been leaders in promoting the use of such language that is less “disabling” (CACL 1997).¹ For example, their publications follow the system of International Classification of Impairments, Disabilities, and Handicaps (ICIDH), developed in the 1970s by the World Health Organization to classify the consequences of diseases, disorders, and injuries, and to distinguish between impairment, disability, and handicap (Roehrer Institute 1996:20).

Impairment refers to the loss of normal function (psychological, physiological, or anatomical structure), while a *disability* refers to the restriction of normal ability that arises from the impairment, and a *handicap* is the disadvantage a person experiences because of the

impairment and disability (Roehrer Institute 1996:20-1). To illustrate, Dr. Gregor Wolbring, who is a biochemistry professor at the University of Calgary, explains that as a thalidomide baby he was born with an *impairment*, no legs, but that this is only a *disabling* condition because the world is designed for people *with* legs, and because society stigmatizes those without legs (Hingsburger 2001b:5). Still, he is not convinced that not having legs has been a *handicap* for him, as he jokes in an interview:

Having legs, what would I gain besides that society would view me in a more positive way, which I think is disgusting to start with? If I get viewed by society based on my legs, I wouldn't trust their judgement... I only get to know people who are nice, because the ones who are normally not very nice can't get around that I have no legs... can't view me as an equal. So I actually have an evolutionary advantage here. (Ibid:5)

Other organizations use different terms, however. For example, the American Association for Mental Retardation (AAMR) states: "A disability refers to personal limitations that represent a substantial disadvantage when attempting to function in society" (AAMR 2002b). I elaborate on the issues regarding different definitional emphases in section 3.3.5. First, however, I present key definitions of intellectual disability.

3.2.2 Definitions of Intellectual Disability

Hauerwas cautions that the "realization that retardation is [also] a social designation should not blind us to the fact that the retarded do have some quite specifiable problems peculiar to them and that their difference requires special forms of care." (Hauerwas 1986:161). The most recent definition of mental retardation used in the USA is found in the AAMR's widely used manual on mental retardation published this year (Luckasson, Borthwick-Duffy et al. 2002). The AAMR has updated this definition *ten times* since 1908 and is in the process of changing its name to American Association of Intellectual Disability (AAMR 2002). Thus, the definition below describes intellectual disability, as well (also see Appendix 3.1). The previous AAMR definition

(1992) was adopted in the Diagnostic and Statistical Manual, 4th edition, (DSM-IV) with the additional specification of an IQ test score from 0 to 70 (APA Task Force 2000).

AAMR Definition of Mental Retardation (Intellectual Disability) (AAMR 2002b)

Mental retardation is a disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.

5 Assumptions Essential to the Application of the Definition

1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.
2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.
3. Within an individual, limitations often coexist with strengths.
4. An important purpose of describing limitations is to develop a profile of needed supports.
5. With appropriate personalized supports over a sustained period, the life functioning of the person with mental retardation generally will improve.

The Ontario Association for Developmental Disabilities (OADD) is a large professional and advocacy organization, which publishes a comprehensive resource manual that includes an entire chapter on definitional nuances in Ontario and Canada (Brown and Percy 2002). Brown explains that Canadian definitions follow American ones but are applied more flexibly (relying more on clinical judgement) and tend to be purpose-specific definitions rather than universal ones (Brown 2002a)². While government ministries and Acts use various definitions and terms, as of 2001, the term developmental disability is officially “now used throughout Ontario statutes” and is defined, in the Developmental Services Act, as “a condition of mental impairment present or occurring during a person’s formative years, that is associated with limitations in adaptive behaviour” (Brown 2002a). The term came into common use in Ontario in the 1970s replacing the terms developmental handicap and mental retardation. It is now used synonymously with intellectual disability, which is more precise (Brown 2002a). Although the term developmental disabilities *technically* includes people with conditions like autism that do not necessarily result

in cognitive delays, its current *social* meaning in Ontario is “those people with lower intellectual functioning who need some type of specialized assistance to carry out the practical and social activities of daily living” (Brown 2002a).

The CACL is committed to using plain language in all materials they produce. Therefore, their definition of intellectual disability is straightforward and conveys a similar meaning as the definition used by the OADD. The CACL definition states that an “intellectual disability is an impaired ability to learn. It sometimes causes difficulty in coping with the demands of daily life. It is a condition which is usually present from birth, and it is not the same as mental or psychiatric illness” (CACL 1997; CACL 2001). The definition used by the Roehrer Institute suggests that people “with an intellectual disability have a cognitive or perceptual impairment that means they master basic and social skills more slowly” (Roehrer Institute 1996:13-14).

3.2.3 Defining Developmental Disability

Intellectual disability, or mental retardation, is most accurately considered a sub-set of developmental disability, although in many cases, all three terms are used interchangeably³. Although each state in the USA has its own legal definition of developmental disability, there is a federal definition that is widely applied, although with some variations⁴.

To be specific, the category of *developmental disability* is commonly said to include people with: mental retardation “and several conditions that can (but do not always) produce similar results: cerebral palsy, epilepsy, and autism” (WSDSHS 2002), as well as other neurological disorders, and “conditions requiring services similar to those required for persons with mental retardation” (CSCDD 2002). The reason that some developmental disabilities are separated from intellectual disability, per se, is that “[some] people with autism or cerebral palsy, for instance, may have normal to high IQs, but have great difficulty expressing themselves or communicating with others, and may also have physical disabilities so severe that they require

24-hour support” (WSDSHS 2002). Films such as Rainman and My Left Foot portray people such as this, whereas films such as I Am Sam and What’s Eating Gilbert Grape? portray people who have clear intellectual impairments. L’Arche primarily invites people with intellectual disabilities but also some people with significant developmental disabilities.

USA Federal definition of Developmental Disability
(ARC 2001; ACDD 2002; CSCDD 2002)

A. The term *developmental disability* means a severe, chronic disability in an individual five years of age or older that:

1. Is attributable to a mental *or* physical impairment or a combination of mental and physical impairments
2. Is manifested before the person attains age 22
3. Is likely to continue indefinitely
4. Results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, or economic self-sufficiency.
5. Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

B. Infants and young children:

An individual from birth to age 9, inclusive, who has a substantial *developmental delay* or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described in 1-5 above if the individual, without services and supports, has a high probability of meeting those criteria later in life.

While the definitions of developmental and intellectual disability are still evolving, key features of these conditions are that once developed they: require some degree of ongoing, life-long supports; can be congenital or acquired; have no total cure but are often ameliorated through early intervention,⁵ medication (see Section 3.3.5), and ongoing supports (ARC 2001; AAMR 2002; WSDSHS 2002). There is some disagreement in the field over whether developmental disability and/or mental retardation/intellectual disability are *medical conditions, disorders* or neither of these. Several organizations, including the AAMR, now use definitions that specify “mental retardation is not a medical disorder, nor a mental disorder” (AAMR 2002; Luckasson,

Borthwick-Duffy et al. 2002; WSDSHS 2002). The authors of the DSM-IV, however, state the opposite, although they concede that in many cases “physical causes have not been demonstrated or are poorly understood, even though biological treatments (e.g. drugs) may be effective in treating them” (see Appendix 3.2) (APA Task Force 2000).

Significant variations in definitions used to identify developmental disability make it difficult to compare figures from different sources. Still, a few statistics will help illustrate the numbers of people who have been categorized as developmentally disabled. Using data for 2001, Gollay and Associates estimate that 1.8% of the American population, or 4.86 million individuals, are developmentally disabled (CSCDD 2002).⁶ This is significantly lower, however, than the ARC’s estimate of a 2.5-3% prevalence rate and 6.2-7.5 million Americans with mental retardation (ARC 2001), especially considering that mental retardation is only a sub-set of developmental disabilities.⁷ In Canada, the CACL estimates that 899,000 Canadians (roughly 3%) have an intellectual disability (CACL 2001).⁸ Of these people, estimates suggest that 80-87% “will [only] be mildly affected” meaning they will learn slowly but will likely be able to live independently, with minimal supports, eventually (ARC 2001; WSDSHS 2002). Of the remaining 13-20%, approximately 90% are classed as moderately retarded, and 10% (i.e. 1.3-2% of all people with intellectual disabilities) as severely or profoundly retarded (WSDSHS 2002).

3.2.4 Key changes in definitions: 1941-2002

In the previous section on definitions, I outlined the key changes in the AAMR definition since 1941, and the significance of those changes. In this section, I describe the evolution of the definition between 1941 and 2002. I elaborate on the *reasons* for the changes later in section 3.3.

Although *social* or *adaptive* incompetence had been discussed since 1941, it was not officially included in the AAMR (then AAMD) definition of mental retardation until 1959. Following that definition, “mental retardation refers to subaverage general intellectual

functioning which originates during the *developmental* period [birth to 16 years] and is associated with impairment in adaptive behavior” (Heber 1959; Smith 1997:5-7). Criticized for lacking specificity, this definition was revised in 1961 to stipulate that “subaverage” meant an IQ score one standard deviation below the mean, or IQ scores of 85 or less⁹. Using this criterion, a full 16% of the population of the United States, in 1959, would have been categorized as mentally retarded (Heber 1961; Smith 1997:6). This definition was problematic (see section 3.3) as too many people who did not require care, particularly immigrants whose first language was not English, were committed to state institutions leading to overcrowded facilities (Trent Jr. 1994:260, 168). The care provided in these under-funded institutions slid until the poor conditions were publicly revealed during the 1960s (Trent Jr. 1994:251-2).

Major revisions were made to the American definition of mental retardation in 1973:

- 1) The IQ ceiling was changed to 2 standard deviations below mean, so that a score of 70 or lower was required in order to qualify for state support. This left just 2.25% of the population in this category. (Trent Jr. 1994:261; Smith 1997:6).
- 2) Adaptive behaviour became a more important part of the diagnosis, (Smith 1997:6).
- 3) The developmental period was raised to 18 years. (Smith 1997:6).

These changes substantially reduced the number of people qualifying for support, although later changes added some flexibility with IQ cut-offs (Smith 1997:7). Reclassifying people as merely “learning disabled,” was accompanied by a significant increase in funding for special education in normal schools from 1976-85, and no children were thereafter admitted to the institutions (Trent Jr. 1994:261). The numbers were influenced not just by IQ and funding changes, but by changing attitudes and programs. Parents and professionals were more hesitant about labelling a child due to the stigma, and early childhood intervention programs also improved (Smith 1997:7). Changes to the definition in 1983 extended the developmental period

from birth to conception so prenatal causes of retardation became eligible for funding and care under this redefinition (ibid:7).

The authors of the 1992 AAMR definition changes hailed it as a paradigm shift towards a functional and social perspective. This definition shifts the locus of the problem from the individual to the interaction of individuals and their environment, and moves the emphasis away from people's deficits to their needs (Schalock, Coulter et al. 1994; Smith 1997:8-11). One major way this was accomplished was by changing from sub-classification into grades by IQ, (See Appendix 3.2), to sub-classification by the *intensity of supports* that someone requires as *intermittent, limited, extensive, or pervasive* (Luckasson, Coulter et al. 1992). The 1992 definition includes a set of four assumptions¹⁰ that guide the definition and recommended supports, name the importance of environmental and cultural factors, and emphasize the ameliorative potential of appropriate, individualized interventions. While this change was criticized for not being rooted in new medical or scientific research, and for simply replacing one classification system with another¹¹ (Smith 1997:9-11), it has taken hold and was adopted by the DSM IV (APA Task Force 1994). Changes included in the recent 2002 definition are minor and improve the sensitivity of the language¹² (See appendix 3.1).

Section 3.2 laid out the current definitions and issues of the field of intellectual disability, with a brief discussion of rationales behind the changes. In the next section 3.3, I elaborate on the socio-cultural, political, and economic dynamics that contributed to these various definitional and policy changes and to the volatility of public attitudes towards people who have developmental disabilities.

3.3 A critical history of the concept of intellectual disability

“Mental retardation is a construction whose changing meaning is shaped both by individuals who initiate and administer policies, programs and practices, and by the social context to which these individuals are responding.”

(Trent Jr. 1994:2)

In this section I synthesize the results from a number of historical analyses to show that the concept of intellectual disability and the social meanings associated with it over time are cultural constructions, as much as biological facts. While I can hardly do justice to the many excellent histories of the field, I provide enough discussion to demonstrate two main points. First, that the changing fortunes of people with intellectual disabilities in Canada and the USA have hinged more on political, moral, and economic factors and professionals' agendas than they have on changes in disabled people's conditions or their responsiveness to education, treatment and rehabilitation (Ferguson 1994; Trent Jr. 1994; Roeher Institute 1996). Second, I show that, although in retrospect the attitudes towards and management of people with intellectual disabilities seem scandalous, the policy makers generally thought that their actions were morally acceptable given the norms of their time. These views were widely held in their contemporaneous professional organizations (Simmons 1982; Trent Jr. 1994).

In order to make these two arguments, I address historical shifts in the professional and popular understanding of intellectual disabilities and the accompanying moral and attitudinal changes. I demonstrate how, until recently, people with intellectual disabilities have been construed as the problem; thus they are the ones who had either to be educated, segregated, rehabilitated, cured, or at least be made to become more “normal” and productive. Mental defectives of various sorts were seen as a problem requiring a social and regulatory response (Barham 1992:78; Ferguson 1994:7). I close with a discussion of the range of current conceptual approaches that are being used in the field and a discussion of currently known causes.

3.3.1 Competition for control of the definition

Foucault has shown us how modern power effectively operates through knowledge, not force; the dominant group seeks to control the definitions of what is considered normal and moral by naturalizing its own values (Foucault 1965:78-82, 195, 69; Foucault 1973; Castel 1991; Fox 1994:22-3). Early on, since the origins and nature of being a so-called mental defective were not understood, there was open competition for ownership of knowledge about the condition between God (sins/grace), nature (hereditary), teachers, administrators, doctors, psychiatrists (Langness and Levine 1986:ix; Thomson 1996:4) and, lately, social workers and rehabilitation specialists. The condition has been named by professionals at different times as “a disorder of the senses, a moral flaw, a medical disease, a mental deficiency, a menace to the social fabric” and mental retardation. The public’s associated affective and moral responses have included pity, compassion, fear, contempt and a desire to control (Trent Jr. 1994:2).

Foucault also demonstrated that social categories are often created as a counterpoint to particular cultural conditions (Foucault 1965:250-2). For example, changes in the contingent social needs of the past have led to mentally sub-normal people being spiritualized, fetishized or demonized (Ferguson 1994:5-7; Krishef 1983:17-34; Ingstad and Whyte 1995; Roeher Institute 1996; Thomson 1996). Christian attitudes to them have also varied; from charitable caring for these “children of God” to judging them as lacking moral piety and condemning them as soulless (Wolfensberger 1975:7; Krishef 1983:18-19). *Systematic* attention to people considered mentally subnormal began in earnest in the early 1800’s (Simmons 1982:8; Ferguson 1994:28-9). The rise in concern occurred because of economic and demographic changes towards industrialization and urbanization which loosened or eliminated the protective webs of local community ties and familial distribution of labour. This left masses of people homeless, poor, and thus problematic for municipal leaders (Radford 1994; Trent Jr. 1994:12; Roeher Institute 1996:1-3).

It was not until the mid-1800s that what we now know as intellectual disability began to be somewhat differentiated medically and socially from other so-called deviant conditions including: poverty, laziness, criminality, mental illness, or physical disability (Goffman 1963; Wolfensberger 1975:3-5; Simmons 1982:2-18; Murphy 1990:112). In the 1840 US census, the term “idiots” was first used officially to refer to this group (Trent Jr. 1994:38). Nevertheless, by that time, a naturalized sense of connection between cognitive abnormalities and poverty, moral weakness, and violence had been forged in the public consciousness (Barham 1992:151; Ferguson 1994:5-45). Stigma and scorn were directed towards this diverse group by the general public as much because they were not economically productive or morally astute as it was a result of their cognitive impairments per se (Wolfensberger 1975; Hauerwas 1986:161; Murphy 1990:81-87; Barham 1992:78, 116; Trent Jr. 1994). The values evident in these negative attitudes eventually contributed to the design of solutions for housing and the rehabilitation of people with intellectual disabilities (Wolfensberger 1975:2).

Foucault shows that clinics and asylums for the mentally ill, who shared a similar historical trajectory, were originally intended as temporary care facilities that would catalyze scientific progress by facilitating patient observation in a neutral, lab-like setting (Foucault 1973:108-12). This scientific ideal was, however, also used as a rationale for poor treatment of the patients, resulting in subsequent iatrogenic effects (Foucault 1973:108-112; Freund 1982b:11). Barham calls the treatment of “lunatics” a “politically sanctioned operation of disposing of the socially unwanted and unproductive” (1992:140). The “paradox of the asylum” is that the public will to isolate sick or deviant people includes both “wanting to help them and wanting to get rid of them” (Barham 1992:9,68) because they lacked socially-valued traits (Foucault 1965:vi; Fine and Asch 1988:16).

Differentiating and labelling people who are already socially marginal often initiates a “cycle of devaluation and degradation” (Brown 2002a). Ferguson argues that labelling is also worse for those who end up on the least-valued end of definitional scales (1994:2-25). Researchers show that once early asylum administrators began to differentiate between their “curable wards”, lunatics (mentally ill or simple) and the so-called “incurables” (idiots, imbeciles, mentally retarded), they refused admittance to the latter in order to optimize their rehabilitative “success rates” (Simmons 1982:3-10, 21; Ferguson 1994:6). Eventually, under public and political pressure to provide room for imbeciles, Canadian doctors opened up “second tier” residences for them in 1857 and 1861 (Simmons 1982:9-11). From their inception, these residences were notably more custodial than rehabilitative in intent (ibid:9-11).

Another distinction was made between the deserving and undeserving poor; the deserving, including mental defectives, were judged as unable to help themselves (Ferguson 1994:41, 7-25). While being defined as deserving meant access to charity, it also coloured recipients’ identities and future with failure and hopelessness (ibid:2-25, 31). Ferguson asserts that this ipso facto condemnation to failure provides disability professionals with a convenient excuse for the inadequacies of their approaches (1994:43). He wryly characterizes the professionals’ foolproof, if tacit, dictum: “Those [defectives] who failed did so because they were unteachable, not because they had not been taught” (Ibid:161). “Failure was held to be a natural limitation of individuals, not a social inequity of incremental reform” (Ibid.:158). This un-stated justification for the lack of improvement also set a poor tone for the quality of care or teaching expected of front-line workers (Ryan and Thomas 1980:14; Thomson 1996:4).

3.3.2 Dominant approaches in different historical periods

Certain professions and their approaches dominated the field of mental retardation at any given time, although there always was, and is, some overlap. Cultural factors also played a part in

which perspectives flourished. These perspectives mediate the manner in which non-intellectually disabled people experience and relate to people with intellectual disabilities.

The Romantic period in Europe (early 1800s) produced a charitable, liberal optimism for the educability and correction of people with various deficits including the “sensory disorders” of the blind, deaf and dumb (Trent Jr. 1994:11-13). Various success stories of the education and rehabilitation of “idiots” in France during the 1820s-30s caught the imagination of North Americans around 1842, while they also grappled with what to do with mentally defective people. (Trent Jr. 1994:12-17). Thus began a period from the 1840s to early 1850s when educators dominated the decisions about mental defectives. This time was a “golden age” for disability care because optimistic predictions for rehabilitation made by school directors generated political interest and funding for buildings and innovative programmes (Radford 1994:13; Trent Jr. 1994:40-60). While some programmes and schools in the US achieved a degree of success in rehabilitation, in the form of returning people to the community as productive citizens, little success was achieved overall (Trent Jr. 1994:29).

The lack of progress was partly due to overly optimistic expectations, intentionally exaggerated by directors who were lobbying for funding. There was also a lack of funds and this meant that most state schools were too big, overly crowded, and lacking in enough well-trained educators to execute the pedagogical programmes properly (Wolfensberger 1975; Simmons 1982; Tylor and Bell 1984; Fox 1994:13; Trent Jr. 1994:15, 57; Roehrer Institute 1996). The early state schools were, in some ways, victims of their own optimism and propaganda because their aggressive claims made their actual modest successes seem like failures (Trent Jr. 1994:94). Public awareness of these failures exacerbated existing negative stereotypes such that when a few progressive directors in the 1850s and 60s tried to help “simple idiots” reintegrate and gain

employment, local communities no longer wished to accept responsibility for them (Trent Jr. 1994:39, 94-5).

Eventually, in the 1870s-80s, faced with under-funding, overcrowding, and lack of paid staff, directors began to train the “simple idiots” for use as labourers in sustaining the asylums and caring for others. Essentially, this initiated the transition from school to asylum, or education to a custodial model (Wolfensberger 1975; Ryan and Thomas 1980; Radford 1994:14-17; Trent Jr. 1994:94-5; Roeher Institute 1996:3, 6). Later inquiries revealed that “inmates” often did more work than the paid staff and that many had higher IQs than the staff (Simmons 1982; Ferguson 1994; Trent Jr. 1994:226-30, 253).

This lack of progress by educators created a gap for a new group to stake its claims. Although medical doctors had been involved in the field since the 1840s, it was in the 1860s that they began to replace educators as directors of schools and asylums for the mentally retarded (Trent Jr. 1994:17, 36, 39). Nevertheless, like their predecessors, doctors made rehabilitative claims in public, while inside the institutions they were planning for life-time custody (Ibid:29). By 1889, one prominent US asylum director admitted that just 10-15% of people in that asylum could be trained to be self-supporting on the outside (Ibid:82).

Even earlier, in 1863, a senior Ontario inspector of asylums for idiots wrote, “All the treatment they [the idiotic] require is simply for such occasional bodily ailments ... their mental faculties obscured from their birth are beyond medical skill, and generally stolid, they require no other attention than a regard for cleanliness demand. They may, consequently, be as well cooped up in a jail if it is so desired as anywhere else” (Simmons 1982:12). The main thrust, in Ontario from the 1860s onward, was clearly custodial, not rehabilitative (ibid.:6-14). Since there were no medical cures for mental retardation, the shift in administrative power towards the medical

profession effectively created a permanently sick and incurable patient (Wolfensberger 1975; Murphy 1990:131-33; Radford 1994:12-17).

While schools and asylums had been cast as means to protect and care for vulnerable people, by the 1880's the public mood shifted to protecting themselves from the "menace of the feeble-minded." The alleged moral weakness of the "feeble-minded" was thought to lead to sexual and criminal deviance (Wolfensberger 1975:27-52; Trent Jr. 1994:84-8). This shift was largely predicated on the strategic, political lobbying and even fear-mongering by asylum directors and doctors. They sought to generate public support for greater funding of their institutions by publicizing the supposed risk to the public of contagious moral corruption (Shakespeare 1994; Trent Jr. 1994:131-83; Bogdan 1996). One example from a medical research conference in 1907 reads: "While there are many anti-social forces, I believe none demands more earnest thought Feeble-mindedness produces more pauperism, degeneracy and crime than any other one force ... affects in some way all our people." (cited in Wolfensberger 1975:34).¹³

Although these professionals believed that their claims were somewhat true, their personal diaries reveal that many regretted that their admittedly exaggerated message had gone as far as it did (Trent Jr. 1994:141-2). Nevertheless, the legacy of the image of a menace held firmly in the public imagination.¹⁴ Even before the 1920s, most doctors had realized their error and abandoned the menace and eugenics rhetoric in favour of optimistic claims that their residents could do well in community placements (Ibid:181). This change of heart was conveniently catalyzed by the dire economic times of the Great Depression but, unfortunately, that same economic reality made community job placements outside the institution all but impossible. The custodial and institutional model continued to be the dominant technology of caring for the mentally retarded through World War II and into the early 1960s. In fact, more public care

facilities were built and expanded in the US between 1950 and 1970 than in any other period (Ibid:250).

3.3.3 Normalization and deinstitutionalization

The normalization movement, which became the dominant ideological framework of care policies for people with intellectual disabilities from the late 1960s onwards, had its roots in three significant forces (Trent 1994). I outline the key points of Trent's historical analysis of these forces and follow it with a discussion of normalization and how it changed the social meaning of the concept of disability. Trent demonstrates how normalization provided an ideological route out of the growing dissatisfaction with institutional care generated by the confluence of exposés of poor conditions in asylums by staff and journalists, parent advocacy movements, and the state's desire to reduce spending on what was alleged to be costly institutional care (Trent Jr. 1994:264).

The exposés began with public accounts of "beatings and torture, depravation and cruelty, even killings," as well as mass benign neglect of residents by staff; the early accounts were written by conscientious objectors (COs) working in institutions during World War II as part of Civilian Public Service Teams (CPSTs) (Ibid:227-9).¹⁵ Those accounts were followed up with more dramatic journalistic exposés of the terrible quality of life in institutions.¹⁶ At the same time, parents of people with intellectual disabilities began to share stories of the value of their children and their hardships in the institutions and, aided by the disclosure of celebrity parents like Dale Rogers and the Kennedys, to mobilize as a political force for change (Ibid.:230-44, 255). Parents and other advocates sought the closure of institutions and the inclusion of their children in public education; they even pursued legal action to achieve their aims (Trent Jr. 1994:257, 260; Roeher Institute 1996: 69,74).

Finally, in addition to these public concerns, the government was increasingly interested in finding alternatives to institutions that were becoming too big and costly (Trent Jr. 1994:5,

260-8). It is important to recall that in 1973 the IQ requirement was changed from 85 to 70 in the US, largely to reduce the number of people being institutionalized (Trent Jr. 1994:261; Smith 1997:6). By the early 1970s, legislation in Canada and the US was initiated to begin the closure of institutions and the movement of people back into their communities (Trent Jr. 1994:261-4; Roher Institute 1996:7-8).

It was in this climate of change that the idea of normalization was imported from Scandinavia in the mid-1960s and “elevated to a principle” in 1972 by Wolf Wolfensberger (Trent Jr. 1994:262; Wolfensberger 1972). Normalization represented a paradigm shift in care and it provided the overt conceptual framework and rationale for deinstitutionalization, alongside the less-publicized cost-cutting rationale (Rioux 1994b:97-8; Trent Jr. 1994:264). In 1975, normalization was adopted by the UN in its declaration of the rights of mentally retarded persons (Roher Institute 1996:22). After participating in the “pioneering” state deinstitutionalization programme in Nebraska in the 1960s, Wolfensberger was convinced that Goffman was right about the iatrogenic and dehumanizing effects of the total institution (Trent Jr. 1994:262). He advocated strongly against institutions and for inclusion of the retarded in normal life by providing support services for them in the community (Newroth 1974:v; Trent Jr. 1994:262). Wolfensberger impressed upon practitioners the message of how detrimental most historical conceptions of the mentally retarded were to their sense of self-worth, well-being and ability to grow because they were always considered deviant and unnatural (Wolfensberger 1975:3-5).¹⁷ He created a new concept of the retarded person as a *developing* individual; this concept underpinned his ideas of normalization and community-based care (Ibid:15-17).

Wolfensberger’s humanist approach recognized that in order to flourish, people had needs and desires beyond physical survival and that the caregivers needed to provide for them. These desires included a place to belong, to develop meaningful social relations, to do meaningful

work, and to personalize one's environment and belongings (Ibid:2-6). His residential model, group homes, incorporated these ideas through small groups living in regular urban homes, and having attendant caregivers who come in for support (Trent Jr. 1994:261-3). These homes had only one or two people to a room, were decorated and welcoming, and encouraged more individual choice for residents, in addition to work and activities. Group homes, and later other models of independent and assisted living, have been the primary models of residential state care advocated since the early 1970s. As I discuss further in Chapter 4, the funding and legislative changes accompanying this movement in Canada, the US, and France were part of what made the L'Arche model possible.

From 1981-85 Canada reduced its 40 large facilities (100+ residents) to 27 and has since remained at this level (Roehner Institute 1996:52). From 1981 to 1992, the number of Canadian residences for people with intellectual disabilities accommodating 4-9 people grew from 60% to 80%, and average residence size dropped from 26 to 14 people (Ibid.:52). Currently, the best estimates of the institutional population in *Ontario* indicate approximately 1,100 people in large congregate care (Brown 2002a). Although US national figures vary, one state, Washington, currently estimates that living arrangements for people, adults and children, with *developmental* disabilities are split as follows: 65% live with their families, 20% have their own home or apartment, 13% live in group care (institutions, group homes, foster care, nursing homes), and 2% live elsewhere (hospital, jail, homeless) (WSDSHS 2002).¹⁸

3.3.4 Problems with deinstitutionalization and normalization

Most stakeholders in the field of disabilities would agree that the current support system web avoids the large-scale systemic neglect, abuse and exploitation of residents by their caregivers that was revealed to be so common in institutions in Canada and the US as late as the 1960s. At the very least, leaving the institution provided more freedom for those who were high-

functioning enough to live on their own and find work. Such people, however, are rather uncommon given that the results of deinstitutionalization have been mixed. Deinstitutionalization did not turn out to be the panacea it had once seemed, for people who were mentally retarded or their families. Lack of proper preparation, training, or material support to those leaving, and to the families and communities they often returned to, has inhibited the success of deinstitutionalization and community care in two ways.

Real social and economic integration has eluded most ex-residents. Neglect and abuse have often continued in the new locales but on a smaller, less detectable scale. In many ways, deinstitutionalization shifted the responsibility, and the burden associated with the many costs of care, onto families, low-paid direct care workers, and community volunteers. This reality was largely obscured by the overtly positive language of independence, community care, family values, and consumer choice. While normalization usefully supported the move to more human-scale residences and systems of support, practitioners had not anticipated the lack of community interest and ability to welcome back those people it had sent out years before.

Lack of funding

One major factor inhibiting the success of deinstitutionalization and community-based placement movements was lack of funding and its impact on the quality of *execution*. Since initially the state's main focus was on getting people out of the institution, little attention was given to preparing the residents to do so, or to supporting them through the transition to community life once they left (Barham 1992:12, 152; Jacobson, Burchard et al. 1992:8; Trent Jr. 1994:229, 270). Departing residents were not taught the necessary life and work skills to survive or integrate well (e.g. shopping, social interaction norms, bus routes, interview skills) (Edgerton 1993 (1967); Trent Jr. 1994:229). The kindest interpretation of this approach is that it was short-sighted; the toughest is to see it as irresponsible abandonment by the state. Follow-up studies

generally show that life outside the asylum can be as bad or even worse for some people (Langness & Levine 1986:195; Barham 1992:10, 24-32, 60; Edgerton 1993 (1967); Ferguson 1994; Trent 1994:270). Some do fair better outside however (Brown et al. 1997; Edgerton 1993).

It is not clear from the literature whether caregivers would have provided more support and follow-up if they had had the funds; this is a moot point, however, because they did not have the funds in the early stages, or later on. In the late 1960s and early 1970s, US state governors began making massive cuts to the operating budgets of institutions, often eliminating up to half of jobs and funds with no initial reduction in clients (Trent Jr. 1994:256-8).¹⁹ Even with many closures, much federal money remained tied up in institutions instead of having been transferred, as planned, to local community service organizations or the family and individual; this resulted in inadequate local budgets (Barham 1992:19; Trent Jr. 1994:267; Morris 1993). Once in the community, former residents were routinely unable to overcome the years of oppressive institutional socialization that had taught them to be passive, dependent and compliant. They lacked necessary reintegration training and community-based supports which could have helped them to become independent enough to create a healthy life outside (Murphy 1990:43-5, 56; Barham 1992:121; Edgerton 1993 (1967)).

Persistent negative social attitudes

A second factor inhibiting the success of community-based living was the persistence of negative social attitudes. Diachronic ethnographic work with intellectually disabled people, who were released from care under the banner of community integration in the 1970s and 1980s, showed that they went to great lengths to hide their past. They endeavoured to create “a cloak of competence” in order to “pass for normal” because of what they felt to be an unbearable stigma attached to mental retardation and the institutions (Edgerton 1993:185; Hingsburger 2001b; Brown 2002a). Former residents often led lives that were “lonely if free” (Barham 1992:24-32).

Other research shows that communities were not ready to accept them. The stigma made employers and neighbours reticent, and even fearful, to interact with people with intellectual disabilities. This made it very difficult to integrate, work or make friends (Edgerton 1993 (1967); Hahn 1985:94; Murphy 1990:85, 132; Barham 1992:60, 152; Jacobson, Burchard et al. 1992). This awkwardness still prevails today and is stressful for the person with a disability (Murphy 1990:122, 86). A 1994 report from Newfoundland, emphasizing the value of supporting individuals and preparing communities better, acknowledged the continued existence of this strain on relations (Roehrer Institute 1996:33).

Social rejection and neglect are not surprising given that the same social values and beliefs that evicted intellectually disabled people from the community years ago have not disappeared (Heal, Haney et al. 1988; Murphy 1990:86; Barham 1992:151; Amado 1993a). Exploitation and active abuse are also still evident, however, generally, and even within families. One example of exploitation is found in a 1989 legal victory by a man with an intellectual disability. He had worked for 16 years in a workshop for almost no pay and won the right to receive *minimum* wage (Roehrer Institute 1996:87). In addition, researchers have shown many examples of emotional and physical neglect and abuse of disabled children by their families (Enns 1999; Hingsburger 2001b). While this thesis does not deal with informal, family care arrangements, it is vital to highlight that home-living is often not a perfect solution for people with intellectual disabilities or their families (Barham 1992:104, 16).

The strain experienced by many informal, unpaid caregivers, such as parents and families of children with disabilities, is partly rooted in a lack of adequate support and respite services provided for them. At McMaster University, the CanChild centre for disability research has been conducting a large quantitative assessment of the negative health effects on informal caregivers resulting from the added stress of caring for a disabled child at home (CanChild 2002). Another

Ontario study found that high stress and lack of support for nurses resulted in the very high absentee rate of 8.5% (Bauman 2001). These studies raise the question of who is looking after the rights of the family and formal and informal caregivers amidst all these changes. Researchers of the ethics of care are also examining these questions (Tronto 1993; Kittay 1999). In Chapter 6, I address the question of how L'Arche supports caregivers.

Lack of support, training, and rationale for caregivers in the new models

Support issues are also a problem for formal caregivers. The third significant factor inhibiting the success of community care relates to the formal caregivers and seems to be the least well-understood, or studied. Jacobson et al (1992) call for more research to understand the effects of the shift to community-based care on staff. They cite staff as the key resource in mental health services, and the key social contact for mentally challenged clients, and point to problematically high staff burn-out and turnover rates (1992:198, 220, 233 244, 260). Jacobson et al demonstrate a positive relationship between support for staff satisfaction and the quality of life of residents (Ibid:11, 221, 233), as have other researchers (Braddock and Mitchell 1992). It seems that, overall, staffs have been trained in the technical details of supporting people in new locales outside institutions. They have not, however, been adequately guided in the new *ideologies* of care and the attitude shifts towards people with intellectual disabilities that these ideologies espouse.

Indeed, it is in the interface of direct care worker and client that the limits of these ideologies of acceptance and respect are most vigorously tested and strained. Yet, care workers have not been supported in order to adjust to the significant changes in caregiving, power-sharing and relationship dynamics that are expected of them (Jacobson, Burchard et al. 1992; Ungerson 1999). For example, caregivers have identified the tension between ideologies that ask them to share power and decision-making with clients while not giving caregivers any substitute means to

feel valued as professionals (Jacobson, Burchard et al. 1992:206, 230). Tension also inheres in goals that ask them to support people's independence; goals that can lead directly to job obsolescence for workers who are already vulnerable and underpaid themselves (Braddock and Mitchell 1992; Jacobson, Burchard et al. 1992:197, 206). Finally, independent living and community care can generate a great deal of role ambiguity for direct care workers. They feel pressure to work beyond contractual agreements; in someone's home, many of the tasks required of them look and feel more like aspects of friendship than employment (Jacobson, Burchard et al. 1992:206, 214-16, 233; Ungerson 1999). Personal and professional boundaries are harder to maintain in the face of a lonely client who is otherwise bereft of support or social contacts.

Part of the issue here is that the ideology of community care, and its daughter movements discussed in the next section, is concerned exclusively with the well-being of the clients. The ideology assumes that by simply declaring that people with intellectual disabilities are worthy, equals, and have rights, a benevolent desire to enact this radical mandate will automatically be instilled in caregivers. It seems that this is not the case, however. In order that the caregivers do this new work well, it appears that two things are needed. The first necessity: a complementary ideological rationale that shows caregivers why supporting community care, independence, and good relations with clients make sense for them too. The second: a system of training that better prepares staff to deal with the tensions of this new power-sharing and more intimate, interpersonal reality as well as ongoing support mechanisms for staff. Both factors are discussed in this ethnography.

3.4 Contemporary approaches to intellectual disability

To the politician "community care" is a useful piece of rhetoric; to the sociologist, it is a stick to beat institutional care with; to the civil servant, it is a cheap alternative to institutional care... to the visionary, it is a dream of the new society in which people really do care; to social services departments, it is a nightmare of heightened public expectations and inadequate resources to meet them."

(Morris 1993:4)

In this section I outline the range of living arrangements available for people with intellectual disabilities and the social movements behind them. Next, I discuss the major approaches to understanding the causes of intellectual impairment and intellectual disability. Overall, it seems clear that there is no single caregiving, support or residential model that is appropriate for all people with intellectual disabilities, given the wide variety of their needs and desires. Nor are any of the four main approaches to studying and understanding intellectual disability adequate on their own; each approach provides a distinct perspective. Even the much-maligned medical approach, which has, in fact, been the source of many problems faced by those with disabilities, continues to play an important role in improving their lives. This broad perspective on the contemporary disability scene provides the final piece of background on which this particular ethnography of L'Arche will be painted.

Living arrangements

Several living and caregiving arrangements are currently offered in Canada and the US; people with intellectual disabilities and their guardians can choose what arrangements seem most appropriate and desirable for each individual. There are advocates of each option and increasing recognition that people with disabilities are not a homogeneous group with identical needs that could all be met by a mass solution (Morris 1993). Unfortunately, funding for the other alternatives has never been sufficient to allow the service system to support everyone who needs assistance (Barham 1992:19; Morris 1993:4; Trent Jr. 1994:274); thus, availability and funding limit people's *actual* range of choices because of long waiting lists for services and placements.

Authorities estimate that the majority of people with intellectual and developmental disabilities live at home with their families. Numbers, however, are impossible to ascertain for two key reasons: people who do not use the social services available or apply for the tax credits are not "known to the system"; many people (or their parents) do not identify as having an

“intellectual disability” in the census due to definitional confusion, oversight and stigma (Brown et al. 1997; Brown 2002a; WSDSHS 2002). When the need for support or physical restraint by doctors, nurses and social workers is too substantial to be accommodated in other forms of care, or if they have found it too painful to adjust to life outside the institution, many people continue to live in large institutions.²⁰ Again, numbers are difficult to estimate; different reports indicate 1,100 people currently in institutions in Ontario, 10,500 to 30,000 in Canada.²¹

A large number of people are living independently; this is a category which can include receiving a number of support services in and outside the home to assist the person in personal hygiene, home maintenance, transport, and access to education and work. There are also people who live in small-sized congregate care, like L'Arche, typically called group homes. As noted earlier, 80% of Canadian residences now support only 4-9 people (Roehner Institute 1996:52). Finally, there are smaller numbers of people in various situations such as hospitals, foster care, psychiatric care, and the homeless. A 1995 Quality of Life survey in Ontario investigated living arrangements for people with developmental disabilities in Ontario *who receive services* and are thus known to the system (roughly 23% of all people with developmental disabilities; 25,500 people) (Brown et al. 1997:15).²² While all those surveyed received some services, 25% indicated that they live independently, 46% with family, 19% in small care, and only 10% remain in large, congregate care settings with more than 10 people (Brown et al. 1997:13-17).

Disability movements

The movements behind this proliferation of options are numerous, although most stem from the earlier initiatives of normalization and community-based care and living. The main ones include: independent living, community living/integration, self-advocacy, consumer model, and disability rights (Rioux and Bach 1994; Trent Jr. 1994:262-5). These movements are linked with broader social movements: civil rights, consumerism (client as decision-maker), self-help, and de-

medicalization (DeJong 1979:24-31). The disability movements all aim to maximize the transfer of control over decisions from caregivers and the state to the people with disabilities in order to minimize dependency, establish legal protection, and to empower people (Busselle 1989; Trent Jr. 1994:272-3; Roeher Institute 1996).

Execution of the ideals, however, is quite another matter and lack of funding, among other reasons, makes these ideal provisions far from common. The government cost-savings agenda tends to dominate the reality behind public statements about community integration, independence, choice, and access (Albrecht 1992; Morris 1993:5; Roeher Institute 1996). American funding agents are as likely to benefit from the community care movement (through cost-savings) as are the clients (Albrecht 1992:244). Independent living and consumer choice principles dodge the issues of structural power imbalances; they effectively spin the lack of funding and “public neglect” into an appearance of “benevolent minimal government” (Ferguson 1994:173). Scarce resources mean prioritizing needs so that while basic physical needs are now usually met, resources to support educational, affective and relational needs are insufficient and this inhibits genuine integration (Jacobson, Burchard et al. 1992:15; Radford 1994:22-4). While people with intellectual disabilities are now more of a *physical* presence in most cities, the majority of these people are still not very *involved* in their communities (Langness and Levine 1986:195; Amado 1988a:294; Desjardins 1998).

Again, the question of order: Is it best to work towards physical integration and hope that this will diminish social rejection of people with disabilities? Alternatively, would it be better to work first, or simultaneously, on changing social stereotypes directly?

Approaches to understanding developmental disabilities

“There are many reasons why people are not able to develop the ability to do the things that are socially expected of them. They include, among other things, genetic inheritance, chance occurrences both before and after conception, injury, social attitudes, environment, and sometimes a combination of several things.”
(Brown 2002a)

There are four basic approaches from which the understanding of developmental disabilities can be established. Researchers at the Roehrer Institute in Toronto have developed a helpful typology of these approaches in order to show the usefulness of each perspective in grappling with the problems faced by people with disabilities in a holistic way. The first two approaches take a *Bio-medical* and *Functional* perspective, and focus on changing the individual (Roehrer Institute 1996:xii, 13-14). The third and fourth approaches, *Environmental* and *Rights-Outcome*, are attempts to show that "disability is more than an individual condition." This means that the disabling effects of the impairment are exacerbated both by socio-environmental surroundings with which the person must interact and by political inequality stemming from inaccessibility of services (Ibid: 14).

a) Bio-medical approach

The dominant approach to developmental disability continues to be *Bio-medical*, which assumes "disability is caused by a mental or physical condition that can be prevented or ameliorated through medical" intervention (Roehrer Institute 1996:14). The individual or foetus is seen as sick or deficient and the impairment or condition is the focus of attention (Zola 1989:349; Hahn 1985:88-9; Morris 1993:35). There are three dimensions to the *Bio-medical* approach: determining causes of mental retardation and intellectual disability and other developmental disabilities, developing ways to cure or alleviate the impairment or disabling condition, and developing ways to maximize prevention of further cases of disability.

The biological causes of *developmental* disabilities are often unknown, but they are most commonly "attributable to mental retardation, cerebral palsy, epilepsy, neurological impairment, or autism" (Busselle 1989:9). Mental retardation and intellectual disabilities "can be caused by any condition which impairs development of the brain before birth, during birth or in the childhood years. Several hundred causes have been discovered, but in about one-third of the

people affected, the cause remains unknown. The three major known causes of mental retardation are Down syndrome, foetal alcohol syndrome and fragile X.” (ARC 2001). ARC, a major US self-advocacy association, identifies five categories of causes including genetic conditions (inherited or caused during pregnancy [e.g. Fragile X syndrome, PKU-phenylketonuria, and Down syndrome]), problems during pregnancy (alcohol, drugs, malnutrition), problems at birth, problems after birth (diseases, accidents, environmental toxins), and poverty or cultural deprivation (See appendix 3.3 for full descriptions) (ARC 2001).

The discussions of treatments, cures and preventative measures overlap. Some medical treatments help to alleviate the disabling effects of an impairment while other precautions, medications, and regimens can dramatically reduce or eliminate the impairment altogether, especially with early intervention. For example, antibiotics and treatments for heart defects have helped raise the average life expectancy of people with Down Syndrome from 10 to 55 years in the period 1910 to 2000 (WSDSHS 2002). “People with cerebral palsy have benefited from medical and technological advances that help them with communication and mobility” (WSDSHS 2002). One research report estimates that over 11,000 cases of mental retardation have been prevented in the US in the last 30 years because of medical advances such as measles, Hib and rubella vaccines, and newborn screening (See Appendix 3.3) (Alexander 1998). Other interventions such as environmental lead removal, child safety seats, and early intervention programs with high-risk infants have also been effective prevention tools (WSDSHS 2002).

Probably the most pervasive so-called solution in recent years, however, is the practice of pre-natal genetic counselling and early screening of the foetus. This solution tests for genetic pairings or abnormalities that point to a risk of developmental disability for the baby (Alexander 1998; WSDSHS 2002). If counselling or tests show a high risk of disability, parents can choose not to conceive or have an abortion in order to prevent the birth of a disabled child (Jones 1998;

Enns 1999). Herein lies, at least in part, the issue of an exclusively bio-medical approach to disability; it assumes that what is abnormal is undesirable. As medical ethicist Hauerwas has cautioned, intellectual disability, unlike cancer, usually cannot be eliminated without eliminating the person (Hauerwas 1986). Other associated methods of prevention have been the segregation, enforced sexual abstinence, and mass sterilization, associated with eugenics, of people with intellectual disabilities (Simmons 1982; McLaren 1990; Trent Jr. 1994).

While as a society we often justify such public measures and family decisions with the argument of eliminating suffering, Hauerwas suggests that we ask ourselves, "Whose suffering are we really trying to eliminate?" (Hauerwas 1986:159-69). While people with intellectual disabilities can experience physical pain, so do many other citizens. Further, it is the pain of social rejection that seems to affect them most deeply, the fault of others, not their own. While most people do not wish prospectively for suffering, many would agree that, in retrospect, it can be full of meaning and insight for them (Wendell 2002). This sentiment is expressed by many parents of children with disabilities who say that despite initial confusion, disappointment, and even anger, they quickly grew to love and enjoy their children (Fine and Asch 1988; Taylor and Bogdan 1989; Bogdan and Taylor 1992; Amado 1993a; Kittay 1999; Landsman 2001).

It is, however, also important to note the very real hardships, stress, and material and temporal resource constraints faced by many families with a child who is disabled (Tronto 1993; Enns 1999; Kittay 1999; CanChild 2002). It is likely that in many cases, these families, particularly poor families, would be less concerned about having a disabled child, and the associated "burden of care," if they could be assured of adequate support services for their child and respite support for themselves (Kittay 1999). It is the lack of these supports which gives credibility to claims that disabled children destabilize families and usurp attention and resources away from other children (Singer 1979; McLaren 1990; Kittay 1999). Lack of support is also a

factor in parent's opting out of life-saving surgery for their children as well as other forms of neglect and abuse (Enns 1999; Hingsburger 2001b).

b) Functional/Adaptive approach

The second possible approach related to the individual is *functional* or *adaptive*. Both derive from normalization principles and an economic perspective on the lives of people with intellectual disabilities (Hahn 1985). This approach assumes that a key capacity of citizens is their productivity and considers people's economic self-sufficiency to be a priority. To achieve this, the *functional* or *adaptive* approach examines closely how the impairment affects a person's "functional incapacity" in the world and seeks solutions to help people adapt and improve their skills for self-care and employment-related tasks (Roche Institute 1996:15). As a behaviour and skill-focused perspective, it has generated many specific techniques for improving motor, vocational, social, and life skills, as well as methods to deter behaviour judged to be inappropriate or non-adaptive because it inhibits social integration (Roche Institute 1996:15). Normalization is manifest here. There is the hope that helping people with disabilities to improve their adaptive, social, and developmental skills will aid them in achieving dignity and social integration (Wolfensberger 1975:17). This adaptive perspective was added to the official AAMD definition in 1973 (Krishef 1983:8; Smith 1997).

c) Environmental approach

The third approach moves away from the focus on the individual and brings into the picture extra-individual factors such as structural environment and material and political inequality. As discussed in section 3.2.4, this approach reflected the growing insight that impairment on its own is only part of the issue; often, environmental and social factors, and a person's interaction with them, are *disabling*. This happens because physical environments are designed with a standard person in mind rather than being adapted or adaptable for people with

diverse abilities and disabilities. Negative social attitudes that stigmatise and exclude people with intellectual disabilities are also highly disabling in both their effect on a person's self-esteem and by the barriers created by discrimination in employment and educational opportunities. For example, when education is only available in one format, or there is no wheelchair-access to classrooms, the effect of a person's initial developmental impairment is greatly exacerbated.

Environmental and social changes have alleviated some of the barriers, dependency and stigma associated with impairments (Roehrer Institute 1996:16; Wolfensberger 1975:2-21). Legislation and changes in funding impact physical requirements for public buildings, accessibility, adapted curricula and ergonomic innovations as well (Cooper 1994; Roehrer Institute 1996:16). In the US, the Americans with Disabilities Act (ADA) has been a major development in this area; it legislates and provides funds for proactively removing environmental barriers. Equivalent legislation has not yet been enacted in Canada (1990; Roehrer Institute 1996:18-23).

d) The Rights-Outcome approach

The fourth approach takes a political perspective on disability concerns. Advocates of this approach prioritize the achievement of equal human rights for people with disabilities by establishing legal protection from discrimination (DeJong 1979:24; Roehrer Institute 1996:14-19). Such protection is more stable than what a charity or liberal goodwill framework might provide (Roehrer Institute 1996:17). Rights are useless, however, if you can't *access the benefits* thereof, such as education, work, and leisure. Disability rights advocates, and others concerned with the ethics of caregiving and social welfare, thus argue that *additional* support must also be provided in order to facilitate access which will lead to equality of well-being; as an *outcome*, not just a possibility (Tronto 1993; Rioux 1994b:86; Gewirth 1996; Roehrer Institute 1996:17; Kittay 1999). The Canadian Federal Charter of Human Rights protects people with disabilities against

discrimination but does not provide the same legislative obligation, or proactive financial incentives of the US ADA (Bach 1999; Cohen 2001a, b).

A rights-outcome approach also encourages a shift away from that side of normalization which has been interpreted to mean that people with intellectual disabilities must be less like themselves and more like some standard, normal person. These advocates, including self-advocacy groups such as People First, reject the historically-dominant view of disability as something deviant and in need of correction (Goffman 1963). They argue instead that disability is a normal, inevitable element in a diverse society (Taylor and Bogdan 1989; Roeher Institute 1996:17, 166; WSDSHS 2002). A rights approach evaluates policies and forms of care in terms of how well they contribute to helping people with intellectual disabilities achieve *self-determination, equality, and democratisation* (Roeher Institute 1996:xii); or, as Rioux put it, rights provide a basis for pluralism (Rioux 1994b:97-8); for being who you want to be. In chapters 4 and 6, I elaborate on how L'Arche further encourages and trains caregivers to value diversity and disability by explicitly redirecting attention from a person's deficits to their gifts.

The legislative solutions secured for people with intellectual disabilities by the rights movement form a strong base to build upon but are insufficient on their own. Integrating people with disabilities into communities must be as much about changing public attitudes as it is about physical placement and legal protection. A rights model is limited; while the state can enforce caring *for* marginalized people materially, it can not force people to care *about* them (Ignatieff 1984:13). Furthermore, a rights-outcome approach must specify differences between groups in order to achieve protections and support for them. This highlights how they are special, whilst some people with developmental disabilities want instead to be "ordinary" (WSDSHS 2002).

All four approaches represent important dimensions of disability that need to be orchestrated in order to develop effective solutions to the concerns that people with intellectual

disabilities face today. Nevertheless, there is a clear need for a way to encourage greater public acceptance of people with disabilities as they are; even an appreciation for the contribution they have to make to society. Current community care schemes continue to falter when faced with public uneasiness with the disabled and this inhibits (re)integration (Radford 1994:22-4). We need to examine the public beliefs that underlie people's discomfort and prejudice, in order to generate a rationale that offers a different perspective on the disability question for them. This ethnography seeks to show that the L'Arche philosophy and model offer at least some promising new insights in this direction.

3.5 Conclusion

This chapter provided a review of the historical and contemporary features of Canadian and American attitudes towards people with developmental and intellectual disabilities and the technologies of care that have emerged from those attitudes. I have argued that the lack of training and support for staff, in order to learn how to adjust to the new models of care, is at least part of the reason the models have not achieved the anticipated change in well-being for people with intellectual disabilities. Institutions, their administrators, and caregivers should not be viewed as the only issue. While some doctors and caregivers were unkind and even cruel, these people are in other ways only the most visible symptoms of broadly held social values. Nevertheless, this chapter has demonstrated how important the attitudes that we bring to our interactions with people with disability are to how we *experience* them. As such, my analysis indicates a dire need for direct attention to changing the attitudes, values and beliefs held by caregivers in the field, and eventually the general public. Although generally further along than the public, families could also use assistance in learning to see and appreciate the unusual gifts of people with intellectual disabilities.

I also argue that we continue to have a need for a variety of residential and care options for people with intellectual disabilities given their diverse needs and desires. L'Arche offers one possible model for greater well-being. It is unrealistic to assume that every family who has a child with a disability is going to be willing and able to care for the child (and future adult) well and provide sufficient stimulation and opportunities for social contact, but also unfair, to the family as well as the child. By placing the full burden of care on a family without providing a proper system of support, the government is ensuring great strain on the family. It also invites neglect or active abuse at the family level and this is no less unjust when it happens in homes than in institutions (Enns 1999; Hingsburger 2001a, b). In Chapter Four, I contextualize the early L'Arche dynamics and philosophical development within the history of disability and care.

3.7 Endnotes

¹ The Roeher Institute was the National Institution on Mental Retardation, and the Canadian Association for Community Living was the Canadian Association for Retarded Children (Roeher 1996:7).

² I do not specify page numbers for Brown 2002 because I received an advance copy of the chapter in which page numbers were not yet confirmed.

³ I found that most medical, statistical and social scientific literature did not specify a definition. This made it difficult to discern precisely who particular studies referred to, and thus whether things such as funding are actually changing, versus simply appearing to change as a result of definitional changes.

⁴ For example, California residents wishing to qualify for lifelong state support must demonstrate that the developmental disability manifested before the age of 18, a full 4 years sooner than the federal definition allows (CSCDD 2002). Second, ARC relies on both this and the AAMR definitions and includes people with developmental issues such as FAS, due to "use of alcohol or drugs by the pregnant mother" (ARC 2001); whereas Washington state, using the same definitions, specifically excludes them (WSDSHS 2002).

⁵ In Washington, fully a third of "at risk" infants "who receive early intervention services do catch up with their peers, and don't need further special services after age three" (WSDSHS 2002).

⁶ Based on a total US population estimate of 270 million (Philip's 2000). But see Brown et al (1997) regarding issues with prevalence estimates in this field.

⁷ Definitional changes in both categories since the ARC's estimate make the numbers difficult to assess.

⁸ Based on a total Canadian population estimate of 30.6 million (Philip's 2000)

⁹ Mental deficiency was then controlled by the National Institute for Mental Health (NIMH) (Trent Jr. 1994:245).

¹⁰ See appendix 3.1 for assumptions. The 1992 assumptions were the same as this 2002 definition except that #4 was not included in 1992.

¹¹ See Macdonald (2000) regarding ambiguous results of label changes on attitudes.

¹² The primary changes are: the addition of a fifth assumption (#4) which specifies that the rationale behind the classifications is the need to develop a useful *support* profile; the term "significant limitations in" intellectual functioning replaces "significantly sub average;" and the description of all adaptive skill limitations has been shortened to "conceptual, social, and practical" in the basic definition, with a separate expanded discussion of specifics.

¹³ And in 1915: "Their fecundity, their lack of control, the menace they are, the degradation they cause, the degeneracy they perpetuate, the suffering and misery and crime they spread ... he is responsible to a large degree for many, if not all, of our social problems" (Wolfensberger 1975:34).

¹⁴ Unfortunately, issues of representation of people with disabilities continue to be a problem even today (Walters 2001; Morris 1993) and continue to frustrate genuine community integration and relationships for them (Murphy 1990; Amado 1993).

¹⁵ The 2000 COs were primarily Quakers, Catholic Workers, Mennonites, and Brethren and their working experience gave credibility to their claims. Incidentally, it was these men who formed the National Mental Health Foundation in 1946 to gain voice for these issues (Trent 1994:227-8).

¹⁶ In 1958, a Life magazine journalist even found many inmates had higher IQs than employees (Trent 1994:253). Two well-known exposés are articles by Pierre Berton (1959, Orillia, Canada) (Simmons 1982:xv) and Geraldo Rivera (1972, Willowbrook, NY) (Busselle 1989:20; Trent 1994:227, 255-8).

¹⁷ His seven positions of the mentally retarded were: sick, sub-human organisms, a menace, an object of pity, a burden of charity, a Holy Innocent, and finally his model - as a developing individual (Wolfensberger 1975:2-17).

¹⁸ Professor Ivan Brown at University of Toronto cautions that statistics in this field must be read with caution because of a lack of consistent definitions. For example, this source does not specify if these figures refer only to people who are "known to the system" or total estimates, nor does it specify if it is based on prevalence or incidence figures. Brown indicated that in Canada for example, there are no records or tracking systems for people who have left the social services system, or who never entered it (Brown, personal communication 2002). See also Brown et al 1997.

¹⁹ Trent shows this state cost-cutting agenda being notably lead by then governors Ronald Reagan and Nelson Rockefeller (1994:256-7). Ironically, these cuts came on the heels of the new (1965) Kennedy foundation for *research* into the condition of mental retardation.

²⁰ A 1995 study found that 95% of people with intellectual disabilities, who still live in institutions, receive support services in "most areas of life." 57% also have physical disabilities and their social workers report that over half of residents have "behaviour problems" (34% are moderate problems and 22% are marked) (Brown et al. 1997:22-6).

²¹ These figures come from (Brown 2002b, Roeher 1996:27, CACL 2001) respectively. Note that the population of Ontario and Canada are approximately 11 million and 30 million respectively.

²² There is little information on the roughly 77% of people estimated to have a developmental disability but who do not receive services (Brown 1997:15) and so these estimates do not include them.

4.0 Emerging and Converging Forces in the History of L'Arche

4.1 Introduction

In many of the L'Arche homes, people take time after dinner to be together socially and sometimes in prayer. One night at La Moisson house in Trois Rivières, Colin, a young university graduate and their new head of house, was leading the reflection time by reading from *Le Petit Prince*. The little Prince was sad and confused when he saw a field of roses that looked just like his own special rose that he had cared for so uniquely. Eventually, the fox helped the little Prince to grasp that it is all of the *small daily things* that friends do together that distinguishes them, not how they look; "It is only with the heart that one can see rightly; what is essential is invisible to the eye." (Saint-Exupery 1943:86).¹

"This makes me think of all of you and the time we spend just being together, getting to know each other," Colin said quietly to the group. A couple of people giggled, seemingly at the unexpected show of intimacy, but went silent when they saw that he was serious. Colin's multiple piercings, tattoos, and alternately aloof and rambunctious ways, make him appear only loosely engaged or implicated in the home life. Inside, however, his understanding of the goals of caregiving were shifting. Later, over a beer, he explained what he sees as the value in what L'Arche offers: "Since living here, I am convinced that spending time together is more important than what we *do for* people or the skills we can teach them. Most of the folks [people with disabilities] aren't used to people choosing to be with them, and genuinely liking them. That's what we [assistants] can really give ... share. And, I think that is what they need most."

This chapter lays the foundation for my ethnography by historicizing the emergence and development of L'Arche. L'Arche materialized out of the confluence of various environmental, legislative and individual factors, which I outline. The L'Arche philosophy and organization reflect both culturally-normative and counter-cultural, unpredictable elements for their time. A close analysis of these historical factors usefully illuminates the early origins of current issues.

Colin's thoughts point to a central principle of L'Arche: the primacy of the heart and affective concerns in human life. Vanier's conception of the human person as fundamentally oriented through the heart and as being in most direct connection with God there, permeates L'Arche (Downey 1986). From that basic premise, the founders of L'Arche developed a new conception of disability, difference, and vulnerability and how to support people classed as such. The conception and support were, and continue to be, radical and effective. Vanier's focus on the heart enabled him to imagine the diverse needs and desires of people with intellectual disabilities, beyond basic shelter and food.

To understand how these ideas emerged and developed into something concrete, it is vital to begin with a close look at the circuitous genealogy of Jean Vanier's formation. I discuss the socio-cultural and interpersonal roots of Vanier's beliefs, and how these shaped L'Arche. In section 4.2, I discuss the founding of L'Arche, its quick growth and at times awkward translation into Canada, and how the mission and charism that it claims today were revealed through intense experience over time to the founders. Charism is a common Christian term denoting the spiritual mission given to a leader or organization from God. A charism is formed when a unique insight about the scriptures is revealed and motivates the recipient(s) to act. How it is enacted can change over time.² Section 4.3 details the elements of the current, clarified mission, and how it continues to change. Next, these elements are compared with other prominent models of caregiving. In section 4.4, current issues related to staff and the mission in Canada are discussed.

4.2 The Roots of L'Arche

4.2.1 Setting the scene: L'Arche and Jean Vanier's pre-L'Arche years

L'Arche is both an intentional faith community and a caregiving organization for people with intellectual disabilities. Assistants and core members live and work together in L'Arche homes and workshops. L'Arche seeks to promote a vision of the value or “gifts” of *all* humans and especially people with intellectual disability. Rather than seeing what people are *unable* to do because of their cognitive impairments, Vanier inverts the equation and asks what are they better *able* or prepared to do precisely because of those impairments. In a supportive environment, these gifts are able to emerge. L'Arche today is a challenge to society and the church, to revalorize difference and to treasure the poor. These ideas can seem odd when stated out of the context, and L'Arche itself was not founded with a clear set of goals and theories initially.

Various writers have recorded the myriad beliefs out of which L'Arche was formed. Although today it is common to talk about L'Arche as synonymous with Jean Vanier, (one of the two main founders), a historical review makes it clear that Vanier's vision was nourished by several people during a long and rich developmental period. The actualization of his vision was only possible with the work of his close coterie and a cast of service-oriented people—spiritual seekers, medical professionals, idealistic youth volunteers, clergy/sisters, and supportive bureaucrats. Vanier himself would agree; he maintains that he is more a catalyst than a founder: a catalyst for revealing an existing secret of the church—that the spirit of Jesus resides in the poor (Downey 1986:ix). Vanier claims many sources of insight and aid, and in his famous, inspiring stories, his emphasis is almost always on people with intellectual disabilities, and what he learns from them (Vanier 1995, 1998, Downey 1986:ix). Vanier's extraordinary gift was his ability to transform inspiration, experience and relationships into a new and visionary spiritual message

that motivated others. Before reviewing his influences below, I explain some linguistic particulars of L'Arche and chronicle Jean Vanier's life.

Particular vocabulary

A short explanation of some L'Arche words, most of them religious in origin, is necessary. Religion, and in particular, Christianity is essential to L'Arche, but L'Arche is not a church and does not seek converts. One Christian term that may be unfamiliar to a secular reader is "vocation," which comes from Latin *vocare* meaning "to call" or a "calling." For believers, it means to listen or pray for spiritual direction from God that will help you to feel or know what God envisions for you on earth. Prior to forming L'Arche at the age of 37, Vanier spent many difficult years trying to discern his vocation.

Vanier frequently refers to the gospel, which is not synonymous with the Bible. Gospel means good news about Jesus' life and thus *can* refer to the whole New Testament (Vorstermans 2002). Vanier and most L'Arche elders, however, are usually referring to the first four books of the New Testament—Matthew, Mark, Luke and John—in which these disciples record Jesus' life on earth³. In the Gospels, as well as in the Epistles⁴, especially *Corinthians I*, words like "the poor, the weak, and the broken" are commonly used to refer to those people who were outcast and marginalized by society at that time, and who lived in both material, social and spiritual poverty. These terms had a broad meaning in Jesus' time that was compassionate and even deferential, not pejorative.

To illustrate, Jesus' life is said to have been characterized by continual movement towards, identification with, and learning from the poor, and in encouraging his followers to do as well. Jesus is credited with saying that anyone who welcomes the poor and weak also welcomes Him (Mark 9:37 in Downey 1986:98; also Luke 9:48 in Vanier 1995:106). While poor and weak in our modern parlance denote a lack of value, (even in many Christian settings) Vanier insists on the importance of employing the terms in this way. He knows that this goes "against certain

cultural norms that want everyone to be strong and powerful,” but writes that the words point to what we share as humans: “We all have our limits and our handicaps. We all need each other. But some people recognize their poverty; others do not” (Vanier 1995:13).

It is recognized in L’Arche now, that to the non-Catholic audience, denoting people with disabilities as “the poor” is not up-to-date with current attempts to develop more respectful terms for this condition (Roehrer 1996). L’Arche is reflecting on how to shed the negative and anachronistic connotations of this language but does not want to lose the important meaning it has in the context of L’Arche philosophy and Christianity in the process (Card 2001). Vanier wanted to work together with the poor to reduce the stigma associated with their conditions in order to mitigate its destructive power.

Chronology of Jean Vanier’s life

Jean Vanier was born in Geneva in 1928, the fourth of five children, to a prominent Canadian family of French descent. He was educated in England for years while his father, Georges Vanier, held various military and political posts in Europe (Spink 1990:10). Early in World War II, the family moved to France to be closer to Georges, but dangerous conditions had them retreating around France and in 1940 they returned to Canada where Vanier attended a Jesuit high school in Quebec. In 1942, at 13 years of age, he decided to enlist in a British naval college; he did field service until he was 20 (Spink 1990:16). He achieved the distinction of officer, and learned much about leading people from a service model that would prepare him well for L’Arche (Spink 1990:16-8). Still, he felt that his calling or vocation lay elsewhere.

At the age of 22, Vanier travelled to *Eau Vive* in France, an innovative, spiritual “community of the heart” which was in loose affiliation with the nearby Dominican monastery (Downey 1986:22). It was founded by Père Thomas Phillippe, a friend of Jean’s mother (Spink 1990:23). Père Thomas invited an eclectic mix of international people to learn about the progressive but controversial ideas fomenting among the Dominicans at the time, “much of which

would lead to, or be fed into the Second Vatican Council” (Spink 1990:23). When Père Thomas was unexpectedly recalled to Rome in 1952, he asked Vanier to lead the little community, which he did for four years, while also studying for seminary (Spink 1990:27-8).

Vanier eventually sought new settings in which to continue his spiritual and philosophical reflections. He spent six years, (1956 to 1962), in rigorous discernment and ministry in various places around Europe (Downey 1986:21-3; Spink 1990:29). He lived simply in prayer, reflection, service and study, earning his PhD in the philosophy of Aristotle from L’Institut Catholique à Paris in 1962⁵ (Vanier 2001:xiii, xv). He visited Père Thomas in the winter of 1963 in Trosly, France, and joined him in ministering to the nearby institution for people with intellectual and physical disabilities. In early 1964, he taught moral philosophy at St. Michael’s (Catholic) College at the University of Toronto during which time he was struck by the difference in how his students related to him and how the handicapped men at the institution had (Vanier 1995:15; Spink 1990:34-5). Sue Mosteller relays his reflections: “Jean was deeply marked by the way the handicapped people came up to him seeking connection and relationship. He realized that they didn’t care what he knew, did or had. Where the students had been interested in his head, Vanier was touched that they were interested in his heart.” (Mosteller 2001)⁶ Beneath their “noisy and often violent” behaviours (Spink 1990:32-4), Vanier sensed a deep yearning for personal relationships in the men and this soon drew him back to Trosly.

Père Thomas invited Vanier back to Trosly (where Thomas was chaplain for a residential institution) to listen to him, work with him, and pray for direction (Spink 1990:18-19). Père Thomas urged Vanier to experience the mystical, spiritual feeling of closeness with the poor in the institution. As Henri Nouwen would later suggest, “It was somewhat secondary that they were developmentally handicapped: [Jean’s] primary concern was that he was looking for some way of binding himself to the poor in a complete and irreversible way.” (Dwyer 1990:50). After several

visits in local institutions, asylums, and poorhouses, Vanier decided to buy an old, local home in which he could welcome some of these men to leave the institution and share life with him (Vanier 1995:15-18; Spink 1990:39-44). In this irrevocable commitment to relationship, L'Arche was born, although Vanier himself did not know it then. He often says that he would have been quite content if it had remained like that—one house where they could all fit in one car and travel occasionally. But part of him also hoped that they could support others to leave institutions and, as it turned out, they did open many more homes and communities.

At this point, I want to historicize the tale that has unfolded so far, by elaborating on the forces which shaped Vanier's life and L'Arche. As Ortner notes, solid ethnography must interrogate the relationship between a local village or organization and the "larger context in which it operates," but also, critically, the organization's own particular "structure and history," (1984:143, see also Ortner 1995:179).⁷

4.2.2 Influential people's worldviews

In this section, I discuss three people who were formative influences in Jean Vanier's life. It is important to emphasize his humanness to avoid the sense of mythos that can surround him, and only serves to create the same relational distance that he strives to break down. His life path has been uncertain and unpredictable and this should inspire new assistants who sometimes report feeling unable to live up to his example.

Georges Vanier, Jean's father

While Georges Vanier's duties as a top military and political official for Canada kept him away from his family for long periods, Georges Vanier lived his life in a way that made a strong impression on his son. After Georges' death, Jean wrote a biography about his father's spiritual life entitled *In Weakness Strength* (1969). This phrase encapsulated his father's core spiritual beliefs and has come to be central to Jean's beliefs and to L'Arche. Georges served as a military

advisor and Lieutenant General in Europe during World War II, and was later Governor-General of Canada (Downey 1986:32-4; Spink 1990:10). Although Jean and Georges Vanier are very different men, biographer Michael Downey convincingly traces roots of some of Jean's key ideas to his father, even though they were developed and actualized by Jean in different ways.

Downey outlined several themes that were important to both men: a spiritual emphasis on simplicity, the value of poverty and weakness, the centrality of love, and unity/ecumenism; and interpersonally, his qualities of welcome, attentiveness, and valuing the family (Downey 1986:32-39). Socially, Georges was known as a great listener who had the gift of helping others to see their own worth, akin to Jean's later emphasis on seeking out people's gifts (Downey 1986:36-8). The Vaniers' welcomed many people into their home for lively gatherings (Downey 1986:36-8) and L'Arche homes are characterized by their emphasis on welcome, and belief that change happens within relationships.

Georges had a spiritual conversion later in life, in 1938, when, at his wife's urging, he was exposed to the heart-based view of God through the Jesuits and Carmelites, and became deeply committed to the notion of a loving God as reflected in the life of Mary (ibid:32-3). For Georges, love was the "central aspect of human faith and God" (ibid:36-8). This idea has also been Jean's overarching theological and philosophical framework (ibid:48). Georges preferred a simple faith, based on love, over complicated theological discussions, and Jean felt guided by this simplicity in relations with people with intellectual disability (ibid:39). As Governor General, Georges sought unity amidst diversity in general and in particular among Christians (ibid:36-8). Jean also faced such questions when L'Arche grew beyond Roman Catholic France.

Finally, Georges suffered greatly from an amputated leg resulting from a war injury and in Georges' biography, Jean wrote that this pain was at the foundation of Georges' spiritual life. He believed that pain and weakness were the clearest routes to communion with God, and in 1960

he wrote, "I feel that only in weakness can I glorify God" (Downey 1986:32-3). In a similar sentiment, Downey wrote of Jean that he has articulated the truth about the ultimate or spiritual meaning that we all feel in the presence of pain:

In weakness we are born ... This truth ... can only be grasped in the face of suffering. Often we spend much of life fleeing from this truth. Only when brought up short do we accept the truth of the radical dependency and fragility of all existence, especially our own" (Downey 1986:70).

This idea that our commonality and humanness is found in our ultimate weakness, not strength, is the basis for Jean Vanier's insight about our radical equality with the poor.

Père Thomas Philippe, Dominican priest

*"Deus Caritas Est. God is love."
(Spink 1990:27)*

Vanier's faith is widely understood to have been shaped by another man of his father's generation, Père Thomas Philippe, a French Dominican priest with a radical, prescient approach to theology for his time. Vanier became acquainted with the priest through his mother while he was still in the Navy and seeking spiritual guidance. When Vanier went to the Eau Vive community that Père Thomas had founded after the war, it was to learn from him. He was drawn to the priest's spiritual teachings and his erudition in science, philosophy and theology. Vanier was drawn to Père Thomas' emphasis on the gospel, the heart, and the value of the poor.

Père Thomas was a scholar and priest and believed that no other system of meaning in the sciences was as good at encompassing and synthesizing the whole of life as the gospels (Spink 1990:34). Echoing the Jesuit, Teilhard de Chardin, he believed that the vital lessons of Jesus' life were about compassion for the importance of "the little people," (Dillard 1999:102). Still it was only through ministry with people with intellectual disability that the ideas set in and pushed Père Thomas to "rediscover all my theology under the sign of the heart" (Spink 1990:34). This focus on the heart is also reflected in Vanier's writings and is used in its biblical sense. The heart is not

“mere sentiment or emotion,” nor is it in conflict with reason or intellect: the heart is “the source of all physical, emotional, and moral life as well as the energies of the will,” and “The central, unifying source of all personal life. It is the place where God resides” (Downey 1986:48, 58-60)⁸. These notions square well with the use of the term “soul” or “human spirit” in many contemporary works on spirituality (O’Murchu 1997, O’Donohue 1997, Moore 1992).

Père Thomas and Vanier both believe that because God only meets us *directly* in the heart, people with intellectual disabilities and others who live “so much from their hearts are [capable of being] open to a privileged relationship with God,” (Downey 1986:42-44). This is not intended to idealize disability or portray people as holy innocents: they both know that 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. L’Arche assistants often talk about their struggle to pray well, or to *feel* a spiritual presence beyond their thoughts. They are often impressed by the spiritual capacity of the core members in this regard. One of the most prominent scholars and practitioners in the field of disability, Wolf Wolfensberger, noted in an article after his first exposures to L’Arche that he was surprised and impressed by the core members’ facility and potential for spirituality (Wolfensberger 1988).

Thomas was a Dominican. The Dominicans, the Jesuits and the Sisters of St. Joseph are all *apostolic* orders, which means that their faith life is bound up in, and nurtured by, active service to others (ministry) (Keaney 2001; Ryan 2001). This contrasts with *contemplative* orders such as the Benedictines and Trappists whose members are called to concentrate their faith life on prayer and reflection (Keaney 2001). This apostolic orientation is evident in the formation and charism, or mission of L’Arche. These orders have been influential in forming Vanier’s visions and supporting him by sharing people and other resources with L’Arche (Vanier 1995; Spink 1990; Downey 1986).

There are three aspects of the gospel that are key for Père Thomas (Downey 1986:42-44, 103). First, he was deeply moved by the role of Mary (Jesus' mother) who "humbly and quietly" attended to Jesus' needs throughout his challenges. Second, Jesus' example of choosing to live through human suffering and rejection teaches us to attend to the lessons of our own suffering. Finally, he believed that the Beatitudes, with their "evangelical values of poverty, simplicity, lowliness and meekness," epitomized Jesus' message. The Beatitudes⁹ (see Appendix 4.1), are found in a short passage in the New Testament, that valorizes the role of the poor as spiritual teachers precisely because of their experience of suffering (Book of Matthew). These values are at the centre of the L'Arche mission. It must be said in conclusion that while Vanier was influenced by Père Thomas, he never adopted his mentor's metaphysical inclinations. As Joe Egan, a former international director put it, "Jean is a very practical, action-oriented man. He has always been rooted in his day-to-day reality, and he attends closely to that, and prayer, for inspiration."

Aristotle, moral philosopher

Another person who influenced Vanier's formation prior to entering into relations with people with disability was Aristotle, about whom Vanier wrote his PhD thesis (Spink 1990:29). Vanier liked Aristotle's realism and how his intuition seemed to come from outer experience (touch, sound, conversation) as opposed to Plato's inner-orientation (Spink 1990:29). Père Thomas, a professor in Paris, and another priest helped Vanier to choose Aristotle's *Ethics* for his thesis (Spink 1990:29; Vanier 1962 & 1966). Vanier appreciated Aristotle's view that justice, friendship and contemplation are the highest (moral) activities of the human person, but Vanier believed that love (including love of God, or faith) transcended these and was our primary moral responsibility (Downey 1986:44-5).

Pottie has argued that Vanier drew from Aristotle's contemplation on the value and nature of friendships and community (2001). Aristotle felt that there were three types of

friendships: those based on mutual exchange of pleasure and on utility or his preferred type, “character friendship that is based on intrinsic values in the character of the other [person] such as goodness and virtue” (Pottie 2001:31). Aristotle also thought that “fostering friendships was inseparable from building the community and doing justice” (Pottie 2001:31). This idea that good relationships could have this sort of social, moral and political meaning and effect is evident in the whole conception and practice of L’Arche¹⁰.

4.2.3 Environmental conditions

There were also broad social trends around the time of L’Arche’s formation which, I argue, played a role in making L’Arche viable and attractive. By establishing what elements came together to make L’Arche possible in the 1960’s, we can better understand what is different today, and how that might change or affect who joins. I introduce three broad, enabling elements. The first two enabling environmental conditions are the religious and social changes that were prominent from 1960 to 1975. Together, they exerted a great impact on the values, spirituality and lifestyle interests of people coming of age at that time. The third enabling element was the fundamental shift in the field of disability care at that time as outlined in Chapter 3.

Religious changes

A radical restlessness was emerging in parts of the Roman Catholic Church through the 1960’s. From 1962 to 1964, Pope John XXIII led a series of meetings with the international bishops—meetings which came to be known as the Second Vatican Council or Vatican II (Abbott 1966). The pope and the bishops wanted to understand and address the rising desire for change in the church that emanated from various sources including leading priests from the orders like Père Thomas’ Dominicans. People were challenging the distant relationship between the church (clergy), and the laity (non-ordained people) (Ryan 2001). Ryan, a seminarian, explained that the pivotal concerns were to rethink how the church could “live in the modern world” and how to bring clergy and laity closer through recognizing their common ‘priestly vocation’ to live a

prayerful life, rather than it being seen as the exclusive domain of the clergy (2001). These ideas played out in various ways, such as opening up the contemplative orders and cloisters of nuns and welcoming lay people *into* the monasteries for prayer and retreats. They also moved the ordained *outwards*, allowing monks vacation and encouraging them to have friendships and connections outside of their orders and monasteries (Ryan 2001). Sister Sue Mosteller, C.S.J., confirms that this opening up transformed the work and lives of many ordained (2001).

These ideas were percolating in France, and among the Dominicans, while Vanier studied for the seminary at Eau Vive, and for his doctorate (Spink 1990). Vanier's alignment with such progressive thinking was evident in his emergent heart-based theology and his commitment to practice a radical closeness to "God's people" or "the poor," not just in ministry, but in life. L'Arche was born in the midst of these religious changes, in 1964. Vanier notes with characteristic subtlety, that L'Arche was partly the fruit of post-Vatican II era changes and questioning (1995:48). The first two decades of L'Arche coincide closely with a period of openness in the church, during which Vanier's message was highly relevant. Mosteller explains the power of Vanier's retreat message in 1968: "It touched many of our longings to be living something that was relevant and close to God and to the poor. This all felt very new and salient at the time" (2001; see also Spink 1990:74). Through their example, L'Arche and its members send a challenging message to the church about the thirst for theology that speaks to lay people's diverse experiences and needs.

Social changes—Intentional communities

Significant secular social change was also moving through the West during the time that L'Arche was founded in the 1960's. Broad dissatisfaction with socio-political norms and values manifest in widespread experimentation with clothes, drugs, poetry and lifestyle. A full review of these times is beyond my aims, but one offshoot of this period is particularly relevant to L'Arche. "Intentional communities" were not invented in the 1960's, but this mode of living and working

mushroomed in popularity during this time (Fellowship for Intentional Communities 1994). Renewed interest amidst the “counter-culturalists” resulted in thousands of intentional communities starting between 1965 and 1975 (Zicklin 1983). Many L’Arche communities began then¹¹, and are in the intentional communities directory. Vanier was exposed to similar experiments in Eau Vive, a Trappist monastery, Camphill¹² and others (Wolfensberger and Vanier 1974:8; Vanier 1995). Vanier has noted that intentional communities were one of the three models that L’Arche drew on, along with religious communities and the professional group home model (1995:54-5). This movement provides a larger context for the L’Arche model and practices and shares similar recruiting concerns today¹³.

One definition of intentional community (and there are many) is: “A group of persons associated together [voluntarily] for the purpose of establishing a whole way of life. As such, it shall display to some degree, each of the following characteristics: common geographical location; economic interdependence; social, cultural, educational, and spiritual inter-exchange of uplift and development,” (Zablocki 1980:19; see also Fellowship for Intentional communities). Many are formed as an alternative to “social ills” that concern them from a spiritual, moral or environmental perspective (Bazinet 1995:8-9), but few communal ventures in North America last longer than a few years (Bazinet 1995:11). Rieff differentiated between movements or sects of *militancy* and *withdrawal*; both stem from malcontent with regular society or “the culture system”, but one seeks to change society directly, while the latter seeks to do so by becoming a living example of the value of its beliefs (Rieff 1966:248-9). Intentional communities like L’Arche reflect withdrawal traits by offering a social and religious alternative. Still, the term withdrawal is only partially accurate since, as Rieff notes, such groups ultimately aim to “preach a prescriptive, remedial lesson to the society external to it” (1966:248).

Here again, we confront the tension inherent in the L'Arche mission that I mentioned earlier. While the term *militancy* sounds quite harsh, it essentially points to that outward-oriented part of the L'Arche mission which speaks of being a sign of hope for change in our world. While L'Arche is not interested in evangelizing/conversion, there is a growing contingent of assistants in leadership who feel that L'Arche has something valuable to offer to people in our society who have a thirst for greater meaning and spiritual depth in their lives, and are not satisfied with traditional religious messages. This contingent feels that the L'Arche message about the spiritual meaning in daily life and relationships, and the power of marginalized people to teach us about these lessons, could be promoted more actively than at the present time.

In likening them to the utopian communities of the 19th century, Kanter writes that most communities “attempted to substitute cooperation for competition, mutual support for hostility, meaningful solidarity [and] relations, for fragmented, non-expressive relations, and involvement for isolation”(1973:5; Kanter 1970:60). Kanter differentiated between “retreat” and “service” communities. Retreat communities are primarily formed around friendship, living together and rejection of mainstream values and are usually short-lived (1972 in Bazinet 1995:10-14).

Service communities “have a strong sense of common purpose, create well-developed structures, impose direction and discipline to their members, and most importantly, see their main goal as that of serving a specific population” (Kanter 1972 in Bazinet 1995:10-14). They tend to last longer partly by creating mechanisms and practices which are designed both to increase commitment of members and to work towards greater harmony between their individual needs and those of the community (Bazinet 1995:11-12). L'Arche fits these definitions strikingly well in intent, concerns, and also in its moral and “small p” political aims to resist or avoid the encroachment of the values of the dominant political economy by creating a safe place in which to create, nurture and live something quite different¹⁴.

Perhaps as important was the influence the movement had on the pool of people who were potential L'Arche assistants. One major longitudinal American study of various intentional communities determined that recruitment success was highly dependent on "historical and socio-cultural circumstances of 1965-75," and that 80% of people joined between the ages of 20 and 30 (Bazinet 1995:9). The popularity of experimenting with alternative lifestyles within the youth sub-culture, then, likely made it easier (more culturally-appropriate) for early assistants to decide to live somewhere like L'Arche¹⁵. Having this large pool of willing and idealistic assistants was likely an important catalyst for the early growth of L'Arche. Without discounting the radicalism of what they did, they were also primed by the counter-culture with values of communal living in a way that today's new assistants are not.

Changes in the field of disability care

The third enabling factor for L'Arche was the current of change in the field of disability care that changed the availability of financial and policy support for people with disabilities to live outside institutions as discussed at length in Chapter 3. L'Arche was one of many alternative approaches to providing care for people with disabilities during the deinstitutionalization movement. Vanier and other leaders at L'Arche learned from the other movements, but also offered the field a radically different vision of care and intellectual disability.

The deinstitutionalization and normalization movements opened up the old system so that L'Arche and other new approaches could form. Western governments began to designate some funding outside the institutions, which was how Vanier was able to secure a small French government "family placement allowance" for each person who came to L'Arche (Spink 1990:39). By 1971, Wolfensberger was collaborating with the Canadian Institute for Mental Retardation¹⁶ on normalization issues, and interacting with L'Arche and Vanier through Steve Newroth, director of the first Canadian L'Arche community (Vanier 1995:58). Despite their different approaches, Wolfensberger and Vanier found several areas of commonality and learned

from each other. Vanier spoke affirmatively of the overall principles of normalization (Vanier 1995:32, 58; Spink 1990:76). While most L'Arche homes held eight to 12 people, including assistants and people with disabilities, Vanier learned from experience and from Wolfensberger that it was important to create different sizes and kinds of housing and living options for the people in L'Arche (Wolfensberger and Vanier 1974:16). Wolfensberger also challenged L'Arche to review their approach with a critical eye to whether they had gone too far in "spiritualizing" the suffering of the people with disabilities rather than working on giving them the support they needed to "transform and grow into maturity" (Spink 1990:76; Vanier 1995:58-9). Wolfensberger further persuaded Vanier that meaningful work (rather than just activities), and working *outside* the home, were valuable developmental goals for people with disabilities (Wolfensberger and Vanier 1974:9).

Wolfensberger wrote about the quality of relationships he saw at L'Arche: "fancying myself something of an expert in mental retardation [sic] I was stunned by the magnitude of what it was that I had missed all these years" (1973:10 in Sumarah 1987:168). He also commented on the depth and value of spirituality in the lives of people with disabilities, and the positive effect the L'Arche philosophy of equality and mutuality had on them; "a movement of qualitatively vast importance for the future" (Wolfensberger 1973:10-14). Wolfensberger was a leader in group home layouts, but he wrote that he only realized how vital the *communal space* in the homes was for facilitating social interaction after visiting L'Arche (Wolfensberger and Vanier 1974:27).

4.3 The founding of L'Arche

“L'Arche was founded to offer a home to people who, because of an intellectual disability, were wounded and unable to find it [home] or manage it for themselves.... We have been surprised to discover that the body [of community], broken by human weakness and blessed by many diverse gifts, offers more than a home, and to more people than the disabled.” (Mosteller 1996:7)

L'Arche has evolved to offer opportunities to people that none of the early members imagined at the outset, as Mosteller indicates above. The early assistants¹⁷ began with small hopes and aims coupled with large doses of faith that the volunteer and professional supports they needed would be provided or found. While the original aims were bold, it was only after living together with people with intellectual disabilities that the most radical insights to emerge in L'Arche were born. Those radical insights which now form the charism, or spiritual mission of L'Arche, are perhaps best seen as the product of the collective experience of many assistants and core members, guided, nurtured and articulated by Père Thomas and especially through the spiritual vision and leadership of Jean Vanier. Placing a full section on the founding or “origin myth” of L'Arche here was strategic, not accidental. As I discuss further in section 4.4 of this chapter, L'Arche in Canada today is struggling with some fundamental issues around assistants that could be mitigated if new and long-term assistants were more aware of the whole origin story, not just the essentialized mythos. In this section then, I present my interpretation of the origin story, and the charism of L'Arche.

If the founders did not know what to expect, then what *did* they imagine? The principles of L'Arche today are so well articulated in community literature that they can seem self-evident or natural to new people as if the whole vision or charism was given to Vanier in a divine dream. Vanier dissuades such notions by admitting the confusion and spiritual loneliness that brought him to Trosly-Breuil in lieu of pursuing his many other opportunities, friendships, and achievements (Downey 1986:27-8). As discussed above, he held a deep reverence for Jesus' life,

the gospel, and the centrality of the poor and the heart. At the local asylum, he was struck by the simplicity of their desire –he believed it was friendship that they yearned for:

Each one [of the men] had so much life, had suffered so profoundly and thirsted so deeply for friendship. Within each gesture and word was the question: ‘Will you come back?’ ‘Do you love me?’ Their cry of pain and their thirst for love touched me deeply.” (Vanier 1995:15)

Vanier bought a small home and invited some of those institutionalized men to share it with him if they wished (Spink 1990:38-40) on permission of the facility director (Vanier 1995:16-17). He opened the home for dinner on August 4th, 1964 (Vanier 1995:22). Three men, Raphael, Philippe, and Dany came, and the first two stayed. Dany’s particular impairments and deep emotional pain led him to be quite violent, and the unstructured environment of the small home exacerbated this. Without proper resources to support Dany, Vanier realized that Dany had to return to the asylum (Vanier 1995:18). Others who have come to L’Arche have also been asked to leave when their way of being in the world jeopardized the emotional or physical safety of others. Vanier explains that difficult experiences, decisions and failures were vital in clarifying his thoughts about the charism of L’Arche (Vanier 1995:30). Even today, L’Arche communities struggle with how much the charism can encompass (e.g. aging core members and assistants).

With the help of a friend from Eau Vive, Vanier chose the name *L’Arche*, as in Noah’s Ark, which saved humanity from the flood and symbolizes the first covenant between God and humanity (Vanier 1997:ix). “The community of L’Arche wants to provide a refuge for people with mental handicaps, who can so quickly be drowned in the waters of our competitive society” (Vanier 1997:ix). L’Arche also symbolizes “diversity, refuge and hope” (Downey 1986:9). It also links to Jesus’ mother, Mary who was named “the ark of the covenant” (Vanier 1995:2). These days, some assistants also suggest there is symbolic value in another meaning of the term as “an arch” or bridge between people with intellectual disabilities and the broader community.

In the early days, Vanier learned to relate to people differently and realized that “the seeds of the divine in the human heart are found in weakness, not in strength” (Downey 1986:27-8). Joe Egan, a former director feels it is philosophically important to remember that L’Arche was founded around loneliness and suffering in both the institution, and in Vanier’s heart (Egan 2001). While Vanier (understandably) prefers his privacy on this matter, he often portrays himself as equal parts *wounded* and *prophet* (Vanier 1998:7). He wrote that he always felt that he was simply responding to the cry of the poor, but that later he also recognized that cry in himself as well, in his desire to be accepted and belong (Vanier 1989:96-9). Therein lies the seed of what has become one of the most important insights of L’Arche: that we all experience pain or weakness in some form, and that it is our most meaningful common denominator as humans. This inverts traditional humanist positions that try to name commonality by emphasizing the strengths and abilities that the weak share with the strong.

4.3.1 Fragments of the charism

I did not realize the full meaning of L’Arche when, inspired by Père Thomas, I started living with Raphael and Philippe. I discovered what L’Arche was called to be as I lived each day, trying to be faithful to the needs of those who had come to create community with me. ... When I began, I was far from imagining the various facets of life and all the power contained in the message of life with the poor. Today in 1995 I am still discovering what L’Arche is ... We are a people on a journey, walking in insecurity but certain that God is watching over us. (Vanier 1995:13)

Vanier has clearly stated that, initially, he was not sure what L’Arche would become, and had not grasped some of the insights for which he is now famous. In this section, I would like to discuss the formation of those insights, using analytical language for clarity, and to represent what I see as their central ideological contribution to the literature on difference, disability and caregiving. I have discerned roughly four stages in which the charism seems to have been revealed to Vanier and other members. I use the term stage for these analytical categories to

indicate changes that seem to represent a progression or maturation of thought, but I do not mean to imply thereby that Vanier experienced them as distinct stages. At the time there was surely much confusion, disagreement, and uncertainty about which directions of thought were fruitful.¹⁸

The first stage was to want to help disadvantaged people. This stage resembles traditional Christian charitable impulses which have been called both social justice and cultural hegemony since this “help” was often imposed on people and was attached to religious expectations and/or attitudes of condescension (Steinhoffsmith 1999). Vanier and Père Thomas challenged that historical norm by insisting that people with intellectual disabilities are fully human and deserve to be treated as such, based on the logic of universal divine love. This respect for diversity reflected the radical spirit of the times, but was by no means commonly applied to people with intellectual disabilities.

In stage two, two things propelled their conceptual state far ahead of mainstream thinking about disability at that time. Vanier and Père Thomas’ devotion to the Beatitudes prepared them spiritually to expect and seek the special gifts of the poor. Second, Vanier decided to live *with* people, deepening his familiarity with their lives through sharing daily routines and practices over time. The anthropological significance of what Vanier and Thomas did, was to show the contingency of culturally-constructed devaluations of difference and disability, and to revalorize difference through their particular religious worldview. The dominant deficit model of disability focused on the burden disability created, based on assumptions that privileged economic productivity, intelligence and physical beauty over other traits (Pottie 2001:25; Taylor and Bogdan 1989).

Vanier and Père Thomas began from different cultural assumptions about value, asking, ‘What does God find of beauty in this person?’ This simple but profound inversion and revalorization of difference seems to have changed everything for them, including how to think

about care, as I show later. Their constructive model of disability and difference shifted their perception to ways in which the social fabric could be enriched through the full inclusion of people with intellectual disabilities.¹⁹ This in turn produced the idea of talking about the social benefits of improved caregiving, rather than just the costs.

Sharing life together was to reveal more insights in the third stage, which flowed from the second. Vanier says that it evolved imperceptibly, not intentionally. He and other assistants had quickly recognized how loving and interesting people with intellectual disabilities were, but soon they realized that they were also *learning from* them. He began to understand that people with intellectual disabilities had gifts that people of normal intelligence generally did not, perhaps because our reasoning gets in the way of, or clouds our access to, those capacities. Vanier and Wolfensberger have both written about such qualities, assets or gifts, some of which include being honest, straightforward, spontaneous, loving, welcoming, and having fewer barriers, and an ability to call forth gentleness and kindness in others (Vanier 1998; Wolfensberger 1988). As Vanier expresses below, the idea of *the poor as the teachers* was not something that any of them predicted or aimed for, but rather it emerged out of the experience and reflection on daily life within the gospel framework:

When I first began in L'Arche, I never would have said as clearly as I say today that people with mental handicaps are prophetic. We discovered this gradually over the years, as we searched for our way, our structures and our identity. People with handicaps have helped me to discover what community is. (Vanier 1995:114)

From the start, we wanted to live with the poor, but "when the idea of the poor educating us came, I don't know exactly. The words of St. Vincent de Paul, 'the poor are our masters' were always there [for us] but when they became a reality I'm uncertain. (Vanier in Spink 1990:41)

The fourth and final stage of the insights relates to the caregivers. The same intensity and intimacy of sharing life that galvanized insights about disability for those living in L'Arche also eventually took its toll on many of the caregivers, including Vanier and Thomas. Many assistants

(caregivers) began to feel burned out and depleted of energy after giving so much of themselves to these unusual and challenging relationships. This was how 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. They realized that their mission to support people to have full lives needed to include both the core members and the assistants. This led to implementation of supports like extended vacation periods away from community, spiritual guidance, and medical resources as I discuss in chapters 6 and 7. Caring for the caregivers thus became an important final element in their basic principles.

4.3.2 Start-up and identity formation

“Faith communities and professional centres for people with handicaps: this reveals the deepest ambiguity of our communities. They must be competent and well-administered, because we are responsible for the people who have been entrusted to us. We need the right medical and psychiatric support to help them grow towards greater autonomy and wholeness. At the same time, L'Arche wants to be a faith community.”

(Vanier 1995:104)

This is a clear statement of a complicated situation at L'Arche. The fire or charisma of their mission is about both their faith in God and the actions in the world that He is calling them to. They are not separable or reducible to one that is more important (Keaney 2001). “I am convinced communal life can flourish only if it exists for an aim outside itself. Community is viable if it is the outgrowth of a deep involvement in a purpose which is other than, or above, that of being in a community.” (Bettelheim 1974 in Vanier 1989:90) Since part of the mission is about ministry, or service to, people with disabilities, it falls into a realm of professional and bureaucratic standards that pull the community in the direction of an agency (Spink 1990:128). While the often competing demands of agency-community need not pull them apart, it can be hard to live in the tension that this creates²⁰. My impression was that people in L'Arche struggle for balance both at the level of macro policy and structures, but also, importantly, in their daily

activities. At each moment, assistants face choices related to this tension as the ethnography shows. Balance is a daily negotiation in practice.

The long-term assistants in L'Arche now know that they need certain structural supports in place to anchor them in the fundamental community dimension since the practical, legal demands of direct care and its administration are always pulling them to an agency focus. One support that has been there right from the beginning, through Père Thomas, was the presence of priests and spiritual guides who were there to listen and try to help make their struggles meaningful through the connection with the spirit of the Gospels and the charisma (Vanier 1995:104). Assistants are encouraged to reassess their calling yearly through solitary reflection or prayer, or with the support of accompaniers (long-term assistants or counsellors). Sometimes assistants and core members seek outside accompaniment of a more particular sort regarding their emotional or psychological health. Again, from the start, Vanier was open to the expertise of various medical, psychiatric and social work professionals for both agency-related issues and for nurturing community members (Downey 1986:17; Wolfensberger and Vanier 1974:13).

L'Arche learned from the experience of other groups engaged in this same balancing act. Vanier has written that in the beginning of L'Arche, he held a few models of community life in his mind where "lay people lived poorly with poor street people," which reflects the charisma of L'Arche (Vanier 1995:22). Those role models included Montreal's Benedict Labré house, New York's The Catholic Worker, and Friendship House. Montreal's Foyer de Charité, founded by Cardinal Leger, also made an impression on Vanier. It began as a prayer community that welcomed people with severe mental handicaps (Vanier 1995:22-3). There was also a spiritual bond with the Little Sisters and Little Brothers of Jesus Order:

[A] common spirituality of humility and presence, close to the poor and the weak; a common call to live with them, not to change them, but to welcome them and share their gifts and their beauty; to discover in them the presence of Jesus—Jesus, humble and

gentle, Jesus, poor and rejected. It is the spirituality of Nazareth: to live daily life simply and humbly, with love: to be present to the poor. (Vanier 1995:58)

In the broader field of caregiving, what set L'Arche apart early on, was the emphasis on being open to two-way relationships between assistants and core members, not just a one-way service model. Other researchers who have studied L'Arche have also emphasized the contribution L'Arche made in facilitating these "gift relationships" (Shearer 1976, Sumarah 1987, Pottie 2001). One family therapist studying L'Arche wrote:

It is this focus on the natural growth that can occur via relationships in all its aspects, including cognitive, affective, physical, and spiritual, that frequently obliterates distinctions between a care giver and care-receiver and [which] sets L'Arche apart as a larger system. (Coppersmith 1984:152 in Bazinet 1995:18)

Vanier continues:

The secret of L'Arche is relationship: meeting people, not through filters of certitudes, ideologies, idealism or judgements but heart to heart; listening to people with their pain, their joy, their hope, their history; listening to their heart beats. (Vanier 1999)

4.3.3 The early steps of growth

The early steps of growth for L'Arche in France were rapid, partly due to its emergence at the confluence of several changes in society, religion and the disability field. Vanier calls it a time of grace, when many people were generous and supportive of L'Arche, in spite of his admitted naiveté about caregiving and community. In addition to government financial support, local women cooked for them, architects and carpenters assisted them with renovations, and psychiatrists and nurses offered wisdom and practical skills (Spink 1990:47-50). He must have been doing something right since after opening his first home in August 1964, Vanier was asked within months by Dr. Préaut and the board of the local institution, Val Fleuri, to take over as director, where all staff had just resigned (Spink 1990:47). He reluctantly took this position by

himself in spring 1965, moving in with the 32 men and initiating several major changes in their lives, akin to what he was living in L'Arche (Vanier 1995:22-3). He divided his time between there and his original L'Arche home. Vanier saw this external request as an important turning point for his vision of L'Arche. He felt that this was a sign that L'Arche was called to be more than the prophetic, but marginalized community it started out as: they were being called forth into integration with state standards, social workers, labour ministry officials, and medical professionals (Vanier 1995:25, 35).

During the 1960s, more people were attracted to the project of L'Arche in Trosly as assistants, professionals and core members, and so there was a fairly rapid process of expansion in the village of Trosly. This process is well documented in books by Vanier (1995), Spink (1990) and Clarke (1974). Two salient points need to be noted here: first, their rapid growth in size caused resentment in the small village, helping the founders realize that L'Arche needs to be integrated into a diverse, broad community, rather than becoming a town unto themselves (Vanier 1995:36). Second, part of the constancy of the L'Arche vision amidst all of that expansion, seems to have come from the "triple authority" leadership structure that Vanier constructed (Spink 1990:56-7, 125). This included the community leader who had to bear in mind the practical, daily needs and joys of the people, and the priest or pastor who could act as a "brother to the poor," hold the original gospel values in his heart and remind the community of that charism. Third is the role of professionals like doctors, psychiatrists and lawyers to be a check on the first two roles regarding established standards of care (Spink 1990:125).

4.3.4 Translation to Canada and beyond

My fieldwork was conducted in nine Canadian L'Arche communities, and as such it is important to outline briefly how L'Arche came to Canada and how it shifted somewhat from the original French version through this cultural translation. The philosophy of care that had begun in

France was translated largely intact on Canadian soil, but there were two unique elements that meant L'Arche evolved slightly differently here. The key differences were a heterogeneous religious environment, and the North American bias towards pragmatism over mysticism.

The vision was disseminated in Canada, the USA and elsewhere through Vanier's lectures and spiritual retreats for special educators, social workers, theologians and religious people (Vanier 1995:30-31). The words and reflections Vanier shared at these retreats and lectures galvanized great interest among people who were searching for new interpretations of their faith in relation to dramatic social change. Egan, an early member recalls: "People were very moved by the new spiritual message that Vanier was announcing. His uncommon insights and interpretations of the gospel were fresh and they really shook people into a different way of seeing the world. And these ideas became the foundations of the L'Arche charism." (Egan 2002). The interest Vanier generated was central to attracting new assistants, credibility and donors. Bill Clarke, S.J., and Steve Newroth, who were at one of Vanier's early Canadian lectures in 1965, went to Trosly as assistants soon after and later became important figures in founding and nurturing L'Arche in Canada (Egan 2002:31, 70). Vanier's first large retreat was at Mary Lake, Ontario in 1968, and attracted two Sisters of St. Joseph—Sue Mosteller and Marie Paradis—who were also both instrumental in founding and strengthening L'Arche in Canada (Spink 1990:74). Sister Donovan of Our Lady's Missionaries was also there and, moved by Vanier's vision, she donated the order's former novitiate house and property in Richmond Hill, Ontario; in 1969 this became Daybreak's "Big House," the first building for L'Arche in Canada (Vanier 1995:31).

The couple who founded Daybreak, Steve and Ann Newroth, were Anglican, and the people with disabilities and assistants who came there had been raised in various denominations or none at all (Spink 1990:106-10). While this is not the place for a full comparison of the way Anglicans and Protestants differ from Catholics, the point is that there *are* differences and that

these created a heterogeneous religious scenario that was distinct from the homogeneous religious and ethnic environment in France. Even today, France remains 88% Roman Catholic and 90% ethnically French (Goldstone 2000:253). Canada on the other hand, is 47% Roman Catholic, 41% Protestant/Anglican, and ethnically diverse (Goldstone 2000:171)²¹.

From the start, there were disagreements and painful schisms in the Canadian communities as people of different faiths attempted to chart a path on which they could walk together in the spirit of L'Arche in France, while respecting ecumenical and interfaith differences (Porter 1998; Spink 1990:106-10). An important turning point in this struggle came in 1986 through the presence and beliefs of Father Henri Nouwen, a Dutch, world-renowned theologian and priest from Harvard who came to live in Daybreak as pastor for a decade²². Sister Mosteller recalls that Henri (as everyone called him) brought hope for resolution into their situation of ecumenical angst (2001). Henri was Catholic but he was unusually open, and his years of teaching in secular universities and in the Third World left him convinced that diverse spiritual beliefs were a treasure: worth celebrating, exploring and being proud of (Mosteller 2001).

Challenges for the L'Arche model in Canada were not just due to denominational differences, but also a different sense of spirituality overall: the North American L'Arche communities realized early that the "spiritual intensity and resources" were less concentrated, and more varied here than in France (Spink 1990:77-8). The dominance of Protestantism lent itself to a pragmatism and professionalism that often felt like it was going to overcome the idealistic spiritual foundation of L'Arche (Spink 1990:77-8). Joe Egan, a former international director, suggests that in its fledgling years, L'Arche in Canada also contended with finding its way alongside the dominant secular movements of group homes and normalization which were much stronger here than in France at the time. The strength of those movements threatened to overwhelm L'Arche and suppress precisely those elements of its approach that were most

important, such as spirituality and mutual relationships. This made for awkward working relationships for early L'Arche leaders with the mainstream agencies and disability associations.

The gift in all of these challenges was that they pushed Vanier to greater clarity on the spiritual priority of the L'Arche charism (Spink 1990:77-8). L'Arche therefore chose to run spiritual retreats and workshops regularly to give their assistants and core members an opportunity to deepen their spirituality if they wished, and to understand better the gospel values that L'Arche was founded upon, which made their perspective special.

Religious belief was not, and is not, obligatory to being in L'Arche however. They welcome people of diverse religious backgrounds or no religion, as long as the person respects the liberal Christian values the community was founded on, and supports the people with disabilities to access and practice their faith (Vanier 1989 in Bazinet 1995:21; Porter 1998, 2001). Neither conversion nor a new denomination are on their agenda, and that seems to make many different people feel comfortable being there (Bazinet 1995:21; Vorstermans 2001). Roughly half of the communities are predominantly Catholic and half are ecumenical or inter-faith (Bazinet 1995:23). The decision to remain open to people's different beliefs had been made early on when Raphael, one of the first core members, told Vanier that he did not want to go to Catholic mass. Through his relationship with Raphael, and his consultations with Père Thomas and with local medical professionals, Vanier came to grasp that what people with intellectual disabilities needed most, and first, was to experience friendship, trust, personal authority and choice, not necessarily religion (Spink 1990:60). Vanier later called this a "pedagogy of freedom, not force," in religion and other spheres (Spink 1990:102). This fundamentally positive view of religious diversity guided the Canadian organization in its movement towards unity.

While there was, and still is, a strong, externally imposed pressure to move towards the values and structures associated with mainstream professional agencies in Canada, L'Arche has

remained true to most of the original elements of the mission. One element which was particularly hard for L'Arche to promote and sustain within the Canadian and American cultures was to insist that independent living, is not the only, or even usually the best, way to ensure people's well-being. Mainstream policy and agencies rank maximizing personal independence as a key priority in rehabilitation for people with intellectual disabilities. This belief has many virtues, but it has also contributed to the existence of many people who live independently but are also very lonely, as I discuss in Chapter 7 (Amado 1988a:294, 1993a; Lutfyia 1991; O'Brien and O'Brien 1993; Brown 1997). While L'Arche agrees with supporting people to achieve autonomy and normal living conditions, these goals need to be achieved in tandem with helping them to grow in love and confidence through supportive relationships and meaningful activities (Spink 1990:77-8). They believe that autonomy is possible in an interdependent or community setting.

4.4 L'Arche in Canada today: mandate and issues

4.4.1 L'Arche today

Today L'Arche has over 100 communities in 30 countries, (25 in Canada) and is more in a period of deepening and strengthening what they are, than expansion. The size of the network pushed the leadership to think about writing up their mission and priorities for clarity and guidance. They developed various statements which articulate different aspects of the community such as its charter, mission, identity, aims, principles and key elements, both at the international and zone levels²³. These documents were created by diverse international teams of long- and short-term assistants, core members and board members. The emphasis in these statements is on what the community is and wants to be, and does not explicitly address how they differ from mainstream caregiving approaches. I present those core documents, but I also discuss a chart developed in one community that addresses their difference from agencies directly.

Though each community continues to maintain a significant degree of autonomy of operations and community life, there is now a system of governance that attempts to create unity, consistency, efficiency and co-operation at various levels. Communities each have a community leader that reports into the director of a “region,” such as the Atlantic region (Maritime provinces), the regions are part of a “zone,” such as Canada, and the eight world zone coordinators report to an International Director and Board. This system has facilitated sharing information and documents. The intention is to identify best practices in areas like recruiting across L’Arche to share with all the communities.

Aims and strategies documents

Two factors complicate these inceptive attempts to harmonize policies within L’Arche. The first is that some adjustments have been required in most cultures to adapt the representation of the basic values of L’Arche to the local context. This facilitates adaptation and survival, but frustrates attempts to find a singular expression of those values globally. Where France may want a deeply Catholic representation of what they live, Canada needs to be cognizant of the diverse spiritual environment it is rooted in, and India or Ivory Coast have more people of non-Christian religions to accommodate. The second complicating factor is the inherent complexity of its triad of goals—to be a faith community, to care for people with disabilities, and care for its caregivers.

There are thus different elements and documents created for different settings, but all borrow from each other and attempt to express what L’Arche “really is” for them. Copies of the primary documents are included in the appendices, but I focus on the basic document for Canada here. In Appendix 4.2 is the International Charter of the Communities of L’Arche, which serves as the blueprint for all communities. The conclusion of the charter touches on the political nature of the organization by aligning themselves with the poor and those who “take part in the struggle for justice” (L’Arche 1993b:3). This document contains aims and principal beliefs that have been

agreed on by all international L'Arche communities. It names L'Arche as a faith community and calls all communities to unity, growth, and integration in society.

The L'Arche Canada zone felt that they wanted to adapt the international charter to a format that was more appropriate for our poly-religious and multi-ethnic society. They also tried to update the language used around people with disability, which differs from Europe. In 1993, a committee of various members of the Canadian communities came together and created what is called the *Mission and Identity of L'Arche in Canada* (L'Arche 1993a) (Appendix 4.3). This document closely reflects the values and aims outlined in the original charter, but uses language which is perhaps more spiritual than religious and somewhat less theosophical and political than the charter is. It uses "developmental disability," as opposed to the charter's "mental handicap." The Canadian document lists four aspects of identity and three elements to the mission, which overlap somewhat thematically with each other and with the charter. The *core elements* shared in the document seem to be: naming the intrinsic value of people with developmental disabilities, their instrumental ability to transform people with their gifts, creating home together, mutual relationships, living a spiritual life according to the gospels, and helping to change society by being a sign of hope²⁴.

Another key document that has served the aim of harmonizing the Canadian zone is the *Key Elements of a L'Arche Community* guideline (L'Arche 1999) (Appendix 4.4). The zone wanted to have a tool that named more clearly the elements of a successful L'Arche community both to help the communities grow well, and to create the basis for accountability to the regional and zone leadership (L'Arche 1999:2). This document uses the same ideas as the others but presents them in a new, applied format. Each of the six sections begins with a sub-title and a summary statement to encapsulate the *beliefs and aims* of the Canadian zone. The document also lists the specific *principles* that underpin those beliefs. The last part of each section is a

prescriptive list of the specific *practices* which ought to be part of putting those beliefs, aims, and principles into practice. As one can see from the document, the sections range from how to ensure that people with disabilities are valued and nurtured well, how to create a home in the spirit of L'Arche, to leadership, management and integration standards. The effort to specify *practices* in this key document is symbolic of the importance of the everyday practice of care for L'Arche.

L'Arche in Canada today follows a model very similar to that born in France years ago. Three key differences are in locale, gender and finances. Most communities are now located in cities, not villages, and men and women now share homes together and are not segregated. In addition to government funding, all communities must actively fundraise to supplement the basic revenue in order to provide the enriching activities that they seek to. Both public and private funding require accountability and carry stipulations and sometimes standards which restrict how L'Arche can use the money. For example, although the L'Arche communities are not wealthy, they have less freedom to choose a lifestyle of simplicity, as was the original vision, given government standards such as having dishwashers in all homes. Funding is allocated to each community to cover costs *directly related* to the "care" of the people who live locally. That funding can therefore not be used to fund the spiritual dimension of L'Arche, or other L'Arche communities internationally.

Even their alternative compensation system is being challenged in some regions as the government insists on higher basic wages for assistants rather than their communal funds approach.

The L'Arche homes are located amidst urban and suburban neighbourhoods as with group homes, and look like the homes around them²⁵. The homes are typically designed for five to ten people (including assistants and core members). A recent L'Arche Canada survey found that their average community size is 4 homes, (range: from 1 to 8 homes), and 18 core members

in a community, (range: 4 to 34 core members), which means an overall average of 4.5 core members per home (Lukeman 2001). Unlike in most group homes, the caregivers and people with developmental disabilities live together in L'Arche homes sharing common space, meals, activities and prayer, (although each person has a private bedroom). L'Arche homes are closely connected with each other within the city for activities and holidays, as well as joint skill and spiritual development for assistants. The aim is to provide "an environment that fosters personal growth" through relationship and shared living for all community members (L'Arche 1993).

Community or agency

The dual mission means that L'Arche is more than simply a caregiving agency, although it shares many of the same responsibilities, funding sources, and techniques. Two long-term assistants at Daybreak developed a comparative list for training and advocacy work that helps to clarify the differences between how things work at L'Arche and how they are done in an agency (McMillan 2001). I adapted their ideas into this chart. Note that the lists highlight their different priorities but both aspects are generally dealt with to some degree in both approaches.

While the chart highlights differences, there are many similarities today between L'Arche and other models of care in agencies, particularly in the group home model. Both enact and support normalization theory and its program manifestations, although to varying degrees. Caregivers in both models ideally hope that rehabilitation will result in the growth and fulfillment of people with disabilities, and they share many techniques in this regard as well. Both models are committed to work with medical and psychiatric assistance and expertise when needed. Both are committed to the importance of meaningful work for people with intellectual disabilities, either in the community or in sheltered workshops, and of engaging people with more profound impairments in activities. Both also advocate for community integration for people with disabilities on principle, although it can play out differently for each, since most ACL facilities are aiming for independent living.

Table 4.1 Comparing L'Arche and Regular Care Agencies

	<u>Service Community</u>	<u>Care Agency</u>
1. Commitment	To a way of life; Member	To a Job; Employee
2. Theory	Spiritual and moral Vision of a community of belonging	Normalization & Community Integration
3. Anticipated result	Interdependence & autonomy	Independent living & autonomy
4. Relations	Potential for Mutuality (2-way)	Staff provides service to client (1-way)
5. Spatio-temporal Set-up	Caregivers live-in full-time & life-sharing	Caregivers work shifts, live at home
6. Accountability	L'Arche structures & Government	Agency structures & Government
7. Compensation	Alternative system (some communal components)	Wages (market-based)
	<u>Moral-Political Dimensions</u>	
A. Political Aims	Critical or Radical	A-political
B. Politics of Care	Fruitfulness	Efficiency & Economy
C. View of Person in Care	Subject	Object or Consumer

I added the moral-political factors to the original list to highlight the distinct positions which underlie the L'Arche vision of care. While there are many good caregivers and administrators in both models, the agency model is designed to be an apolitical tool of the existing health care system to take care of people who cannot otherwise care for themselves. In

this model, the people with disabilities are most often constructed as objects of care in a system that sees care as a one-way delivery process. In L'Arche, they are also cared for, but the process and structures attempt to construct them as subjects of care who are the central decision-makers in their own lives to whatever extent possible.

The politics of care at an agency are guided by efficiency and economy while at L'Arche, they are guided primarily by the notion of fruitfulness, and only secondarily by efficiency and economy. L'Arche itself is a grassroots political-moral statement against the marginalizing and poor treatment of vulnerable people in our society. As such L'Arche offers an indirect critique of status quo public attitudes and aspects of the care systems, while also being a part of the systems.

4.4.2 Staff today: role, importance and issues

In all direct care organizations, including L'Arche, staff or assistants are central to every aspect of operations from the budget to the quality of care, and will thus also often be the source or subject of many major issues they face (Jacobson et al: 1992:198, 220). Below, I outline some research on common human resource issues and attempts to explain them. Following that, I introduce key human resource-related issues at L'Arche today.

Many studies have indicated that in social service organizations providing direct care, staffing problems are their central operational issue (Braddock and Mitchell 1992:8-9). One survey of 2000 care facilities for people with intellectual disabilities found that 85% listed staff-related issues (recruitment, retention, and development) as the most important operating problems they face (Bruiniks et al. 1980 in Braddock et al. 1992:9). Researchers found in a literature review that direct care workers' wages are well below the national average even for "women's work," and that turnover is higher than average and rising (Braddock and Mitchell 1992:41, 79). Not surprisingly, they found that turnover is highly inversely related to wages (ibid:21, 41) and that higher wages were essential to stabilizing the workforce in direct care facilities (ibid:87).²⁶

Stability is important because turnover²⁷ adds significantly to the cost of operations for the care provider, and also has a negative impact on quality of care, (although measuring this is an inexact process) (Braddock and Mitchell 1992:14-16, 41, 85-7; see also Jacobson et al. 1992:220). This impact is not surprising given that direct care workers form the bulk of the client's interpersonal contact in human service facilities (from 75-90%) (Braddock and Mitchell 1992:14-15). The quality and consistency of caregiver contact is considered especially important for people with intellectual disabilities who usually have limited social networks (Braddock and Mitchell 1992:14-15; Bercovici 1983; Amado 1993a; Lutfiya 1991; Pottie 2001).

L'Arche strives to be a place where "caring is both a practice and a disposition" (Tronto 1993:104), and is both about the labour of caring for others, and the interpersonal dynamic of caring *about* them (Kittay 1999:155-7). But this kind of care entails a higher degree of interaction and interdependence between caregivers and the cared for than traditional models of care, and requires a new kind of caregiver; one who is willing *and* able to engage in it. This ethnography explores what it means to people to become assistants, and how L'Arche harnesses their initial willingness to serve and enculturates them so that they are also *able* to do it well.

Recruiting

One of the main issues L'Arche has identified is recruiting. This means figuring out what kind of person can do this work well, and then creating tools to attract and invite them to join. In Chapter 5 I discuss why people go there, and why recruiting has become an issue for L'Arche. Inviting people to L'Arche today is a very different proposition than it was in the first two decades of L'Arche. The community needs to find more and different ways to reach a smaller pool of likely candidates. They will have to work harder to invite those they do find, because the step out to this lifestyle feels more radical today for young people. Finally, these people need to be trained in a different way than assistants 20 years ago, beginning with a stronger phase of unlearning and consciousness-raising since they enter L'Arche with varied understandings of its

radical nature. Wolfensberger suggested early on that direct care workers had to be idealists, prepared to make big sacrifices, bear burdens, and share in others' suffering (Wolfensberger and Vanier 1974:37). While quite one-sided, this statement suggests why it is hard to find good people to live and work in L'Arche, and in the field in general. The result is a chronic shortage in many L'Arche communities—further straining the assistants they do have and usually inhibiting the quality of care and lifestyle that they can produce for the core members.

Formation and foyer lifestyle

For the assistants that are in the community, two key and inter-related issues are lifestyle and formation. Lifestyle questions tend to centre around how the charism is executed, and constraints on doing this well. Many assistants seek to continue to live the L'Arche philosophy but outside the home, or as a married person and these requests are difficult to accommodate given their current ideology, policy and compensation rules. Formation challenges are tied to how to train people in the alternative moral culture of L'Arche in a way that supports them to live it well and to stay. Together, these issues mean that most assistants do not stay as long as L'Arche would like, and not enough of the new assistants seem willing or able to take on leadership roles; both of which cripple the community's organizational capability.

In Canada, the chronic shortage of assistants and increasing bureaucratization in the disability field have meant more time spent on the bodily physics of care and less time available for the affective and spiritual dimensions of care that drew them to L'Arche initially (Davis 1995; Lukeman 2001). This scenario has led a few people in leadership to question the viability of the foyer model of homes with live-in assistants. Discussions are ongoing. Since a central distinction of L'Arche is its expansive conception of caregiving, and in-depth formation, it needs to ensure that there is time for those affective, spiritual dimensions, if the mission is to be achieved. Making time for that is difficult in the increasingly regulated political economy of care and disability where the government and insurance companies who pay for care continue to impose

homogeneous standards that privilege time spent on rehabilitation, and skills development for independence (Albrecht 1992:135, 169) to the exclusion of less measurable or profitable goals like social relations or spiritual health. In Chapter 6, I elaborate on L'Arche's non-traditional conception of what counts as productive labour and why it is difficult to defend within existing health care frameworks.

Paradox of care

Another area that can create confusion and stress for assistants in L'Arche is what I call the "paradox of care". The paradox is that this model of care asks assistants to accept core members *as they are*, but also to encourage *growth* in skills and autonomy²⁸. Having these two priorities is what makes L'Arche distinct, but holding them in constant tension is difficult for assistants to do. It is especially hard when a core member does not want to grow or develop in a way that the team of assistants and/or doctors feel would be in his or her best interest, such as exercising, dieting, or pursuing social opportunities or hobbies outside L'Arche. Vanier insists that L'Arche is not intended to be a womb to hide in, and thus stasis, or decline is not on the agenda for either core members or assistants. He believes that humans need a balance between the comfort of acceptance and the challenge of growth (Vanier 1998:11), and that someone who refuses to adapt or grow, in maturity and capacity, unfairly increases stress in the home for others (Wolf and Vanier 1974:11).

This paradox of care is linked to a broader concern in the field of direct care, and that is the effect on caregivers of the shift in emphasis towards independence and residential care through fee-for-service models (Braddock et al. 1992:86-7; Ungerson 1999). While such de-reification of the role and authority of caregivers can be positive in many ways for clients (Zola 1989; Ungerson 1999; Albrecht 1992), it can, and has caused substantial role confusion and a feeling of devaluation for many staff (Jacobson et al. 1992:206, 214-16; Ungerson 1999; Ryan & Thomas 1980). From a staff perspective, this shift is at least partly about their potential, eventual

professional obsolescence, which is not exactly motivating and makes it difficult for caregivers to value their role positively, or deliver high-quality care (Albrecht 1992:185-210). These feelings are not conducive to promoting better staff-client relations. The L'Arche approach seeks to support caregivers and help them see the value of their role in a different framework. Their experience of working within this ambiguity may be instructive for other agencies.

Mental health

The final issue is how to ensure the psychological and emotional well-being of the assistants in the intense cultural environment of L'Arche. Vanier was aware early on of the unhealthy patterns or burnout that some people can form in this service culture, and advocated for supports like accompaniment and therapy (Wolfensberger and Vanier 1974:13). Many have written of the need to support caregivers with retreat or respite time to prevent them being overwhelmed by the emotional and moral demands of direct care (Wolfensberger and Vanier 1974:40-3; Kittay 1999; Tronto 1993). But some assistants have still lost themselves in the group, or overexerted themselves (Spink 1990:69). While such problems are partly a result of pre-existing personal issues, they are not exclusively an individual issue.

While mental health is not a central topic in this thesis, the prevalence of burnout and stress as idioms of illness in L'Arche is problematized in relation to their organizational ideals. High levels of caregiver stress and burnout are common in direct care (Albrecht 1992:185, 191; Braddock et al. 1992), but organizations should bear some responsibility for prevention (Kittay 1999). These issues are a serious concern for long-term assistants in particular but also for new assistants who are being shaped tacitly, as much as formally, about how to live in L'Arche.

4.5 Conclusion

This chapter was intended to accomplish three goals. The first goal was to augment the historical foundation for the ethnography started in Chapter 3, by providing a clear sense of what L'Arche is like ideologically, theologically, and structurally and how it got that way. Later, I

evoke what the daily experience is like for assistants, and this background will help to make sense of some contemporary issues in L'Arche. Second, I wanted to clearly situate L'Arche in relation to the other modes and philosophies of care and disability that were discussed in Chapter 3, so that the reader understands both the similarities and differences between L'Arche and mainstream care approaches. Finally, I aimed to demystify the emergence of L'Arche, and to some extent what it takes to be a good assistant there, by presenting a more complete, contextualized history of L'Arche than most assistants are exposed to. My goal in so doing was to suggest to new assistants, some of whom I hope will read this, that being uncertain about what it means to be an assistant, and whether they are called to it, is a natural feeling and not something that signals a lack of fit. In the next chapter, I examine the primary research of my fieldwork in detail in regards to what it means to people to become a L'Arche assistant.

4.6 Endnotes

¹ The Prince then turns to the other roses: "you are not at all like my other rose...as yet you are nothing. No one has tamed you (*apprivoisé*)...[my rose] is more important than all the hundreds of you other roses because it is she that I have watered...it is she that I have listened to, when she grumbled, or boasted, or even sometimes when she said nothing." (Saint-Exupéry 1943:86-7)

² Father G. Arbuckle notes: "The Greek word '*charism*' means free gift: St Paul introduced it in religious language to mean a gift God bestows for building up the faith community of Christ." For example, St Ignatius received a message of what the charism of the Jesuit Order was to be. This term is unrelated to charismatic religious movements.

³ In the Roman Catholic and Anglican liturgies, the Gospels (the words of Jesus) are considered distinct from the rest of the New Testament, which consists of *interpretations* of Jesus' teachings by disciples that were intended to encourage and help the people to become Christians (Vorstermans 2001). The bible begins with the Old Testament, which holds the history of the Jewish people prior to the year AD 0, which Christians consider to be the birth of Jesus and the advent of Christianity.

⁴ *The Epistles* are letters from disciples, which interpret Jesus' words. *Corinthians I* is Paul's letters to the Corinthians on how to live according to his understanding of Jesus' teachings. These letters are central to Vanier's interpretations and theology as well (Vorstermans 2001).

⁵ His thesis is listed in the bibliography by its publication date of 1966.

⁶ Vanier was often invited back for guest lectures on his radical theology, and these are legendary in the history of University of Toronto. He recently gave two standing-room only lectures for professors, clergy and students at St. Michael's College (spring 2001), and at the annual CBC Massey Lectures by national public intellectuals (fall 1998) at U of T Convocation Hall.

⁷ Feit refers to this as attending to the internal micro-politics (1985:60).

⁸ This perspective was also put forth by Thomas Aquinas in the 13th century (Ryan 2001).

⁹ From a Sermon on the Mount where Jesus declared that the poor, the weak, and the persecuted are blessed. Also called the preferential option of the poor; suffering deepens their closeness to the divine.

¹⁰ Note that an important point of divergence between Jean and Aristotle is that Aristotle believed that status imbalance would prevent “genuine” friendship between people in different social or class positions (Aristotle 1976 [1955]:259-93, especially 286).

¹¹ In the five countries where L’Arche has the most communities, (France, Canada, UK, US, and India) 34% of communities began before 1975, and 77% before 1985. L’Arche continues to grow, though more slowly, both in these countries and internationally, right up to the present (Vanier 1995:121-24).

¹² Camphill is also a service community for people with disabilities, but in rural farm settings. It is grounded in anthroposophy.

¹³ I drew extensively from Bazinet’s MA thesis (1995) for the discussion of intentional communities.

¹⁴ In a critique of Habermas’ notion of the neutral democratic public sphere, Fraser has written about the need for off-centre safe discursive places as “subaltern spaces” where a minority group can safely develop their position and strategy before entering into the main “public sphere” of discourse where their voices will have to struggle to be heard because they speak from different assumptions and values (1994).

¹⁵ Indeed, the Intentional Community Directory website indicates that from 1989 to 1994 only 50 new intentional communities were started! www.ic.org. The website and information manager there told me that most new start-ups are co-housing or co-operative ventures and have a more economic and simple living slant than the classic values-based communities. Age at entry is also rising, likely given the increased cost of entry into these co-housing models.

¹⁶ Now called the Roehar Institute at York University.

¹⁷ Presumably the original core members also had hopes, since they came by choice, but I have not found any published record of how they felt about things. In those days of course, it would not have crossed many people’s minds to ask them, as it was not the norm.

¹⁸ Robert Fulford explains that treating history like a *story*, “keeps us from understanding that the final result was not preordained.” At the time, the “future for them was a matter of contingency, accident, surprise,” (Fulford 1999:38).

¹⁹ Contemporary researchers Taylor and Bogdan call this approach a “sociology of acceptance” (1989).

²⁰ In Chapter 5 I discuss a recent L’Arche survey revealing the stress caused by this issue (Lukeman 2001)

²¹ Canada’s ethnic make-up has just 44% in the largest group of British origin, 25% French origin, 20% other European, 4% Indigenous, and 7% other. For perspective, the USA is 25% Roman Catholic, 61% Protestant (incl. Anglicans), 2% Jewish and 12% other/non religious, and US ethnic make-up is 84% white (includes Hispanic), and 12% Black, 1% Chinese, 1% Indigenous, and 2% other (Goldstone 2000: 600)

²² For more information, contact the Nouwen Foundation, Richmond Hill, ON.

²³ There have also been particular efforts by individual communities; Ottawa has a special community mandate for which all members pledge responsibility (Amato 1999); Calgary has a document dedicated to clarifying the LTA vocation (Favaro 2000).

²⁴ This reflects the brevity and clarity endorsed by Sumarah who suggested that the four key dimensions of L’Arche were: the value of people with disabilities, mutuality, community and spirituality (1987:165).

²⁵ There are a small number of rural communities remaining in Canada, including one in Cape Breton, N.S., which is part of this ethnography.

²⁶ Turnover was also found to be inversely related to age and tenure, positively related to education, but was surprisingly neutral for gender (Braddock and Mitchell 1992:20-21).

²⁷ Includes both absolute turnover and turnover variability (i.e. unpredictable degree of turnover).

²⁸ L’Arche hopes that “the gifts of each person are nurtured and called forth” (Downey 1986:9) (see also Vanier 1998:27).

5.0 Assistants' Initial Motives and Expectations

5.1 Introduction

“Of course there are many, many reasons to come to L’Arche but I am increasingly convinced that most people come here searching for greater meaning or purpose in their lives. You listen to new assistants and you get the sense that they were not finding that elsewhere – or at least not enough to satisfy them. Sometimes we joke that people come here when they’re tired of shopping.”
(MacMillan 2001)

In this chapter I present my analysis of why people say that they wanted to live and work in L’Arche, and what it meant to them to make that choice. It certainly seems worthwhile to examine these people’s motives for working in L’Arche given that the conditions of the role, at least on the surface, involve an abdication of individual freedom and leisure time greater than most occupations, as well as minimal financial rewards. “We live in an era when all accounts of motives have become subject to doubt ... [and] suspicion,” wrote Wuthnow for his research on altruism and compassion (1991:62). Any account can conceal even as it reveals so we are taught that “motives are not always what they seem.” (Ibid:62) Beyond the hardships, however, being a L’Arche assistant is also a meaningful, rewarding and potentially transformative experience and candidates are at least partially aware of this when choosing to work there. Echoing MacMillan’s thoughts above, one new assistant, Kayley said: “I’ve always been searching for something to do that is meaningful, satisfying and helping people. It’s very important for me to help people. To make people feel valued and understood.”

Once people have worked as assistants in L'Arche, they experience and observe in others the growth potential of the role, as I discuss further in chapters 6 and 7. Before that, however, they can only have a partial sense of the lifestyle or the growth it offers. So what *did* they anticipate beforehand that moved them past their uncertainties? Does their anticipation affect what kind of caring work is possible in that organization? While individual combinations of expectations were varied, common themes included a range of personal interests such as fulfillment, belonging, personal growth and adventure, as well as pragmatic concerns like job skills, learning a language, and income. Most assistants also 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. Assistants' backgrounds affect how they think of their social and moral responsibility as good citizens and this effectively weaves their personal and social interests together.

The analysis for this chapter is primarily based on assistants' self-narratives from interviews, a pre-arrival questionnaire I ran with twelve new assistants at L'Arche Daybreak, and participant observation in the communities. It has been argued that self-narratives can not establish who someone "really is" or their "true motives" since the narrator can strategically edit and revise the facts in order to produce certain effects, such as an optimal self-representation (Wikan 1995). What interviewees choose to report is also influenced by the interviewer's questions, hypotheses, and personality (See Chapter 2). These problems notwithstanding, self-narratives are important sources of information because they are stories we tell about who we are and who we want to be (Sartre 1964). As such, quite aside from their value as objective truths, they contain symbols reflecting the narrator's values, beliefs, and aspirations (J. Bruner 1986:15).

5.1.1 Relevance and Outline

There are three reasons to include an extended discussion of assistants' motives and expectations of L'Arche in this thesis. First, a person's reasons for caring for others affect how he or she will care for them (i.e. the quality of care). One researcher of caring and compassion argued that: "The very act of caring may be sabotaged by not having the right motives." (Wuthnow 1991:63). Other researchers attest to how motives, attitude and commitment all affect the quality of care possible (C. Taylor 1994:183, Phillips and Benner 1994, Steinhoffsmith 1999), and I demonstrated in Chapter 3 the deleterious effect on the quality of caregiving provided when caregivers and professionals are not driven fundamentally by caring motives (Trent 1994, Day 1981, Enns 1999, Hingsburger 2001a).

Second, a motives assessment establishes a baseline understanding of what people wanted to accomplish or to receive by becoming an assistant. Knowing what assistants initially perceived and wanted helps to gauge what effect living at L'Arche eventually has on them¹.

Third, L'Arche requested help to understand why people go there, why they leave and what might help assistants stay longer. My analysis suggests that assistants' initial hopes and expectations influence their *long-term* satisfaction with the community and the work. Below, I show that assistants enter hoping to make a difference in the world; something that many envision on a macro scale. In the short-term L'Arche effectively redirects those hopes towards small but important ways to make a difference on a micro level through the daily practice of caregiving.² In the long-run, however, many assistants report a resurgence of their desire to make a difference on a broader scale. When there are no obvious ways to enact that desire within the community (because of the more urgent daily care needs), some assistants become unsettled and dissatisfied.

I begin with long-term assistants' common beliefs about what makes a good assistant and thus whom they would like to recruit³. I show how aspects of their backgrounds make them open

to service-oriented work as well as influence what they consider to be fulfilling activities. Using examples, I illustrate the moral tension regarding living one's values that drew many people to L'Arche. Finally, I discuss how these people often incorporate personal and altruistic or social service goals in their sense of meaningful fulfillment. Overall, the choice to undertake the role of assistant was connected with fairly ordinary human desires, concerns, projects, and histories.

5.2 Internal L'Arche perspective

5.2.1 Barriers to internal analytical clarity on the issues

It is not uncommon for non-profit organizations to lack the financial resources or skills to perform effective research on questions such as recruiting and staff satisfaction. Here however, there are also L'Arche-specific reasons which have inhibited research and record-keeping. Referring specifically to organizational structure, while all communities are connected through the L'Arche mission and regional and national directors, the communities are still relatively independent in many ways. Recruiting and most staff-related concerns have been handled locally and there has been little sharing of information about the composition of assistant bodies, standard role descriptions, or recruiting criteria and best practices. Co-ordinated efforts have thus been rarely initiated and difficult to execute since most communities are too small to afford a professional researcher.

Particular L'Arche cultural beliefs as a faith community have also acted as barriers. Their language, and ways of thinking about assistants in the past, have tended towards notions of vocation or calling more than advertising or recruiting. A cultural belief among some assistants was that those who are meant to be assistants will be called there. One's *vocation* can be discerned through prayer and practice; for Christians, that means God is calling you to a certain line or place of work. A person can be called to something in order to give and use his gifts, or

special talents, but can also be called to a place because God wants that person to receive something of grace: a timely lesson, relationship, or message for example.⁴

In the past, this cultural belief in vocational call had two significant impacts relevant to L'Arche's recruiting and research of assistants' motives. First, the corollary to the belief that the right people will be called to L'Arche is that no recruiting is necessary. This belief might even risk attracting people who would not flourish in or be right for the role. The thoughts of Michel, an older LTA, are representative of this point of view. He shared stories of the sense of grace he discovered in the work and lifestyle of an assistant when he came to L'Arche in his late thirties. Asked how he thought that L'Arche could articulate the kind of rich experience he had to help recruit good assistants, Michel explained in his characteristically quiet, light-hearted manner, his reticence about recruiting:

A vocation must come from inside of you. Then you will be able to sit well with the hard times too. I do not think that we should be out looking for assistants like that—let them come to us when they are ready! (*laughs*) Ah, but I suppose I am revealing my idealism.

Although Michel's point about the sustaining power of feeling called to a vocation is important, the issue of assistant shortages remains.⁵ The residual effect of the vocational ideal was that for years little formal effort was directed towards understanding the issue of declining numbers of applicants. This is changing now, however, for most assistants. The leadership has recognized that people can not feel called to the vocation of L'Arche assistant if they have not even heard of the organization (MacMillan 2001).

The second salient effect of the spiritual, vocational ideal is how assistants describe their reasons for working there, especially once they are already assistants. I found that when people explained why they went to L'Arche, they typically began emphasizing spiritual reasons or a sense of call as opposed to personal interest factors. Two survey responses provide examples: "To follow God's path. To live a different lifestyle of simplicity and good morals" and "A calling in

the name of my faith. A desire to love and serve in a community for the rejected”⁶ (Lukeman 2001). This is not surprising given that they had by that point experienced the community’s rich spirituality. But with further discussion, most assistants said that the role was very different from what they had originally imagined, which implies that the sense of spiritual calling emerged *after*, not before, arriving. In addition, as our discussions unfolded, virtually all interviewees indicated that, in fact, many circumstantial and personal interest factors contributed to their initial motivation to work in L’Arche or somewhere similar.

Such biases need to be accounted for in the interpretation of peoples’ responses and narratives. This has been difficult for internal researchers to do given their implication in those same beliefs and positions. In most L’Arche studies, assistants’ answers conflated their reasons for going to L’Arche with the reasons for staying. In addition, the question formats did not provide a way to assess the relative importance of their motives.

Analysis of motives is further complicated by the dual roles of caregiver and community member that are involved. Some assistants focus mainly on just one of these roles in choosing L’Arche. Francois, a former seminarian, had left his role as assistant the year before I interviewed him. He liked his experience overall, but was disappointed that L’Arche was not as spiritually involved or prayerful as he had anticipated. He had been drawn to L’Arche in order to experience living out the gospel values of solidarity and *relations* with “the poor” but admitted that he had not fully considered the substantial *labour* of care that this commitment entails. Others, such as students from social work programs, who went to L’Arche for the caregiving aspects, were sometimes surprised by the spirituality and intense interpersonal environment in a faith community. Once people understand L’Arche, their goals often shift to include new possibilities.

5.2.2 Whom L'Arche wants, and whom they get

In this section, I introduce a basic sense of whom the L'Arche LTAs would *ideally* like to hire as assistants based on their experience with what kind of person does well in the role of caregiver and community member. As noted in Chapter 4, the centrality of valuing diversity in the L'Arche mission makes some LTAs feel awkward placing parameters around whom to hire. In addition, history has shown them that a *wide variety* of people have become excellent assistants and community members⁷. The depth of what people live in the daily practice of care seems to be strong enough to incorporate, and temper, many differences. Trevor, a former community leader noted that most LTAs feel that many kinds of people can flourish in L'Arche: "We are learning to trust in the power of the experience itself to have a profound effect on people, and sometimes, to call them to L'Arche for longer."

Although no criteria for assistants have been formalized across all Canadian communities, I have developed a vernacular description of the common traits they seek. As discussed in Chapter 4, the communities ideally want to find people who can be competent and satisfied in both the roles of caregiver and community member. The first essential requirement is for the candidate to be willing to live in a L'Arche home where they are fully engaged in daily life, caregiving, home maintenance, and developing relations with core members and assistants. Many people who are volunteers, employees, board members and friends of L'Arche develop close relationships there and contribute enormously to the communities without living in one of the homes. Still, most of them would agree that living in the homes is an experience that confers singular insights to those who do. While there has been some internal debate regarding how many years assistants should live in, and many LTAs eventually move into separate quarters,⁸ it continues to be a requirement of new assistants for at least their first few years.

The other basic criteria for being an assistant include: being legally bondable, possessing a work visa, physical capability of transferring people as needed, competence in the local language, good mental health, and the maturity and capacity to learn to handle medications, hygiene routines and basic health care decisions for the people with disabilities with whom they will live. Other traits that are considered desirable are having a driver's license and the energy to handle long days and a full, diverse, often unpredictable schedule. Particular attention is also now being paid to people's past leadership experience and potential to develop as leaders.

There are several other less tangible traits that the LTAs are looking for in assistants, some of which are difficult to assess without actually seeing people in the role. To be clear, these profiles are products of my research and are not official L'Arche policy. The characteristic I heard most often when I asked people to describe what makes a good assistant was a general *openness* to difference. Among the different sorts of openness that assistants stipulated, by far the most important was for candidates to be open to people with intellectual disabilities and to mutual relationships with them. Secondly, they suggested that new assistants need to be open to the L'Arche model of caregiving as a mutual and relational practice. Finally, assistants are ideally open to, and supportive of, the spiritual lives of others in the community even though they are free to exercise their own personal beliefs. Assistants should also be compassionate and prepared to make a strong commitment of time and energy to the community, including the accommodation of others' needs and beliefs (Vanier 1989:73).

As an assistant and participant observer, I have developed one final theory about what helps an assistant to do well in L'Arche. Those who thrive seem to manifest a healthy, sustainable balance between being *centred* and *striving*, or *being* and *becoming*. They want to explore, grow, and try new things and this helps them adapt to the radical approach to difference, disability and caregiving that L'Arche requires of them. That is often the easy part for the idealistic young

people who are the majority of new assistants. But there are also many times when not much changes and, on the surface, the house routine can start to feel repetitive or even boring. At this point assistants need the capacity to be grounded in the present and content with what is given. An assistant needs to be able to find the beauty in “the little things,” as they say in L’Arche, such as a spontaneous smile or a small initiative by a core member, or simply time spent together.

This capacity to be centred, or “just be,” is less common among young people and yet it is essential to their ability to stay motivated as an assistant. In Chapter 7 I elaborate on how L’Arche intentionally cultivates this in assistants as part of the process of nurturing relationships across difference and disability. Sam, who was 27 and had been in L’Arche almost three years at the time of our interview, is one example of this process. He explained that he naturally revelled in both the highs and lows, or intense predicaments of life as an assistant, but that he found the in-between times more difficult to appreciate: “It has taken time and experience ... and prayer too, for me to learn to understand the gifts that the quiet, routine times in L’Arche offer – and to be thankful for them too. I have tried to watch and listen to LTAs whom I respect, and that’s helped me to learn how important it is to use those simple times to really centre myself ... and I try to be very present, very open to whatever comes up.”

I asked several interviewees whether they thought there were bad reasons for coming to L’Arche, or reasons that they were cautious of. As noted, assistants are reluctant to rule anyone out in general terms, given what they believe about diversity and the power of the experience to redirect people. Angie, an insightful, seasoned LTA who has served both in the homes and in various leadership positions, adds that even those people who come with little understanding of what L’Arche is, or who just wanted to travel, can contribute much to the community: “Things can get a little tired with the same old group, so people who just come for a short while bring a

vital fresh energy to the community; they shake things up and keep us real. It can be very good for everyone, including the core members, provided their departure is handled well.”

Only one motive was cited as sometimes undesirable. Some LTAs cautiously allowed that when people come *primarily* because they feel lonely, their great need to be loved tends to demand significant energy from the other members of the house. As Catherine, an LTA put it, “When their needs are greater than what they are able to give to the house, then that makes things hard. It is like they are looking for a place to be cared for, rather than to give care.” Beyond the practical burden this can create, there are moral conflicts as well. Although our society accepts that acts of kindness often end up conferring benefit on the giver⁹, we disapprove morally when someone’s main goal seems to be the benefit, rather than the service (Wuthnow 1991:55, 96-7).

Vanier writes that when giving comes from a place of poverty, not from love, it is psychologically and emotionally demanding of others (1989:67). As discussed in Chapter Four, however, Vanier also acknowledges the universal experience of loneliness, and urges people to be honest about it. While this seems like a paradox, it is more a question of degree. Karina, another LTA explains: “While living with a very needy assistant can be overwhelming, I do question the honesty of assistants who claim that loneliness is not at least somewhere at the root of compelling us towards community and relationships.”

Whom L’Arche gets

While there are only minimal records of the composition of the assistant body in L’Arche, the leadership is beginning to address this paucity as they move towards national co-ordination of certain policies. In 2001 L’Arche Canada conducted a lengthy survey, the primary aims of which were to assess and compare the various financial and benefit arrangements across the country (zone) and to ask LTAs about their concerns for the future (Lukeman 2001)¹⁰. Certain demographic data were also gathered and I will outline those aspects relevant to the discussion of

motives and recruiting. The survey included information on the 327 assistants living in the 20 communities which responded to the survey (out of 25 in Canada).

The average age of new assistants when they start is 21 and the main age range is from 18-35, although a small number of older people also join the communities. Excluding summer interns, fully half of the assistants in Canada are under 30 years of age, 33% are 30-50 years old, and 17% of assistants are over the age of 50. The average length of time that assistants work in a community is 1.5 years (again, excluding interns) but this figure does not tell the whole story. While about half of assistants stay less than two years, the other half make much longer commitments: they are split equally between those with 3-9 years of service and those who have worked there for over 10 years.

Of note, men are well-represented in L'Arche in comparison with mainstream direct caregiving organizations (Braddock et al 1992), constituting almost a third of total assistants (31%). Among assistants with less than two years of service, roughly one quarter are men (26%). This is partially due to the communities' desire to provide same-sex care for personal hygiene routines as much as possible. No data has been collected on ethnicity, faith or social class.

5.2.3 L'Arche research on why people want to live and work there

In Canada, L'Arche does not have substantial national research findings on recruiting and retaining staff¹. A few questionnaires were done but limited to one community or region. Although L'Arche conducted two national surveys containing salient recruiting questions, the data was only partially analyzed due to their time and resource constraints. Still, it is useful to review this work.

The 2001 survey noted above also had an open-ended question asking LTAs: "What brought you to L'Arche?" This is the most recent internal research on this question (Lukeman 2001). People mentioned a number of topics in their answers ranging from how they heard about

L'Arche (book, radio, friend) to their practical expectations and philosophical hopes; responses averaged three to four motives each. This is consistent with other research on compassion which found that people usually give many reasons for why they volunteer or do good for others (Wuthnow 1991:59-62). Wuthnow also found that most respondents were conscious of how critically we evaluate such accounts in our society for an "agenda" or self-interest and thus carefully considered the types and order of reasons they gave (Wuthnow 1991:59-62).

The LTAs who analysed the anonymous survey data grouped the many assorted expressions of motives into ten themes. The comments which they classed as "community life" were by far the most popular, capturing almost half of respondents. Other categories that they created which were mentioned by more than 20% of respondents include "spiritual journey", "people with disability", and "Jean Vanier books" (see appendix 5.1 for key findings).

I have no quarrel with those findings nor with findings in the other surveys that I review below, aside from my earlier cautions on how they are interpreted. There are problems with these internal studies, however. They do not provide the leadership with a clear sense of how these factors operate in people's lives or how they are inter-connected and prioritized for them. Nor do these surveys really add to the leadership's existing, intuitive understanding of the situation and how to improve it. I will attempt to do that with the ethnographic research below, where I also incorporate some of the raw data from this survey.

I reviewed two other L'Arche survey reports done in Canada since 1992 (but not their raw data). The analysts of the 1992 national study indicated their concern for community life, given that half of STAs did not designate "the L'Arche emphasis on community" as a motive for working in L'Arche (Davis 1995). A sense of calling or vocation was reported as a "major factor" for assistants, as were the spirituality and philosophy of L'Arche.

An Ontario questionnaire for STAs was administered, asking what was interesting about L'Arche, how they heard about it, and what helped people to come (Zinyk and Egan 2000). Again, many assistants pointed to multiple reasons with the top four reasons each garnering 20% support: to get experience with people with disabilities, curiosity about the lifestyle, spirituality, and philosophy. Roughly 10% found community, self-knowledge/renewal, or life change important. Nevertheless, with no ranking of factors and broad, polysemous categories like "spirituality," it is difficult from this report to generate a better sense of what it means for people to work in L'Arche (See appendix 5.1).

In section 5.2 I have presented what traits and skills the L'Arche leadership believe commonly make for good assistants, as well as their latitude in welcoming people with diverse intentions. The demographic profiles of the assistant body as a whole provide an initial outline of the group which I build on with more detailed individual profiles of various assistants in the following sections. My analysis of the LTAs' interpretive challenges with research on motives alerted me to these same ambiguities and contradictions in my own data. Below, I use my primary research to enhance the present understanding of motives and how people came to have them. In order to do this I expand on how those known factors are connected and prioritized in individual lives. I also situate those motives in other research.

5.3 Background and circumstance

In addition to analyzing assistants' narratives for common themes about why they want to work in L'Arche, it is important to examine how those dimensions work together. In this section I outline the most common motivations that people discussed, related to their backgrounds and their circumstances at the time they chose to go to L'Arche. While simple circumstance may seem trivial, it often provided an important impetus for people to change the direction of their lives or a short-term opportunity to do something they perceived as unusual, such as L'Arche. Shared

elements of their backgrounds are important determinants of what types of activities and work that they consider to be fulfilling.

A broader framework is provided in Wuthnow's research on the language Americans use to describe their motives for being compassionate and caring (1991). He discovered four primary traditions were used: biblical, utilitarian, therapeutic, and fulfillment (Ibid:58). I found significant commonality between my and Wuthnow's findings around motives among L'Arche assistants in Canada, as I outline throughout this chapter; however, I also want to highlight three distinctions in my ethnography. I attend more closely to how personal history, and practical needs factor into assistants' motives to serve and to work in L'Arche.

Second, I found that, even though assistants to some extent employed all of the reasons Wuthnow identified, two of the categories dominated. Not surprisingly, biblical or religious reasons were common, although, as with many of Wuthnow's interviewees, most of these assistants avoided traditional Christian charitable language of sacrifice (1991:105). Assistants felt that it was an anachronistic and unhealthy way to view altruistic work that was, in fact, often quite rewarding and growthful for the giver. The other common narrative theme for assistants was a sub-theme of what Wuthnow called the fulfillment genre. It consisted of people who were not shy to admit that service, volunteering, or social justice work involves sacrifice and hardship, and that it could also be very fulfilling for them (Ibid:106). But the personal fulfillment and growth benefits were inseparable from the fact that assistants (and Wuthnow's interviewees) sought them at least partly in order to support, or further, their service goals. This dual commitment provides clues to those aspects of morality and fulfillment that I discuss in sections 5.4 and 5.5 which follow.

The third distinct theme that should be evident in the cases that follow is that in L'Arche, there is a difference between assistants' official and unofficial ways of talking about sacrifice,

fulfillment, and their own contribution to L'Arche. The official discourse, or what Arbuckle calls the public myth about sacrifice at L'Arche, is best reflected in a phrase that is used regularly there¹²: *People come here to give, but in the end, they receive more than they give*. The intention of this official maxim, derived from Vanier's emphasis on the gifts of the poor, is to name and enhance assistants' appreciation of core members' gifts. It is also intended to downplay the assistants' sacrifice by playing up the reciprocity in giving, or the utilitarian benefits. While the public myth is not untrue, it is not the whole story.

The unofficial discourse of daily life in the homes, however, reveals another version of reality. Informal sharing of stories acts as an outlet for some of the stress of this lifestyle. In this discourse, a more common refrain is to describe the work as *hard but good*; something assistants use seriously but also often utter jokingly, tongue in cheek. 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.

Is it wrong to talk about the sacrifice or hardships involved in such work? Prominent researchers firmly state that some use of the language of sacrifice is vital because it reminds us that the giver must indeed make real sacrifices if the help is to be more than token¹³ (Wuthnow 1991:103-5; Bellah 1985:33, 48, 285). Although assistants acknowledge some degree of hardship and sacrifice in this work, the L'Arche ideology encourages them to transform their perspective: rather than maintaining a negative outlook, hardship can be seen as meaningful by pointing to the lessons that can emerge from it.

5.3.1 Circumstance: opportunity and impetus

Assistants' stories often contain references to a range of ordinary circumstances in their lives just prior to deciding to work in L'Arche. It seems that sometimes even a small change in those circumstances can create an opportunity for them to change directions or take stock of their options. Sometimes the change in circumstances provided the necessary impetus or catalyst for them to act on a long-held desire. Initially, I overlooked the significance of these ordinary circumstances since the interviewees often presented them casually as part of the landscape, and thus did not spend much time discussing them. Later while reading the transcripts, however, it became clear to me the essential role that these ordinary circumstances, such as losing a job or meeting a former assistant, played in the creation of the space for change.

Deon, for example, was a university student interested in social justice issues, and in search of a summer job, but not sure what he was going to do. One night he was having dinner at a friend's home, and her mother was trying to convince her to go to L'Arche: "She never did go, but I got convinced [to go] instead!"

Wikan insists that chance events are as important in defining who a person is as those events that one plans. She argues that we all live in "a world of urgency and necessity," responding to things that are outside of our control, more so than a world of intention and order (1995:266). Below, I outline various examples of elements of chance or circumstance which create situations of "urgency and necessity" for people, providing them either with the impetus or opportunity to choose to work in L'Arche.

Before going to L'Arche, Vicky recalls that she was working happily as a professional in applied science, doing well and moving up the corporate ladder. She was involved with her church and happened to get a last-minute spot on a spiritual retreat that Jean Vanier was leading. What she heard there planted a seed in her heart that eventually grew into a desire to work in L'Arche: "It was a pivotal moment for me because Vanier's retreat was about fruitfulness and

[doing] work that was life-giving. Basically his message was saying [that what was of value was] the opposite of productivity and in the mid-80's productivity was *the* culture in my profession, so it really hit me as unusual." Nevertheless, working in L'Arche can be a big decision for anyone and leaving your job to do it is an even bigger decision. Although she was intrigued to learn more, it took more than one catalyst to move Vicky to act. She only chose to go to L'Arche when other changes at work and needing new living arrangements opened up a space where she felt that the time was right for her.

Changes in circumstances work in conjunction with other factors, such as moral, spiritual or interpersonal projects and desires, to become a motivation for changing one's direction, job, or lifestyle. In most of the self-narratives that I heard, each individual's decision was the product of complex, interwoven desires and circumstances. Kayley's story is particularly layered but not unlike many other assistants who come to L'Arche in their early twenties when they are experiencing many changes in perspective and responsibility. Kayley, who had only been at L'Arche two months when I met her, was a soft-spoken, gentle young woman. She had finished university approximately two years earlier. I found her incisive and reflexive but her principle self-description was as a good listener: "I like to make people feel really heard. I didn't feel too listened to at home, so I guess I know how much people need that, and like it." She explained her decision to work in L'Arche as the unlikely result of a confluence of a number of simultaneous changes in circumstance, personal developments and desires.

She was dissatisfied with her full-time job in a Christian camp and then was temporarily laid off from it during the down-season. While considering what to do while temporarily laid-off, Kayley had an unfamiliar "restless feeling" and desire to try something "unusual and different." "But," she said, "I'm not the type of person to move away, or do anything too strange - it's just not me." She knew of L'Arche because the camp had hosted a group of people with intellectual

disabilities for a week and among them were people from L'Arche. She enjoyed working with them and felt drawn to do something more with people with intellectual disabilities. The spiritual dimension of L'Arche was also appealing to her. Her friends and family, however, were sceptical of it and strongly discouraged her.

In the end, in spite of their protests, she decided to do a short internship at L'Arche. In addition to the aforementioned reasons, she said, "I figured it was a chance to travel and get rid of my restlessness." She assured others that she would find "a good job" in a few months. At the time of our interview she said she continued to be uncertain about whether she had done the right thing. This is hardly surprising given the sheer number of issues she was trying to sort through.

At other times, people noted circumstances that were more singular; for example, those people who were finished university or high school and wanted a chance to travel, learn English or French, or learn about another culture before pursuing a career.

My pre-arrival survey of summer interns also revealed a variety of practical needs. Mia, a psychology major, wrote, "This gives me practical experience in the area I want to specialize in, which is very hard to get into." Sareena, an undergraduate, indicated, "I needed a summer job and I wanted to do something where I was useful and helping." Leore included a practical, personal benefit as well as a help-oriented one: "I want counselling experience related to my degree, and to help improve the quality of life for people with special needs." Several people, such as Noel, came to L'Arche for an experience of a less structured faith community life in order to help them figure out if they were well-suited to a seminary or a more formal religious order.

Matthew's narrative combines several of these themes. He had worked for several years in a field that he loved but a growing feeling of fatigue led him to consider taking a year off to work on a farming property, something he had always wanted to do. A rugby injury set-back the plan and then "out of the blue," a friend suggested that they travel to L'Arche in Canada, which

also had a farm. He had never heard of L'Arche, and had no experience with people with intellectual disabilities. He quickly shifted, however, to feeling that L'Arche could fit with his other desires, such as working outdoors, and exploring the possibility of a vocation in the priesthood. There were other important factors in his decision too, as I discuss below.

5.3.2 Personal history and predispositions

The assistants came from a variety of backgrounds but they shared some formative experiences that contributed to their choice to work in L'Arche. From their self-narratives, I ascertained three common themes related to their backgrounds: religious family upbringing or a developing spirituality, a helping orientation developed in family or school, and experience with, or interest in, people with intellectual disabilities through jobs, school, or their extended families. Many assistants spoke of all three elements being present in their lives, although others shared just one or two. In addition, the degree of importance of the elements varied for each person. These background factors contributed to their pre-disposed choice of an experience such as L'Arche.

Humanitarian, helping orientation

Most assistants included some form of humanitarian or helping ideals as part of their reasons for working in L'Arche; for several people it was the only one of the three aforementioned themes that they brought up. This motive needs to be highlighted and elaborated on because it was culturally underplayed in L'Arche where there is an aim to create a greater recognition of the balance and reciprocal benefits in the caregiving, or helping, relationship.

Roughly half of the assistants discuss, in their self-narratives, having been involved in service or helping activities as a given; it is "just what I do," they say, because it seems right. Several assistants explained in interviews that their choice of livelihood was between a set of possibilities which all fell within a social responsibility or helping framework. When I asked Sam, a three-year assistant with a university physics degree why he was an assistant instead of

working in a lab, he explained, "I guess this is just what I do. I like to be part of things that are good for people. When I think about my choices ... sure, some of those jobs are attractive too, but I have this desire to be accountable to myself which means I don't feel as good when my life is just for me somehow."

This theme of social responsibility was a natural, or intrinsic, part of who they were, and was also present with most board members and administrative staff whom I interviewed as well. Camilla, for example, vividly recalls her father's generosity when they grew up. He would give away the family clothes to poor neighbours and regularly overlook the overdue accounts of local people with his store when he knew they were broke. When asked to articulate why she has been involved in so many volunteer roles (including being on the L'Arche board for years) in addition to her career as a professor, she seemed uncomfortable with thinking about it in terms of reasons or motives: "I guess it just rubbed off on me somehow." When I asked her to comment on why her siblings did not have the same interest or track record of giving their time, she simply ascribed that to personality differences: "That's just how I am!" Sara, who initially lived as an assistant and now works in one community's office as an administrative employee, told me, "I have one purpose in my life and that is to make a difference in the world." During our interview, she explained that she accepted the lower salary and fewer formal training opportunities at L'Arche because she felt good about the meaning and purpose of her work there. Most board members whom I interviewed also seemed deeply committed to social responsibility and service. Most of them are professionals in fields that have little to do with disability or even social service. Despite this, their narratives are full of other types of volunteering or social justice activities that are described as part of their normal flow of life and civic responsibility.

Wuthnow suggested a theory regarding explanations like those offered by Sam, Kayley, Camilla, and Sara which suggest that doing good is "just who I am" or something that "I just

believe is good to do.” Wuthnow argues that these are narrative techniques which people employ in order to “naturalize” or “subjectivize” their motives (1991:76, 70-2). Naturalizing is a technique used to downplay one’s free will and thus avoid the stigma of appearing to be seeking credit for being altruistic (Ibid:76). Subjectivizing is another strategy through which people try to avoid judgement or suspicion for their good acts by constructing their motives as simply personal taste, and thus beyond criticism (Ibid:70-6). In order to explain why people would want to deflect attention from any altruistic involvement, Wuthnow returns to his assertion that because “caring is in some ways deviant” it “makes us feel compelled to give an account of ourselves.” (1991:72). In addition, he suggests, “The issue arises, I suspect, because we want to take some credit for our actions, but there is also a stigma against taking too much credit for them.” (Ibid:76). It is of course also possible, that people simply find it hard to put words around their complex motives and so to say “it is who I am” is just plain easier.

Among newer assistants, there are many who are motivated almost exclusively by the helping or social justice theme. As an example, a number of young Germans come to work at L’Arche in Canada each year with an official program for conscientious resisters, in lieu of Germany’s compulsory military duty. They tend to have strong social justice values and experience with voluntarism but often have neither experience with people with intellectual disabilities nor a prominent theme of faith in their self-narratives. L’Arche also welcomes a number of summer students and university co-op students for four month placements. Many of these students are broadly interested in social inequality and injustice and health issues. They are thus enrolled in social work, special education or other therapeutic programmes but have no prior experience with people with intellectual disabilities.

Religion

Religion, in some form, was a part of most assistants’ formative years, although the degree of involvement with their faith varied both in their families and as they began to make

their own choices about religion. For many, their experiences with religion were formative in predisposing them to the possible value of life in a spiritual community. One survey respondent explained how her desire to serve in L'Arche was connected with her faith: "My desire was to live community with the poor; those people who do not have a voice in our society. The simplicity and spirit of the Beatitudes attracted me. I also wanted to discover the gifts of the core members." (Lukeman 2001). In many cases however, it was a struggle with religion, or aspects of it, which led people to L'Arche in order to explore its alternative version of faith.

Theo was raised in "a very Catholic family" with several relatives living as religious people.¹⁴ Nevertheless, he remembered himself in his teens in school as rebellious on all counts, including how he related to religion. Below, I have selected parts from a much longer segment of our interview to give a flavour of his experience with religion. Although he struggled with Christianity and experimented with different faiths, he remained drawn to faith in some form.

Theo: "I was taking all kinds of different courses at university but I became very disillusioned with it.... I felt like it should have been more intense. Eventually I took religious studies, philosophy, sociology and stuff and really liked them.... I became vegetarian and very philosophical - actually I was probably a pain in the ass - I was quite argumentative. I upset my mom all the time, and I was very idealistic. My uncle was a Jesuit... we talked a lot about my questions, and he encouraged me to look around if I wasn't happy with Catholicism.... It wasn't that I had a problem with religion per se; I just didn't see how it could be fair to say that being Catholic was any more 'right' than any other choice. So I was looking for the commonality in many faith traditions to see what I could hold onto and believe in."

Pamela: *Why do you think the question of faith and beliefs was so important for you to sort out?*

Theo: "I don't know.... I thought about things a lot. Well, I had some close friends who didn't have any faith, but I could see that they were plainly good people and that challenged me. How could I think there was something wrong with them?"

Adrienne's self-narrative was also replete with struggles with Catholicism but for different reasons, and she worked them out in a different way. For her, it was a part of her identity

and, as such, she felt drawn to it and comfortable with it; yet there were aspects of religion that continually frustrated her. As she explained though, religion clearly shaped her views on social responsibility and the kind of vocation to which she felt called. Although she was raised as a Catholic, it was “mainly a Sundays thing,” until her high school Religious Studies teacher presented the class with a radically different perspective on religion. He was “anti-establishment and unconventional but still very passionate about Christianity” and taught them about issues the church was facing in Central America, with missionaries, with native people, and women.

“It was a very social justice perspective. He talked to us a lot about living with integrity- linking our beliefs and lifestyle – like, how I live affects people around me. And I started feeling like I wanted to choose a life that is somehow in harmony with other people in the world. This all got me involved in lots of activism stuff,” and it gave me “purpose and meaning. But it was also ... it was rebellious, it fit in I guess with where I was at developmentally as an adolescent to be *against* things.”

Adrienne continued with these interests at university, pursuing philosophy, peace and religious studies and becoming an activist. She struggled with finding a place in the Catholic church as a woman, however, and eventually gave it up altogether for a period. Subsequently, she decided to try again; living in L'Arche was part of that effort to find her way spiritually. When I asked Adrienne why she kept returning to the church, considering her concerns with it, she explained:

“I guess I still wanted a *place* to belong, to be connected with, and for me that had been the church so I guess I just didn't want to drop it.... I felt that I couldn't run away from being Catholic; for me, being Catholic was like being Italian. Like it was part of my identity, part of what formed me. It's familiar to me, it's a culture, its' a story. I think I was drawn to the familiarity and frustrated by it at the same time. But that's the same as being Italian for me – but you can't shake it- it's part of who I am. So I thought I'd choose to work within it. I thought about changing churches but others have their issues and inconsistencies too.”

Struggles with faith were, however, not ubiquitous among assistants. Seth's family, for example, were strong Catholics and he was “plunged into a sense of the value of a life of Christian service... [and the] values of sharing, and respecting others.” In his youth, along with

many of his friends, he was involved in a myriad of community service-oriented activities either through the Boy Scouts, his church or school. He explained that he never felt a need to question his faith, that it was connected with many positive experiences and friendships for him. He had even considered being involved in some sort of vocation directly related to the church.

Maria is a friendly, straightforward woman in her late twenties. She was raised in a small, Canadian coastal village with her parents, both teachers, and a vibrant extended family. Of religion she explained casually that Catholicism was “never something very deliberate for me, it was just sort of there.... I didn’t really question it much. We had a simple faith.” She participated in various clubs and volunteer activities that were faith-oriented.

Kayley was not raised in a formal religious tradition but developed an interest in it through friends during high school. One reason she was interested in L’Arche, as noted above, was its particular spirituality, a contrast to her denomination: “I picked up on something in the L’Arche message that sounded interesting. The whole idea of *suffering* in Christianity had been bugging me: Why do I have this crummy job, God? Why did you [God] put me here?” L’Arche, she said, seemed to offer some helpful explanation for the meaning or role of suffering.

Desire to work with people with intellectual disabilities

Given the nature of the actual labour of caregiving required of an assistant, it is not surprising that many people who went there had either experience or a desire to work and live with people with intellectual disabilities. A small number of assistants had someone disabled in their immediate or extended family. More often, however, their exposure, if any, had been in other circumstances. Seth, for example, first became interested when he was asked to welcome and assist a disabled boy who joined his Scouts troop. Seth found it fun and rewarding to support the boy and get to know him and was struck by how different the boy’s opportunities were from his peers’. This experience eventually led Seth to a degree in psychology and special education; he eventually became a professor in the field. In his L’Arche community, Seth is a dynamic,

sociable figure and clearly delights in his joking, good-humoured relationships with core members.

Maria's enduring interest from high school onwards was directed toward people with learning and intellectual disabilities. Although she had a disabled cousin, she says that her interest developed by chance after she had read a novel about a disabled person. She had read much more on the subject through her teen years, hoping to work in special education: "I was struck by that idea of being able to...just in very, very simple ways, to help let what [good] was inside of a person come out." In high school, she worked during the summers as a daily accompanier with an autistic boy and his family. She was intrigued about what made him happy or scared and she enjoyed growing comfortable with him, and having fun. Maria discovered that she had something good to give and connected with his parents, who appreciated her energy and ease with their son. She worked in other mainstream agencies later, but felt uncomfortable with the social distance they prescribed between client and staff. Maria explained that L'Arche was attractive because its philosophy resonated with her own emerging sense of how to relate to people with intellectual disabilities.

Several survey respondents also noted an interest in people with intellectual disabilities, in assisting them, and getting to know them. Two examples are insightful: "I worked in an institution and did not agree with some ways people were treated. Drawn to people with intellectual disabilities. Vanier's words resonated with something inside me," and "Desiring a better life for people in institutions; enjoyment and delight in people with intellectual disabilities; desire for community; personal spiritual journey; reading Vanier book" (Lukeman 2001).

Benjamin worked from age 15 to 18 as a counsellor and director in a summer camp. Each year for a week or two, the camp would host several children with intellectual disabilities and integrate them into the activities of the other children. He recalls feeling very comfortable with

them, unlike several of the other counsellors. He enjoyed their spontaneity and joy and was moved by how much they seemed to appreciate the opportunity to be supported in outdoor activities. Benjamin had a deep sense of well-being and enjoyment when working with people with disabilities. This contrasted with his later work throughout university with juvenile delinquents which did not leave him energized or motivated.

In section 5.3, I have shown how particular aspects of assistant's backgrounds commonly played a formative role in choosing to work in L'Arche. Background is only part of the answer, however, and in the following section I discuss the question of authenticity as a motive for working in L'Arche.

5.4 Authenticity and resolving moral tension

"All the beautiful sentiments in the world weigh less than a single lovely action."
(James Russell Lowell)

The theme of authenticity emerged regularly in assistants' stories about why they went to L'Arche. Although they had some difficulty in articulating it, what came through was that at a certain point they experienced a sense of moral tension over what they were living; they wanted to resolve this tension by undertaking some kind of significant action. The degree of tension ranged from a creeping but quiet realization, to a rapid, heightened feeling of inauthenticity. Various assistants described an unsettled feeling that arose after reflecting on what they wanted from life and finding that the answers did not align with what they were actually doing. That feeling of moral misalignment sometimes continued for years before it was strong enough to push the person to make actual changes. While modernism now privileges moral subjectivism and relativism (C. Taylor 1989:16), authenticity and morality were originally connected with *reason*, which allowed them to be compared and evaluated (Ibid:19).

In what novelist T.S. Eliot (1950) referred to as “the endless struggle to think well of ourselves,” and to have others affirm us in that effort, we can employ discursive strategies but sometimes *actions* are necessary to convincingly achieve the desired effect (Wikan 1995:266). As novelist Timothy Findley put it in the context of soldiers’ ethics in *The Wars* (1977): “We are known only in what we do.” If one’s identity includes being a caring person but one’s life does not include much actual caring, this eventually creates a drive to correct that paucity through action. Theo’s story is representative of this moral dilemma or crossroads. After three years of studying philosophy at university, Theo reached a point where “just talking” about issues of justice, right livelihood, and spirituality was not enough. “[I wanted] to live something real. To do it and not just read or talk about it,” he said. Survey respondents expressed similar feelings: “I was at a place in my life that I wanted the gospel to be lived out, as opposed to talked about, in my life.” “L’Arche was a place to live what I believed” (Lukeman 2001).

It appeared to me that, in choosing to become part of the work that they had been merely talking about, they were also acting to maintain the integrity of their self-image. The action was and is an essential *embodiment* of their values. Their actions helped to craft and construct the parameters of who they are (to themselves) and also who they can claim to be (to others).

Michel, now in his late forties, described coming to a point of tension connected to religion. He was a civil servant before becoming an assistant at L’Arche. He grew up in the country, loved being outdoors and physical work but he eventually pursued a practical finance career in the city. Michel worked well for years, but felt increasingly discontent: “I was stagnating at work and didn’t feel fulfilled; papers and more papers don’t make you happy.” He tried many ways to alleviate the discontent, including therapy, moving out of the family home, exercise, volunteering, and new relationships. While these changes helped, spiritual and moral questions continued to pull at him. Eventually Michel met a therapist who introduced him to an

alternative to the rules-oriented religion of his youth. To his surprise, he found these conversations peaceful and a relief from his daily routine. Michel grew certain that he wanted to find work that was more closely aligned with his spiritual yearnings. That was how he began to volunteer for L'Arche. The desire for change seems to emerge from a feeling of inauthenticity. He felt that his work and lifestyle did not reflect his beliefs or nurture him to grow as a person.

"One must live the way one thinks, or end up thinking the way one has lived."
(P. Bourget)

The stories of two talented women who faced similar situations are instructive although because they were at different stages of moral-spiritual tension, they responded differently. Karina and Judi both had a religious upbringing in closely-knit families and spent high school and university involved in various social-service activities. They are both self-described over-achievers with boundless energy. Both also found themselves accepted for graduate studies at prestigious American universities. Karina had spent almost two years in a European L'Arche community. While graduate school had been a long-held desire, Karina could not shake the feeling that she was being called back to L'Arche; she felt that further formation in L'Arche would strengthen her values. This would help her later to stay her path and resist what she perceived as the competition and materialism in law school culture. As such, she resolved to work in a domestic L'Arche community for another year.

Judi faced a similar decision after her exploratory month working in a L'Arche home. Judi and I met at a L'Arche retreat house where we were both staying one night. After someone else mentioned that I was in graduate school, she shared her dilemma with us, asking for our perspectives. She was plainly torn about whether to engage *now* in her long-held desire to live a more deeply Christian lifestyle or to push that personal project off again and begin her Master's degree first. She was excited about being accepted to a prestigious programme and also felt

pressure from her parents to follow the academic path. As she said, "My parents are telling me that I can always do L'Arche later, once I am done my education."

Unlike Theo or Karina, it seemed that Judi was not experiencing enough moral tension in the decision-making process to push her to make the more unconventional choice of L'Arche. Her desire for spiritual development was genuine but less of an immediate priority than professional development. Judi chose school but is apparently planning to return to L'Arche later.

Another sort of moral tension experienced was a feeling of having lost one's moral compass. Several assistants described feeling instinctively that they needed to be in a place like L'Arche so that they would be shaped well. Being in L'Arche was an intentional surrender for them in some ways. Nina, now an LTA, explained that she decided to leave her risky, fast-moving street lifestyle because she realized, "I felt right out of control and I needed some reining in, but there was no one in my life who could do that. As much as it was fun out there, I started realizing that it was an escape for me too. I didn't want to deal with stuff like family issues and questions about my sexuality." She had heard of L'Arche years before through a family friend and felt intuitively that the structure of home-life, the bigger purpose, and responsibility for serving others would get her on track, personally and spiritually.

Audrey's experience reflects a similar sense of losing one's moral compass. She had always been socially active but while working in the years following high school, she began to feel disillusioned and lonely with her life and friends: "Partying together gave us some sense of community but really there was no commitment. I started to see that it was so false. If I talked to my friends about it though, they thought I was too intense.... After awhile, I just felt more and more outside the circle." Eventually a bad relationship and an unwanted pregnancy scared Audrey into realizing "something has to change." She made lifestyle changes on her own, such as less partying and trying to pray for the first time; this helped to some degree but she still felt relatively

lost. She decided to live and work in L'Arche because she believed, as did Nina, that being in a structured community environment would help her to change those habits she had developed that she considered unhealthy.

Although Vanier often cautions that people should not choose L'Arche as a way to hide from the world, Daniel, a community leader, believes that even when people come to “lose themselves in the community,” their presence in the homes can be turned into something fruitful with proper guidance: “Good religious communities try to *work with people* to name those fears, and challenge them to get beyond the fears. We want our communities to be places of growth so that people can be out in the world and radically committed to service and people, not staying in and losing their personality in the group.”

5.5 The twin dimensions of meaningful fulfillment

“Ta pathemata, mathemata ~ The suffered, is the learned.”
(Burke 1962 [1945]:40-1)

In making a decision about whether or not to come to L'Arche, people considered what could come of the experience that was beneficial. All assistants expressed having been motivated by personal self-interest *and* collective or altruistic goals. They described the outcome of such interwoven goals in terms of what I will call *meaningful fulfillment*; fulfillment with a socially responsible dimension. I present the dual goals as interwoven here as was the case in their narratives. For example, while some people sought a sense of belonging in L'Arche because this would be personally enjoyable, it was also noted as something that would allow them to continue to give care (See also Wuthnow 1991:106). Working in L'Arche offered a chance to do good and make a difference in the world, and in turn felt rewarding for them. As deToqueville pointed out over a century ago, the experience of being involved in public service can transform egocentric motives into “reasons transcending private self-interest” (Bellah 1985:168).

5.5.1 Work-related concerns

About half of the assistants named work-related factors as a motive to work in L'Arche. Younger assistants were especially likely to mention the benefit of work experience; 80% of respondents to my pre-arrival survey volunteering "work-related experience" as relevant. This makes sense given that they are at an early stage in their careers. Younger assistants seemed to feel pressure to justify their chosen experiences by assigning them an instrumental value related to career development. Leore, for example, was considering doing a Master's degree in Social Work. She explained her motives: "I hope to gain an understanding of how people with disabilities live each day, and to build relationships with them and other assistants. I hope to have a broadened view of life and find out what exactly my career goal is – if social work is really for me or not."

Mia, another respondent to my survey, wrote that she hoped for, "A break in my life as a student. Time to reflect on my personality and how to have a better attitude. To be patient, to help if I can, and to have some good relationships. To learn a lot about people with disabilities who I would like to keep working with later." In interviews, assistants indicated that at the outset, the possibility of these intrinsic benefits, (e.g. personal growth, direction, relations) made up for the lack of extrinsic job benefits in L'Arche (e.g. money or prestige). They also helped encourage the assistants to continue on as caregivers.

When LTAs mentioned work, it was usually related to their desire to do meaningful and fulfilling work. Betty explained to me that after four years in full-time church ministry through music, she knew it was not right. She felt the work was meaningful, but something about it did not feel fruitful for her. She went to L'Arche originally for a transition year to consider her future vocation and direction. Peter had enjoyed working and studying in the field of disability advocacy for several years before he decided to go to L'Arche. While both meaningful and fulfilling *professionally*, advocacy work did not nourish his soul. At a spiritual retreat, an acquaintance

gave him a book by Jean Vanier, suggesting that the ideas might resonate with Peter's own ideas. While he did not actually read it for a year, once he did, he was indeed moved by the message.

A final example is Calvin. Now a seasoned community leader, Calvin is a passionate, energetic man, the son of an immigrant family. He worked extensively in various large care organizations but once he attained a certain level of authority in them, he realized that the work was demanding much more of him than it was giving back. The structure there did not allow him time to nourish other important things in his life such as religion and family. He believed that he would be able to balance these elements better in a L'Arche setting.

5.5.2 Adventure, becoming and growth

Having a special, out of the ordinary experience was an important theme in at least half of the assistants' narratives. They saw L'Arche as a chance to explore new terrain. I had not anticipated the prevalence of this element of adventure. My original conception of what assistants did fell within the more serious frameworks of caregiving and social activism. One survey respondent explained her multiple curiosities succinctly:

I knew I liked people with intellectual disabilities, and I wanted the chance to travel. I read Vanier's writing and looked on coming to L'Arche as a bit of an adventure! I was also interested in community – creating community (Lukeman 2001).

This motivating factor is important to discuss because I believe it is underplayed in L'Arche. The axiomatic belief in L'Arche that people go there seeking *belonging* makes it easy to overlook the fact that going to L'Arche was also an act of *separation*, an uprooting, and a movement away from their previous community or home. Anthropologist Michael Jackson notes that humans have twin, conflicting longings to feel rooted at home and also to reach out and explore the frontiers of "otherness" (1995:3). Jackson argues that while philosopher Simone Weil extolled the soul's fundamental longing to be rooted (Weil 1952:43), we "have an equally strong need to uproot ourselves," to avoid stagnation, and continue to seek inspiration (Jackson 1995:3).

Most people found it hard to explain their attraction to exploring difference, but it was nevertheless compelling for them. As Sam explained, “I just thought it would be really neat to be able to get to know a few people with disabilities better – to just look at someone who is so different from me, and try to understand what is going on inside of them.” Rivers, who was studying for his Master’s of Divinity, hoped that in his summer term at L’Arche he would “develop my compassion for those who are different from myself” because he felt that this was fundamental to a life of ministry. Their hopes reflect a “yearning to open oneself up to the world at large” and a desire to reach out across differences and connect with people (Jackson 1995:4).

For others, it was not specifically the difference of disability that attracted them but the whole package of alternative living that L’Arche offered with its intense, intentional community lifestyle and its alternative spirituality. When Benjamin finished school, he had no romantic relationship or job holding him at home and so was able to indulge his desire to travel to Europe, and live in L’Arche there. When I asked him if he was looking for anything in particular, he said, “An experience – I told myself, I am young, why not do it? Leave home, live on my own.... I wanted to grow - to be different by going away. I wanted to be enriched, to know myself better, and to know the meaning of my life. What do I want to do? I asked.”

Maria’s story reflects the same sentiment: “I was looking for time away from school. And I think I was looking for something out of the ordinary. I wanted to do something different so that if I did go back to school, then at least for one year I did something really out of the ordinary.” Both are still in L’Arche now, years later.

5.5.3 Belonging & home

The need for belonging is the counter-point to the desire for freedom and adventure. Assistants named a desire to be part of something good, and to be with people with similar values and spirituality. L’Arche assistants commonly say that they were attracted to L’Arche for

community, belonging, or a sense of being at home¹⁵. Other L'Arche scholars have also discussed this theme of wanting a place to belong (Pottie 2000:8-11; Bazinet 1995; Sumarah 1988; Vanier 1998). Philosopher Charles Taylor situates such feelings of anguish over not having moorings or a sense of belonging as typically modernist (C. Taylor 1989). An interesting facet of these stories is how the desire to belong often supported both personal and altruistic aims.

From a personal interest perspective, assistants said that it would simply be more enjoyable to work in an environment where people shared the same fundamental values. This seemed especially desirable for people who had experienced difficulty enacting their moral or faith beliefs in regular life or with finding like-minded friends. Benjamin, for example, said that although he had many wonderful friends, he felt lonely in some sense because they did not share his faith or his perspective on finding a meaningful vocation. It is difficult, as Taylor has noted, to live out counter-cultural values on your own, in a modern society biased towards social atomization and consumerism (1989:7-9).

This perceived constraint is ironic considering that Canadians and Americans commonly work on the assumption that we have great moral and religious freedom due to our secular, therapeutic culture (Rieff 1966, Rimke 2000, Bellah 1985). A partial explanation for the constraint could be the deviance that is associated with compassion and altruism in our society where their uncommonness makes them seem like suspect behaviours (Wuthnow 1991:72). As Theo and I discussed various factors which led him to L'Arche a decade ago, he tried to recollect his original hopes:

I guess I'd say I wanted to know more about community. I wanted to belong somewhere that was more like how I was. I also wanted to learn about love. At that time, I recall thinking that I was interested in things, but I didn't feel that my heart was engaged in them – I felt sort of numb and I didn't like that.

The desire to find a place to belong was also rooted in altruistic aims. Several people suggested that being around like-minded people would provide some of the support necessary to

continue doing social justice work. Wuthnow also found people in his research who said that benefits such as relationships, support, and community were essential for helping them to rejuvenate so that they could continue to volunteer or do intense, emotional, caring work (1991:96). Of one interviewee he writes: "Caring for others...presents him with challenges, teaches him lessons, makes him stronger so that he is better able to care the next time than he was before." (Ibid:106). When Maria moved from traditional care facilities to L'Arche, she hoped to find the collegial support and values-driven environment that she needed and thrived in; this support enabled her to provide care that she felt was both morally just and mutually nourishing.

Trevor, a former community leader, now in his early forties, bounced from management in social services to small business and construction after graduating. He had been raised in a rural protestant faith tradition that was no longer meaningful for him and he was somewhat adrift spiritually. He had not developed meaningful relations with his many colleagues. After several visits and volunteer days with the L'Arche community where he lived, Trevor realized a high degree of compatibility between the L'Arche mission and his own beliefs:

It was the first time I realized that there were people who were living something intentionally that sort of resonated with some of the themes in my life...[such as] the L'Arche articulation of the beauty and sacredness of human life...and a very personalized vision of community...where each person's value was upheld rather than being treated merely as patients or employees.

Although L'Arche assistants often spoke of ways that they had grown, most did not explicitly name ways in which they felt they were weak or in need of acceptance. Vanier names the Western reluctance to admit personal weakness as "the absent cry of the rich," in contrast to the more familiar "cry of the poor" (Vanier 1989:89). While most people are drawn to L'Arche primarily in a spirit of generosity, Vanier insists that they are also moved by their own *need* for relationships, spiritual strength, love, support, and other healing (Vanier 1989, 1998). As Matthew puts it, "I wasn't a lost soul. But there was something – I felt an emptiness."

5.6 Conclusion

In this chapter I have presented a wide-ranging discussion of why people choose to live and work as assistants in L'Arche communities in Canada. Assistants do not enter L'Arche as a homogeneous collective, neither are they completely different from each other. They shared a passion and energy for learning about L'Arche and people with intellectual disabilities, although most of them did not enter with the intention of a long-term commitment. They also shared a blend of self-interested and altruistic aims that they hoped to work towards during their time in L'Arche. This is significant in understanding how they experience and make sense of their time in L'Arche. It can also provide clues to assistants' eventual reasons for leaving. A finer analysis of this issue could help LTAs develop ways to accommodate some of the newer assistants' social change projects within the community.

In chapters 6 and 7, I show that the L'Arche approach to care and community is challenging and requires different things of the caregivers than do mainstream approaches. The outlooks, values, and motives which bring assistants to L'Arche, imbue their practice with rich and unconventional meaning. It is, in the end, in the daily practice of care that a person will grow or not grow, not in their hopes and talk alone.

5.7 Endnotes

¹ A study with similar evaluative objectives assessed the effects of enculturation in medical school. To do so, researchers compared students' before and after statements of their motives for being a doctor and their beliefs about what makes a good doctor (Good and Good 1993).

² This does not mean that they want assistants to abandon their broader social justice concerns; indeed, as I detail in Chapters 6 and 7, those concerns are part of the moral and spiritual framework that gives noble meaning and purpose to the simple daily activities. As Geertz has written, "It is in placing proximate acts in ultimate contexts that makes religion, frequently at least, socially so powerful." (1973:122).

³ Note that within L'Arche, instead of saying "recruit to work there" they would say "invite to share life in the community" but for clarity here, I use the term work. I discuss these distinctions later.

⁴ A vocation may involve great hardship but if one is truly called it is felt that it should feel fecund on balance. While less common in English, Vanier explains that in French, fecundity or *fécond*, infers fruitfulness for both the giver and receiver; it is "the capacity to give life" while also growing oneself (Vanier 1989:68). To feel called to the vocation of assistant means you feel balanced and able to give and receive in a mutually healthy, sustainable way. Not all assistants seek such discernment.

⁵ Research on compassion in America indicates that most Americans have little sense of duty to sacrifice themselves to help others; most want their giving to be personally fulfilling (Wuthnow 1991:105). His American survey found that roughly 85% of people felt the concept and language of sacrifice were unpalatable, even with people who do sacrifice time and energy to volunteer (Wuthnow 1991:100-5).

⁶ These quotes are both taken from the raw data on the anonymous L'Arche survey of LTAs, as are all subsequent *quotes* that I cite as *Lukeman 2001* in this chapter.

⁷ I define what excellence involves in the next several pages.

⁸ In 2001, 23% of L'Arche assistants in Canada lived outside of the homes (Lukeman 2001). It is of note that the families of L'Arche assistants often adopt cultural aspects of L'Arche in shaping home life. This can include; prayer at meals, candles, reflection time, and weekly check-ins with each other.

⁹ Wuthnow found that 91% of Americans believe you get a lot when you give to others (1991:55).

¹⁰ All figures cited in the next two paragraphs were extracted from Lukeman's 2001 summary report.

¹¹ No single community had enough resources to launch an effective recruiting or marketing effort. Pooling resources, collaboration, and a unified message are needed. Recently, L'Arche initiated a national recruiting committee, with a full-time director, and produced a national assistants pamphlet in summer 2002.

¹² By "myth" Arbuckle does not mean something apart from truth. In its original meaning, "Myth comes from the Greek word 'muthos' which means story...transmitted in a symbolic way, with authority and certainty" (Vanier 2001 prophetic paper:7).

¹³ There is an exception in the case of celebrities who simply connect their name or reputation to a charitable cause and can generate immense benefit for the cause without making much sacrifice themselves.

¹⁴ That is to say as priests, or brothers or sisters (nuns) in a religious order.

¹⁵ L'Arche surveys consistently found that half of assistants' volunteer community-related reasons as a major reason for working there, and most other people name it as a secondary reason (See Exhibit 5.1).

6.0 The Enculturation Process of a Local, Moral World

6.1 Introduction

L'Arche has created a local, moral world in its communities¹; a provocative cultural space for imagining and practicing an enriched way of living with the kind of personal and group differences that are usually devalued in mainstream, Western society. Within this cultural system, L'Arche seeks to expand the scope and principles of caregiving by producing elements of care that are not normally included in a caregiving agency's mandate. In this chapter, I elaborate on several enabling factors that L'Arche has developed in order to achieve those elements or outcomes. I discuss the constructive effect of these factors, but also their unintended and sometimes harmful side-effects.

The L'Arche objectives for creating such a system are described in Chapter 4. Here, based on my analysis of their mission statements, observations and interviews with informants, I identify three important outcomes that must be generated in order for L'Arche communities to reach their goals. These outcomes are: *core-member well-being*, the creation of *mutual relationships across difference*, and *transformed caregiver subjectivity*. These outcomes are intertwined and mutually enabling.

The first outcome is the *well-being* of the people with intellectual disabilities who come to live in the L'Arche homes and communities. Well-being need not mean that every person in L'Arche is entirely content. Like anyone else, people with intellectual disabilities have ongoing concerns and projects related to their home life, relationships, work and general emotional state that require support and effort. Well-being refers to, but is not limited to, legislated elements of care such as housing and feeding people and providing basic skills training (L'Arche 1993; Rioux 1994). L'Arche aims to create a safe place for people with intellectual disabilities to live and work where they can learn to feel that they are accepted for who they are as whole persons, and with, not "in spite of," their disabilities. Once they gain a greater degree of confidence and self-acceptance, they are then supported to grow and move outwards into wider social networks in their workplace and in the regular community. Although this goal is fundamental to the mandate and governmental rationale for the existence and funding of L'Arche, I do not evaluate it directly in this thesis².

The second outcome L'Arche requires is healthy *mutual relationships across difference*. The model of care applied within L'Arche communities involves people sharing home life together and reducing the social distance that has become the norm in caregiver/patient relationships. Since most people with intellectual disabilities in L'Arche and elsewhere will always require some form of paid-care relationships, L'Arche asserts that effort is needed to ensure that they do not experience themselves as dependent, devalued or inferior in these relations. Having mutual relationships requires recognition, especially by the more powerful person (i.e., assistants), that the caring and benefits flow both ways. When assistants acknowledge what *they* receive, they contribute in a small way to changing the negative conditions under which all people with disabilities live. I illustrate the nature of these mutual relationships in Chapter 7.

The third outcome, *transformed caregiver subjectivity*, encompasses the professional role of the caregiver, and their sense of self as a person within and outside of the L'Arche homes. Coming to terms with both the community aspects of living and working in L'Arche, and the new experience of being with people with intellectual disabilities can be likened to culture-shock for many new assistants. The stigmas that surround people with intellectual disabilities mean that most adults feel uncomfortable around them (Murphy 1990:86). Being *able* to be touched by, or learn from them then, does not come naturally for most people³. Assistants need inspiration, role models, and supports to move from a simply compassionate and subjective position to a subjectivity with the emotional, moral, psychological, spiritual and technical skills required to turn the compassion into an active, living practice. An extended period of adjustment and learning or enculturation is thus needed.

Given that the realization of the first two outcomes requires a certain type of participation on behalf of the assistants, the processes involved in their enculturation into L'Arche are extremely important. The subject of this chapter is that enculturation process. I identify and describe two important *tactics* (spatio-temporal organization and storytelling) and three key *strategies* (redefining productivity as fecundity, revalorizing difference and providing care for the caregivers) that L'Arche uses to enculturate assistants in their approach to caregiving, and through which assistants negotiate everyday interactions, tasks, and relationships in L'Arche.

6.2 Tactics that support the enculturation strategies

In this section, I examine two tactics—spatio-temporal organization and storytelling—that L'Arche employs to achieve its strategies and goals, including the enculturation of new caregivers. Tactics are “manoeuvres used, or plans followed, to achieve a particular aim or task” (Sinclair 1994:1569). In other words, tactics are not important as ends in themselves, but rather for how they serve other strategic ends, in service of the organizational goals. Tactics are as vital

to accomplishing aims as any other part of the plan even though they operate at the micro-level. Though they are not theoretically complex, without them, a plan or goal would remain unfulfilled. The first tactic, spatio-temporal layout, includes how space and time are arranged within the homes and the communities, and how activities and projects are prioritized. By sketching out a typical “day in the life” of assistants, I show how spatio-temporal factors are often intentionally used to influence how experience is constructed for them.

The second tactic used at L’Arche is storytelling. Transforming one’s caregiving and relational experiences into narratives, is a vital didactic mechanism for enculturation into the local moral norms and caregiving approach within L’Arche (Cushing 2002). Although storytelling is a widespread practice at L’Arche, in my observation its power is undervalued and has been given little critical consideration at an organizational level. As such, it is a prospective area for analysis regarding both its challenges and its potential to improve training and L’Arche’s effort to relay its message more broadly.

6.2.1 Spatio-temporal layout

Shared space and decisions

Cooper (1994:110) has argued that the design of buildings can partially “structure the parameters of people’s daily lives.” There is an ongoing dynamic between built structures, spatial discourses, and people’s experience of them which feeds back into changes in the meaning and uses of built space (Cooper 1994:93, 110). Vanier intuited that the space one inhabits can both reflect beliefs and affect one’s sense of well-being within it. This intuition led him to invite Raphael and Philippe to move from the institution into his home; it is also reflected in his belief that living together, in the same conditions, is necessary for caregivers to develop genuine solidarity and relationships with core members. The moment when Vanier and the men moved in together was “when a meaning was given concrete form in space.” (Cooper 1994:94).

New meanings can be produced in the ongoing dynamic between spatial discourses, built structures, and people's experience of them (Cooper 1994:93, 110). Sharing living space changed how Vanier perceived the core members, and bore fruit in his evolving notions of mutuality, but has also influenced more recent decisions about spatio-temporal layout in L'Arche. Core members are now asked for greater involvement in planning and decisions, even where that adds substantially to the length and complexity of the process. One Canadian home that needed a new, fully accessible bathroom for people with diverse impairments, held extra meetings involving the core members in discussions and demonstrations (of options) with the architect, plumbers, physiotherapists and technicians. This kind of engagement is progressive (Rodman and Cooper 1989), and is an example of a shift in assistants' sharing of power by conceiving of the home as a space to be shaped by each person in it.

These same principles continue to be applied today, where assistants live full-time in the homes, at least for the first three years that they are involved with L'Arche, and often for much longer. Assistant and core member rooms alternate throughout the homes and are similar in size, furniture and access to amenities like bathrooms, which are shared. It is difficult to emphasize how significant this single design variable is in realizing the L'Arche ideology and lending a feeling of personal "authenticity"⁴ to the assistants' project of living and working in a way that "makes a difference." This is a classic example of how "places [can] produce meaning and that meanings can be grounded in place" (Rodman 1992:643).

Most homes in a L'Arche community are typical of urban or suburban houses. One spatial design principle that developed, once L'Arche was in operation, was that each home should contain an eating area that is large enough for everyone to eat together, and a comfortable, welcoming, common living room area, large enough to hold house members and friends. The belief is that the physical space would facilitate (by virtue of existing) occasions for coming

together to share stories about the day and celebrating life's milestones. This is a spatial design principle that was noted by outsiders as unique and effective when it was introduced (Wolfensberger 1973).

Symbolism in décor and scheduling

There is not enough space here to outline *all* of the ways in which L'Arche designs their space and time/schedules to reflect their ideology. Instead, I name some salient ones to evoke a sense of how life in L'Arche feels and looks quite different from mainstream group homes and institutions. Candles on the kitchen table and in the common space are often cited as an essential element of a L'Arche home. When I arrived for a visit in Hull, Quebec, I gave them a large, autumn-scented candle, and a long-term assistant at the table smiled and said, "Ah tu comprends déjà L'Arche!" In common areas, candles are often simply set on a table, or they are included in a small altar, around which people sometimes gather to share quiet time, stories or prayer after dinner and on special occasions. The candles are incorporated into many rituals and the lighting and snuffing of the candles provides a ritual beginning and end to dinner.

Candles are also utilised in private spaces, reproducing the group emphasis on reflection and ritual. Many assistants and core members have candles and some also have personal prayer spaces in their rooms. When lit, the candles suggest a slowing down, a quieting of the mind, and a turn to reflection on the travails and gifts of the day, however small. In this sense, spatial and temporal principles overlap, as the candles also symbolize a change from the time of day when everyone is involved with their own activities, to a time when they are open to being more connected with the group, be it in sharing food, stories, prayer or laughter.

Temporal principles are perhaps best illustrated by a few aspects of scheduling and time priorities in a typical day for an assistant. Most assistants live in the homes, although across Canada an average of 23% eventually live out, some of whom have spouses and children (Lukeman 2001). The scheduling of a typical day for a live-in house assistant is perhaps the best

illustration of how L'Arche ideology is reflected in the temporal principles of L'Arche homes. The assistant typically wakes early in order to get house tasks and routines underway before helping core members to get ready for their days. The assistants in Ontario's Green House begin with the laundry and then undertake various kitchen-based tasks, such as getting out the breakfast foods, brewing fresh coffee, and packing lunches for core members to take to work. In other homes, such as Unity House in British Columbia, the core members do most of these tasks for themselves and are simply guided by the assistants.

The efforts made to have core members participate in as many of the daily operations of the house as possible, can be used to illustrate how temporal priorities are used to enact the L'Arche ideology in the homes. Although assistants aim to facilitate core members' inclusion in household chores in order to maximize their sense of independence and control, it often requires more of an assistant's time and energy to support a core member to do a chore than to do it himself. This is an issue of skills, but also of core members' desire; over time, many core members seem to have either gotten bored or decided that laundry is *not* really a meaningful task and would prefer that an assistant does it while they, themselves, do something more interesting.

As a result, many of the household chores are sites of ongoing negotiation of rights and responsibilities between core members and assistants. There are at least four intersecting and conflicting interests at play here: the organizational goal of supporting people with intellectual disabilities to grow in skills and minimize dependence on others; the well-being of the people with intellectual disabilities, which includes where possible their desires (e.g., not to do chores); the assistants' well-being, including the chance to do more than housework (e.g., to support others to learn the skills, have time to plan outings, etc.); and the reality that negotiations and supportive training are necessarily bounded by the limited time and number of assistants available to undertake these tasks.

In my observation, such complex situations were always resolved through some micro-negotiation of the particular priorities at hand between the assistant and core member, and often consultation with other assistants as well. For example, in my house, watering the plants was Donna's (a core member) responsibility and she liked it. It took her a long time and she needed an assistant to be with her. When we had enough assistants in the home for other vital tasks like making dinner, we would support Donna through this chore. If we did not have the time or people to support her in a way that did not rush her and make her agitated, then one of us would water the plants. An assistant must constantly make micro-decisions like this. They must develop a facility to quickly weigh the competing claims of multiple ideals within the parameters of ethical practice and resource realities. The second tactic, storytelling, helps assistants learn to navigate this moral domain (see section 6.2.2).

Dynamics of personal hygiene routines

Waking people and providing help with personal hygiene routines and dressing are other key aspects of life in a L'Arche home. A few core members need only minimal help with this. Many need to be supported through the whole process in the morning and again at night. Routines are often occasions where the organization's values are reflected in temporal structures. In formal training and, ideally, in the role models provided by long-term assistants in the home, the message is that routines are not merely a task. Rather, routines are an opportunity for a profoundly respectful human interaction with the person who is being cared for, and a time for assistants to recognize how difficult it must be for core members to experience such vulnerability in the bath every day, with different caregivers over time.

The assistants are encouraged not to rush people through their routines like an assembly line, but rather to try to be sensitive to how the core member is feeling and to make it as comfortable for them as possible. If the core member's ride to work is waiting or some other issue emerges, expediency will prevail. In my observations, however, the idea of routines as requiring

and deserving extra time, is commonly respected. Indeed in interviews and informal conversations with assistants, particular stories about this are frequent, as I illustrate in the next section on storytelling.

The intimacy of routines, again, tends to create many delicate situations and conflicts between the parties involved. For example, for those core members who are not “morning people,” their desire to stay in bed is often a source of stormy confrontations with assistants who are responsible for supporting them to make it to the bus and to work on time. In so doing, the assistants help the core members learn to balance their responsibilities and their desires. Once again, I observed many multi-factored scenarios that required that the assistant and core member negotiate the terms and parameters of acceptable choices.

Sometimes the daily squabbles and mini-power struggles are not connected to health issues or more significant concerns. In these cases, assistants support each other by sharing tactics that help make the process less quarrelsome. For example, Henry likes to curse at the assistant who is with him, as he sometimes feels that it is the assistant’s fault that he must get up. To diffuse the tension, prevent the escalation of the behaviour, and to give Henry, who has a good sense of humour, something else to focus on, the assistants and Henry now commonly accentuate the humour in the predictability and frequency of the scenario. For example, if Henry calls the male assistant a name, he might joke that Henry was being too easy on him; “Is that the best that you can come up with this morning? Boy! Guess you did not sleep too well!”

In cases where this reluctance or refusal is out of the ordinary for a core member, the behaviour is taken more seriously as it might signal that something else is possibly bothering the person, such as a health or emotional issue. Such unexpected behaviours are especially helpful in flagging concerns for people who do not use words to express themselves. One such refusal led the team to realize that a man had a toothache that he could not articulate, and another revealed a

core member's distress over the departure of an assistant that she had liked. Taking the time to be attentive to someone in routines is thus also a practical way to help identify and resolve issues that a person is facing⁵.

Meetings and decision processes

Among home team members, informal discussions about the meaning of events that are points of conflict within a home are on-going . These issues also become an important focus of the weekly team meeting. Although in relational matters and recreational time there is an attempt to minimize the staff-client distinction, there are also set times when the assistants in the home come together to plan a weekly schedule and discuss any issues salient to people's well-being. L'Arche meetings usually reflect and reproduce aspects of the community philosophy. In this way, participation in the meetings functions secondarily as a means of socialization for new assistants. There are three main emphases of home meetings: establishing the status of, and contributing factors for, core members' well-being; attending to the well-being of individual assistants; and organizing administrative responsibilities.

The meetings always begin with prayer. This often, though not always, includes a time for individual petitions and a short silent time for reflection. Long-term assistants explain that these rituals serve many functions. They quiet people's minds, bring their thoughts fully into the space and purpose(s) of the meeting, and they re-establish a front-of-mind awareness, among those present, of the broader framework of faith and social justice in which their labour operates and derives significance. For many assistants, prayer also calls on the power and presence of the spirit to be there to guide the discussion. This ritual is usually followed by a "group check-in." Assistants may speak of personal, familial or professional topics. They can choose to mention something that is going well, or something challenging or sad that is weighing on them. The aim of sharing is to provide people a chance to be heard and to help the team be aware of each other's

state of mind so that they can support them or give them space, as needed. Making time for these practices contributes to caregivers' well-being.

The bulk of meeting time is spent discussing the well-being of core members including their medical health, efficacy of medications, psychological and emotional health, sociability and opportunities for physical fitness. These categories are often significantly overlapped and each person tries to share information and interpretations to help create a holistic picture of the person's overall well-being. Core members are not treated as a group. Rather, they are discussed as individuals with highly particular ways of being in the world, desires and responses to particular triggers. For example, if a team plans a birthday party with guests for one core member who loves to socialize, they might need to also ensure extra support for another core member for whom a party will be anxiety-provoking.

The rest of the meeting is taken up with scheduling the presence and activities of people in the house to ensure that enough assistants are around to take care of basic responsibilities throughout the week and month. This process is fluid: efforts are made to accommodate the varying needs of everyone in the house, although compromises are often needed. They attempt to make the daily routine similar to those in a regular home. An assistant's scheduled day away can change in response to either a house need or the assistant's own desire. This flexibility reflects their philosophical emphasis on minimizing the institutional rigidity of the milieu.

Issues of sustained liminality

The space-time structure of L'Arche communities bears some parallels to the liminal phase of the rites of passage model. In this model, there are three stages through which initiates proceed: entry (symbolic and spatial separation from regular life), liminality (period of learning and growth), and exit (re-integration) (Gennep 1960; Turner 1964). Although this model is generally not appropriate for understanding experiences of people in complex, modern societies (Cushing 1999), it can be used to understand two aspects of L'Arche communities. First, while

L'Arche ultimately does not intend to be a "time out of time" or temporary space, assistants do frequently speak about their entry into L'Arche in terms of a separation from the "real world." Second, the L'Arche moral sub-culture regulates and rewards behaviour in different ways than mainstream society, and in this way can be likened to the liminal phase of the rites of passage model. The potential for change inscribed in the L'Arche philosophy generates a sense of urgency, energy and vitality, similar to the liminal phase, that inspires people to take chances and experiment in ways they would not normally feel open to (Turner 1986). This is part of what makes it such a growthful time and place for many people.

There are at least two unintentional and negative outcomes for assistants that arise as a result of the liminal quality of life in a L'Arche home. These are burnout and feelings of separation from society. The first problem arises because there is no real temporal limit to the liminal phase of life in L'Arche, other than leaving permanently. Whereas traditional rites of passage last for a very short period—generally a week—all assistants at L'Arche stay for much longer than a week, many are not sure how long they will stay, and some stay longer than five years. Therefore, they spend extended periods of time in an environment that is partially structured to reproduce the restless, dynamic energy of a liminal period. Yet, it is nearly impossible for one to sustain that kind of energy over an extended period. This problem is complicated by the fact that assistants are called to balance the drive for change with a grounded sense of a safe home. This balancing act is difficult in an environment where there are always people in need. Consequently, many assistants who stay a year or more experience some degree of burnout, emotional exhaustion and feelings of inadequacy. Finding a better balance involves identifying one's limits, learning ways of disengaging from the liminal space for periods of time to recuperate, and reflecting on when and how to engage again.

The second disadvantage of the *felt* liminality of the communities is that it encourages a continued separation of its members from the rest of the society. This unintended outcome reduces L'Arche's ability to make their message relevant to a broader audience, as I outlined in Chapter 1. Rachel, a well-regarded assistant of two years agrees, saying:

Yes, I agree that the separation is a problem. I love L'Arche and I love the people in my house, but the longer that I live here the less connected I feel to the rest of the world. That was not what I envisioned when I came here, but it gets so busy that it is hard to make time for external connections—personal or professional.

The result is that assistants do accomplish a degree of growth, as any initiate should, but then they are not provided any clear exit or reintegration rituals that would specify a time to settle, take stock and integrate the growth into daily routine. Exit and reintegration rituals could also foster dialogue with other professional disability or caregiver associations to give assistants opportunities both to share the knowledge and experiences they have gained at L'Arche, and to learn of further challenges and opportunities in the field. This, in turn, might decrease their sense of separation or stagnation, and would likely return vital energy and new ideas to their L'Arche communities as well.

6.2.2 Narrative: informal storytelling

Following Wikan (1995:263), I define narratives as “stories or talk that have intention, characters, and plight.” This definition aptly describes the stories that are commonly shared among L'Arche assistants. In fact, informal storytelling among L'Arche assistants is so common that most assistants seem to find it natural and enjoyable, but unremarkable. In this section, I examine the forms that stories take in L'Arche and the contexts in which they are told in order to highlight the role of stories in the production and reproduction of knowledge and cultural norms (i.e., enculturation). I argue that informal, everyday narratives constitute productive activity insofar as they endorse or undermine particular social realities and structures of L'Arche ideology (see also Kingfisher 1996). Ethnographic stories are used to illustrate the common uses and

intended aims of these stories, and to demonstrate the effectiveness of narrative as a didactic tool. I also discuss how the prevalence of informal narratives in L'Arche can have unintended and sometimes detrimental side-effects for the assistants, their relationships and, indirectly, the quality of care for the core members.

The prevalence of storytelling among L'Arche assistants probably originated from listening to Jean Vanier, who is an eminently gifted storyteller. His convention of formal storytelling at retreats has become a common element in most L'Arche community gatherings, training sessions, spiritual retreats and some meetings. In this section, however, the focus is on *informal* narratives that are shared frequently in the homes and in daily interactions. While this practice goes on among *all* members of their communities, including core members, I focus on the workings of this process primarily in assistant-to-assistant interactions. I think it is important to identify the vital teaching role that assistant-to-assistant stories are playing because the tendency in L'Arche has been to underplay that role in favour of highlighting the teaching role of core members⁶. While the core members' role is vital, I try to show here that other techniques are at work in helping an assistant become open, and able to learn from core members.

For context, I note that narratives are not commonplace in the landscape of busy mainstream healthcare systems, where the lack of resources and taboos on intimacy with patients often result in a substantial loss of engagement. One striking example of this comes from research showing that a majority of American state hospital nurses in the study could not recall *any particular stories* about particular patients in the preceding month (Benner 1994:58). Other research suggests that when specific stories are told, they are often about *incidents* or *non-compliance* with section rules. Thus, stories often function solely to justify further constraints or, indirectly, the lack of attention given or rehabilitation achieved (Rhodes 1991; Young 1993; Chambliss 1996).

The lack of shared stories about clients with intellectual disabilities can be particularly problematic. Typically these people are under long-term care, many are non-verbal, and the agencies that care for people with disabilities generally have high staff-turnover rates. The result is that there are large gaps in individualized understandings of how to give the best possible care, as much that is learned about an individual client is never written down. Preferences that are discovered by one staff person over the course of a year, such as where someone likes to go for a walk, who she enjoys spending time with, or what kind of juice she likes with her medications, are often lost when that staff member leaves the agency. Informal storytelling has become a key tactic through which L'Arche works towards holding and passing on a person's history.

Narrative theory, intended aims and roles of stories

Before I discuss the functions and genres of informal narratives among assistants at L'Arche, it is necessary to outline the theoretical strands that informed my analysis of these narratives. I am interested in how the narratives provide a window into the ongoing dynamic between the ideology of L'Arche and the agency of its assistants. The ideology of L'Arche functions like that of other institutions, which, to paraphrase Young is to “convince people to do what they would not otherwise do; subvert and devalue rival perspectives; [and] serve important interests by changing or overwhelming resistances” (Young 1993:116)⁷. Narratives are clearly sites of reproduction of the L'Arche ideology, but they are also rich sites of creativity that assistants use, intentionally and otherwise, to adapt and personalize the ideology. Assistants also use stories to achieve other self-interested and community-building goals. The assistants' informal narratives convey information—often positive—about themselves, which speaks to both their wholeness as actors with multiple projects, and their agency or capacity to enact those projects⁸. Their agency is not limited to self-interest. Stories that assistants share about experiences and relationships also create a sense of commonality, continuity and connection with other assistants, and within the community as a whole, and mutual support.

This is not the place to do a comprehensive analysis of the construction of these stories, but I outline some common norms. As Bruner explains, the Russian formalists identify three aspects of all stories: the theme (mythic plight, moral leitmotif), discourse (plot; variation on the theme), and genre (language, position) (1986:17-18). The five most common themes of informal L'Arche stories overlap and support each other. These are: commonality and difference; the relations between the strong and the weak; personal responsibility for unjust power imbalances; the power of spiritual faith; and the importance of the little things.

The discourse or common plot lines are more numerous, but usually focus on the inversion of expected roles for people with intellectual disabilities. Typical of any good story, "to be worth telling, a narrative must run counter to expectancy" (Bruner 1996:139; Bruner 1986:19). The most common stories revolve around what an assistant learned from a core member, often through the course of a difficult experience. Such a story inverts the social assumptions that i) caregivers teach the clients and ii) difficulties are always bad. For example, one talkative young seminarian often tells people the story about spending one practicum week in a L'Arche home where none of the core members used words to express themselves. The twist in his story is that at first he thought that this would be a painfully uninteresting experience for him given his love of conversation, until someone helped him to see the opportunity to enjoy the gifts of quiet time implicit in the core members' silence. Other peoples' stories that I share in this thesis, reveal instances when the core member has been the wise sage or exhibited extraordinary humour, good sense or absolute cunning.

Functions of informal narratives

Informal stories shared in L'Arche have four primary roles or functions that relate to *sociability, problem-solving, identity* and their utility as a *didactic tool*^p. The roles overlap in significant ways. They are primarily analytical constructs that I've developed, not everyday discursive categories of assistants (although a few assistants use them). Narratives can play overt

or covert roles, or both. The covert roles are not always intentional. Rather, they can emerge as a culturally normative practice that is sometimes reproduced with little thought. The first two roles are somewhat self-explanatory, and do not directly contribute to the chapter's aim of elaborating on the reproduction of the L'Arche ideology and the process of enculturation of assistants. The discussion below, therefore, focuses on the roles of narrative in a) teaching and b) identity production.

a) The use of narratives as a didactic mechanism

In this section, I demonstrate how storytelling is effectively used at L'Arche to reproduce knowledge of the agency's ideology of caregiving. I also point out ways in which narratives sometimes fail to produce desired effects and can result in problematic side-effects. New assistants are subjectively reconstituted as they listen to, and learn to tell stories in a particular manner. Participating in exchanging stories also changes their relation to the core members, who are the objects of narrative knowledge—usually a positive shift. This teaches them to be the particular kind of caregivers and people that L'Arche needs.

Bruner argues that in narratives, action is always portrayed as happening for a reason (1996:136). He observes that what “people do in narratives is never by chance, nor is it strictly determined by cause and effect” (Bruner 1996:136). People tell stories when the protagonist, (who is also often the teller), could have made other choices, but did not, and he wants the listener to know that. Conveying what he did not do, (for example, taking the easy way out), can be as important to the purpose, force and meaning of the story as what he did do. Narratives are thus intended to tell the listener something about the teller, the actors and the culture, as well as the event or explicit object of the story. Narratives contain information about what constitutes unacceptable or acceptable behaviours or actions in a particular scenario. Many stories are formed

around an instance where the assistant telling the story made a poor choice, and the core member plays the role of demonstrating or teaching them why this was unhelpful or inappropriate.

Narratives can teach moral lessons. While spirituality is fundamental to the origins of L'Arche, and many assistants experience spiritual growth and conversion (Hyrniuk 2001), the subjective transition of assistants is also significantly a moral shift, made possible by providing them with an alternative moral framework. I argue here that the most significant role of storytelling in L'Arche is that stories fire the moral imagination of the caregivers. Stories always hold in tension the details of a particular event and the often moral, universal themes within which the stories make sense, and to which they speak. The particulars of an event help stories to resonate with caregivers' everyday experience and make the ideology liveable for them. Details also humanize and individualize people with intellectual disabilities in a way that formal ideology and training never could because they are inherently generic. Stories allow the few L'Arche principles to be continually re-told, re-lived and re-produced without seeming "tired" because they are freshened with new characters and particulars¹⁰. As Charles Taylor has noted, it is in the particulars that genuine compassion is forged (Taylor 1994).

The following story exemplifies how the narrative is used to teach lessons and morals in L'Arche homes. Jacob has lived in his L'Arche community in Ontario for over twenty-five years. When he first came, the community had farmland and he loved to work with the animals. He still works at another farm nearby on some days, while on other days he does various jobs around his L'Arche community such as delivering the mail from the office to the houses. When Jacob arrives in a home, he calls out for an assistant to come and read out the names on each piece of mail. Assistants usually enjoy this ritual for a few weeks, but then most seem to grow tired of it and try to avoid going through it. What often turns their behaviour back around is a simple story that has been told innumerable times. If experienced assistants are around, they will often tell their version

of the “why it is important to read the mail with Jacob” story to the new person¹¹. The premise of the story is that, unlike some people with intellectual disabilities, Jacob is very aware that he is different from the assistants, and he is conscious of the imbalance between them. This consciousness pushes him to be very independent. For example, he rejects assistance with his daily hygiene routines. He also often does nice things for other people, and assistants who have known him a long time think that this is partly his way of restoring some of the balance to his relationships. Doing the mail together is another way to acknowledge the productive role he plays and therefore to restore some balance.

An assistant who hears these stories about Jacob, with their embedded moral lessons, now has an alternative interpretive framework for understanding Jacob’s actions and his motives. Ideally, she uses that framework to inform her own (now) moral decision about how to respond to Jacob’s mail visits more empathetically. Joanne, a former assistant, told me that she still thinks about Jacob yelling “Mail!” and how it always reminded her of how important it is to acknowledge what other people mean to her, and to spend time with them when she can, rather than rushing around. The assistant also learns more general lessons from this story about the L’Arche approach to caregiving, including how to talk about experience and how to interact with core members.

Neil is a former L’Arche director. He often tells new assistants a story about a significant conversation he had years ago with his friend, Frank, who is a core member. The context for the story is that high staff-turnover rates cause constant disruption in routines and relationships for people with disabilities (Braddock and Mitchell 1992). Many assistants leave at the end of the summer to go to school. One year, Frank was finding this exodus particularly hard. Frank is thoughtful and very expressive, and he and Neil had a good conversation about how they both

found this situation sad. Neil relates how he wanted to encourage Frank to see what had been accomplished, not just the loss, in saying:

You know there is also the good side. You really changed those assistants' lives by welcoming them to share your home. Many assistants have told me how much they learned from your example, and who you are as a person. Frank paused to think about that for awhile. Then he looked up and said, "If that's true, Neil, then how come no one has ever thanked me?"

This conversation happened years ago. L'Arche is much more conscious now of cultivating a spirit of gratitude among assistants. Still, the story contains lessons that might never grow old. Neil claims this story as a turning point in his understanding of how to be a better L'Arche assistant. He also uses the story as a didactic tool to convey those embedded lessons to new assistants. The story conveys particular details about Frank and his response to staff turnover that would be important for people who live with him to be aware of. It also evokes a way of perceiving a person with intellectual disabilities that is not obvious to new assistants. For example, the story indicates the depth and complexity of Frank's emotions, and his awareness and potential vulnerability in relationships. It also reveals that Frank's feelings about at least some of his caregivers have grown to surpass employee status. This all highlights the unavoidably moral nature of engaging fully in dependency relations (Kittay 1999).

i) How narratives teach

This story also reveals something about *how* narratives can teach. Bruner argues convincingly that narratives are rarely innocent or "unsponsored" (1996:136-8). To grasp what he means, we must first consider how we learn to think about and interpret experience, and how we learn to evaluate experience in moral terms. Neither one is natural or obvious. Reiff (1966:261) suggests that what "is moral is not 'self-evident'... [but] becomes and remains self-evident only within a powerful and compelling system of culture."¹² L'Arche is clearly a cultural system, in that it prescribes moral norms, but a cultural system's effects go even further. It also provides the

categories of thought that construct *how* we experience life, and how we make sense of it. This in turn influences what parts of the flow of our lives we come to consider narrative-worthy, *meaningful* experiences. “What *counts* as experience is neither straightforward nor self-evident” (my emphasis) (Scott 1992b) (see also Turner 1986:35). So *experience* itself is always already an interpretation, and that interpretation has been partially shaped by listening to more experienced people’s narratives, which indirectly teach the listener what is significant.

Narratives thus teach through indicating, and thereby reproducing, the norms and parameters of a particular cultural system. Narrators choose to include certain experiences or events and not others in stories, which tacitly teach new caregivers *what counts* as experience or moral behaviour and what does not count (in this particular moral world). It is as important to attend to what themes are not included in stories. As Wikan argues, what is *not* said can be as telling about cultural values as what *is* said (1995:266). For example, in L’Arche, it is rare to hear conversations about a core member’s etiology, medical or psychiatric diagnosis or private history outside of team meetings dedicated to this purpose; this is considered disrespectful. This reinforces L’Arche’s desire to help others see them as individuals, not as their disability, and to mitigate against the tendency for people to see them as chronically sick or abnormal.

However, this unofficial narrative regime also has its shortcomings. Along with the sincere attempt to heighten assistants’ awareness of the gifts and lessons of core members by encouraging stories about them, a corollary tendency has developed whereby assistants seldom speak about *their* gifts or contribution to the home and the people they care for. Assistants’ gifts are discussed in annual reviews, or if the assistant is going through a hard time, but they are only a minimally sanctioned topic of everyday, informal stories. Some assistants found this lack of acknowledgment hard over time, and some felt it usurped their ability to feel good about their work and presence in the home. As one former assistant explains:

I guess the thing I found hardest was that there was little care or attention paid to the assistants, who were mostly these young, idealistic, searching people who were sacrificing a lot of themselves... [but] life mainly revolved around the people with disabilities ... and not the needs of the assistants.

Long-term assistants counter that they are aware of this concern but that a concentrated effort is required to enculturate new people into an appreciation of core members' gifts. Moreover, they point to the fact that L'Arche is not intended to be a therapeutic community for assistants. I cannot resolve this issue here, but it is important to recognize both the constructive and limiting dimensions of the subtlety of a narrative regime.

ii) Unpredictable effects of narrative

Assistants can have very different experiences in L'Arche in spite of the common culture. In this section, I discuss two caregivers whose time in L'Arche shared many common elements, and yet their responses to the environment were quite divergent. I argue that the enculturation of these two caregivers, or lack thereof, was in part the result of the strengths and limitations of applying narrative practices in everyday care. The first person is considered a L'Arche success story, while the second person's situation is not thought to have been fecund for him or those around him.

Raoul was 19 years old when he came to L'Arche after a year of university followed by a year working at small jobs. He became an assistant in Blue House, a home with a full complement of experienced assistants, in a community that was not facing any major issues at the time. Raoul thus received solid modelling by experienced assistants through stories, observations, retreats and formal training. By all accounts, his time as an assistant was fruitful for both himself and those he lived with and cared for. We had a casual discussion when he had been there for about a year. He talked about hearing a story, told by the pastor, Joe, that contained lessons similar to the story of Frank and Neil. I asked him whether that story affected how he interacted in the home with Jeremy. Jeremy is in his mid-thirties and loves country music, dancing with a

partner who wheels him about, and being with friends. He uses a wheelchair as his body is significantly underdeveloped and his muscles very tense. He does not use words to communicate although he often vocalizes. The following passage is Raoul's response to my question:¹³

Joe's story was pretty moving because he also talked to us about what we could do differently after that. But since being here, I've heard lots of stories from different assistants about core members. For sure looking back, all of it made me realise that Jeremy is a lot more than just someone that can't eat by himself and yells a lot. You don't think about that at first because you are just a bit overwhelmed by him. He's so different from anyone I've ever hung out with obviously. So it was hard to know how to relate to him. Like at first in the bath, I just sort of did the bare minimum of what needed to be done, because it felt odd to be in there with him naked – I didn't know what to do.

But later Chris told me a story about a time when he noticed how incredibly relaxed Jeremy's muscles and body got when he stayed in the bath longer, and how happy he seemed because the water eventually relieved the constant pressure on his joints. Still, he can't be in there alone—someone has to stay with him so he doesn't go under. Since he told me that, I've tried to stay in longer with him, and do different things to make it fun like playing guitar or reading, or even prayer. We both like music, and we've found one song to play that he really seems to like a lot! Anyway, I would definitely say that I am more in tune with him now—I can pick up on when he's feeling anxious or uncomfortable, like if some guest to the house is staring at him ... and I can respond to him better, I think. The same goes for other people in the house now—I am more creative now about trying to get inside their head to figure out what they'd like.

Raoul's case is a classic example of enculturation through storytelling, but it also illustrates two other points. First, as I noted with Frank's story, narratives teach particular details about caring for and relating to a certain individual well, but there is also enough interpretive latitude for the lessons embedded in them to be adapted to other situations. Second, it demonstrates how teaching through stories can give caregivers a sense that they are an important element in the caregiving mix, and not just doing physical labour. The latitude in stories helps caregivers to feel that their choices, interpretations and creative initiative will actually make a difference to the person's well-being¹⁴. This is so because, as I wrote earlier, narratives imply that things could have been otherwise without the (moral) agency of the protagonist. Narrative provides the assistant with the space to decide *how* to apply the lessons in particular situations

that are often morally ambiguous. As Raoul talks, he recalls negotiating and testing the moral terms of what is “due” Jeremy beyond basic physical care.

Liam was 18 years old and just out of high school when he came to the same community and house one year before Raoul arrived. In spite of living under similar conditions in the home and hearing roughly the same stories from the same people, Liam never seemed to grasp the ideas that were being conveyed to him in narratives. At L’Arche, there is a cultural reticence to give people direct orders on how to be or behave¹⁵, which seems to be a by-product of their commitment to diversity. With Liam, the issue was not that he did not perform his role well, but that he did so without actually believing in the value (for others or his own growth) of being that way. My aim is not to determine *why* that was so for Liam, rather it is to discuss how Liam and Raoul illustrate two important *limits* of narratives as enculturation mechanisms.

First, although narratives are often credited with conveying moral lessons (Narayan 1989), in many situations informal, everyday narratives are *morally ambiguous*. They gesture at a definition of appropriate behaviour but they do not provide rigid guidelines or prescriptions. In this case, for example, although a certain level of physical care and respect is required at L’Arche, the narrative form of teaching gave Liam and Raoul a degree of autonomy to decide what they felt was “morally sufficient” care for Jeremy. Thus, even when used as a didactic tool, narratives are generally used by narrators to hint at, rather than specify, the behaviour or belief they hope to evoke in their listeners.

Occasionally, the ambiguity of narratives plays a role in unfortunate scenarios with assistants. I interviewed a handful of people¹⁶ who had tried to confront their respective communities about how they were being treated personally, or regarding concerns about how the lived reality in their homes did not match the official rhetoric. All of them, however, found it hard to argue their case about unmet expectations because the expectations laid down in the narratives

are ambiguous to begin with. Assistants talk about how leadership uses that grey area or ambiguity to deflect criticism and avoid responding to it with clear answers (see also Johnston 1987:7). This issue deserves more attention than I give it here, but it seems to point to the need for a mechanism for processing anonymous feedback that would pose less risk to the assistant. For instance, keeping some kind of professional person who is associated with the community on a retainer fee to be available to listen to, and report back on sensitive issues and feedback. The person must be familiar with but external to L'Arche, (e.g. nurse, conflict management consultant, human resources consultant, therapist) and be broadly perceived as politically neutral and thus able to both hold the source of the feedback in confidence, and report back honestly and constructively on this issues. They should report to a committee of people from varying levels of experience in the community, including core members, in order to ensure openness and follow-up, or corrective, action.

To return to the two young men, the fact that Liam (*intentionally or not*) did not undergo or undertake the subjective transformation that most assistants do, suggests that narratives are *not binding*. Their efficacy is often based on the assumption that the listener is ready, or is willing, to accept the particular moral system that supports that reality. As has been explained in relation to the *limits* of the human rights model—you cannot legislate someone to care (Ignatieff 1984; Ignatieff 2000).

b) Identity production

L'Arche assistants also use stories to construct their own identities or sense of self, within L'Arche. This function of the narrative is covert, as it is a sub-text of the stories, which conveys information about the teller. People craft themselves and hope to influence others' perceptions of them through the role that they, themselves, play in the stories they tell (Kondo 1990; Wikan 1992:464; Fulford 1999:14). This tool is particularly potent and popular in L'Arche, partly because it is an environment in which many traditional tools and measures for crafting

one's identity, status and achievements have been stripped away or are not culturally legitimate in this sub-culture that advocates anti-materialist, anti-competitive and anti-individualist values.

Whether intentionally or inadvertently, assistants regularly infuse their stories with messages that represent their beliefs, prove their growth, elicit affirmation and acknowledgement, or enhance their status, authority and credibility by showing competence in core L'Arche values like patience, forgiveness or spiritual growth. Most often this works very well because of the shared understanding that it is inappropriate to express their personal qualities and achievements in a more direct way. There are, however, two problems with this practice in L'Arche. First, because it is indirect, the competitiveness that can underlie such messages is not usually named as such. Competitiveness is not culturally legitimate in L'Arche, so assistants sometimes tell the stories as if the identity/competition agenda does not exist in order to create the effect of an unsponsored story. In such cases, their healthy desire to give and serve can become lost, or at least disfigured and insincere.

There are also cases where people present themselves in stories as if they continue to enjoy the role of assistant, when those around them experience them as becoming stagnant, closed to change, or dissatisfied, but unwilling (or unable) to leave. The tacit claim to wellness in their stories makes it difficult to discuss other options with them. A few assistants even take advantage of the story-telling practice by telling petty or unkind stories about another assistant, which is much less productive than dealing with the person directly. This is not terribly widespread.

Second, the daily narratives often made the long-term assistants, appear destined for this vocation in their own stories. Although long-term assistants occasionally also share stories about times of confusion, these are infrequent in everyday settings, and tend to be shared in formal sharing or training sessions. While I am not suggesting that long-term assistants should reveal their vulnerabilities and uncertainties every day, I want to highlight how the relative infrequency

of such stories inadvertently creates an image for new assistants that may be misleading and unhelpful to overall organization goals. Many short-term assistants that I interviewed expressed that they liked L'Arche very much, but that they felt inadequate in terms of their commitment to the ideology or their ability to have good relationships with core members *in comparison with* long-term assistants.

The part they are missing, and which I was privileged to hear in interviews with many long-term assistants, is that these people also went through times of significant conflict and lack of understanding with the ideology, the lifestyle, the people and other dimensions of this calling. Fulford (1999) explains that our habit of treating history like a story, "keeps us from understanding that the final result was not preordained... A story implies that events had to turn out the way they did" (Fulford 1999:38). Instead, we must remember how people experienced events at the time when "[the] future for them was a matter of contingency, accident, surprise ... things we forget when we assemble events into stories" (Fulford 1999:38). Stories are powerful tools for engaging the imagination of caregivers and helping them to imagine themselves into a new way of being. Perhaps if long-term assistants had more systematic forums and forms in which they could relate their past experiences, they could be encouraged to add that layering dimension to how newer assistants perceive them. This concern deserves further attention from L'Arche given their current desire to extend assistants' tenures and to address the reasons why many assistants leave after just one year.

Other than helping people to position themselves in relation to others, the stories that indirectly tell us about the teller can be a healthy way for assistants to claim a degree of agency. Assistants use the stories to establish and express their interpretation of L'Arche ideology, or how they feel it needs to be adapted to suit a particular person, house or time period. Sam for example, considers L'Arche's message about "accepting people for who they are" as essential. This is

reflected in his behaviour with core members and assistants, and is also apparent in his stories, which tend to underscore his delight in people's idiosyncrasies. Lisa believes that the L'Arche attempt to minimize sedative and mood-altering pharmaceutical interventions is symbolic of the overall respect for people's rights, and her stories often reflect that belief. Everyday narratives help assistants to articulate, negotiate and express their agency, which lends intrinsic satisfaction to a vocation.

6.3 Strategies

To achieve the outcomes described at the beginning of this chapter, L'Arche uses three core strategies—redefining productivity as fecundity, revalorizing difference and providing care for the caregiver—in tandem with the tactics (storytelling and spatio-temporal layout). I discuss the value of these strategies in supporting L'Arche's goals through ethnographic examples, as well as the inadvertent side-effects that the strategies can engender in the culture of L'Arche. It is not meant to be an exhaustive list of L'Arche strategies, but rather an attempt to name those most salient to my analytical aims. Future researchers, with different questions and disciplinary backgrounds, could usefully add to these three. More space is given to the third strategy, care for the caregiver, simply because many examples and points related to the other two strategies are discussed elsewhere in the thesis. However, they are all equally important.

Ethnographies should be concerned with revealing both the desperations and aspirations of those we study (Cassell 2000:619). For this analysis, I have taken this directive to mean that the research should reflect both what people are aspiring to be or accomplish, and what sort of desire, deficiency or desperation with the status quo is the source of their need to do something differently. The three strategies discussed here are all notable partially because they are not frequently undertaken or employed in our society. In this way, the strategies reflect the agency of the assistants in their desire to engage the world in an atypical way. These strategies are both

conceptual and grounded in practice. They are adopted, adapted and sometimes rejected by assistants and core members depending on their own projects and particular aspirations.

6.3.1 Productivity redefined as fecundity/generativity

One of the core strategic concerns of L'Arche is to present and promote an alternative, broadened interpretation of the common Western notion of productivity. Doing so helps to create a space for (re)valuing the lives, gifts and activities of people with intellectual disabilities. I provide a detailed description of their alternative concept below. This strategy is reflected in what is expected of assistants, how "success" is measured for core members, and in how the organization's priorities are worked out. I discuss the ideological and spiritual history of this strategy at length in Chapter 4. Descriptions of how this strategy is enacted in L'Arche can be found in section 3.1 of this chapter, and in section 7.4.1. In this section, I briefly outline the strategy whereby productivity is redefined as fecundity, and describe how assistants understand the strategy. I then examine ways in which this notion of productivity contributes to some issues, such as the blurring of personal and work boundaries that can have an array of problematic effects for assistants.

In the following passage, Downey (1986:48) paraphrases Vanier's central thoughts on the place of standard ideas of productivity in L'Arche:

In accord with the original aim of L'Arche, work productivity, and efficiency, important as they may be to the growth of any group, are seen as secondary to human and spiritual progress. For Vanier, this kind of progress is rooted in receptivity, respect, and a profound desire to see each person in the community achieve the fullest development possible.

Productivity is important but it is secondary to more humanistic concerns. Following Vanier's early lead, L'Arche has come to advocate for the primacy of what the French commonly call "fecundité" as its alternative to productivity. Since fecundity is not commonly used in English, words like fruitfulness and generativity have been used in the English North American

communities. Henri Nouwen, A Dutch preist who lived in L'Arche Daybreak used to say "When we die, God will not ask us whether our lives have been successful; God will ask us if our lives have been fruitful" (MacMillan 2001). In an interview, Diane, a long-term assistant explained:

I wouldn't stay if I didn't feel that my life was bearing fruit. I think this aspect of fruitfulness is an important theme in L'Arche... the fruitfulness of core members' lives means acknowledging that they can give life to others.

Assistants are there to help create space within which to draw out those gifts. Fruitfulness is different in character from either merely producing physical care for people, or from a straight modernist notion of self-improvement. Jeff is particularly articulate about this. He is a former long-term assistant who lived with L'Arche in two countries. He says:

The whole idea of personal change—the majority of the time it's utilitarian and feeds into the capitalist ideology where 'better' is equated with productiveness, so the more productive you are, the better, or more valued, you are... At it's truest point, L'Arche is not intent to fix or better things, or make people something they're not. It is about being yourself, and unbecoming all the false stuff that we carry around... Again it is the example of the core members that compels us into that honesty.

The brief dictionary definitions of productivity, fecundity and fruitfulness sound quite similar and the latter two actually include the word productive¹⁷ (Sinclair 1994). In common parlance, the word productivity is more closely associated with capitalist enterprise and industry than the other two, and its definition is the only one including a reference to industry. In the West, the particular capitalist understanding of productive activities has become hegemonic since it is woven into our legal-political definitions in a way that limits other sub-cultural groups from choosing to follow an alternative way (Povinelli 1993).

The Latin roots for productive and fecund are not dissimilar, meaning "to bring forth" and "offspring" respectively (Sinclair 1994). It is salient here, however, that the root of fruitfulness or fruit, comes from the Latin *fructus* or *frui* meaning enjoyment. This seems to capture at least part of what L'Arche is trying to achieve in its redefinition of productivity as

fruitfulness, in that it refers to people enjoying each other's presence and having the time to learn to see, appreciate and celebrate non-traditional gifts. Living in a L'Arche house reveals that most core members enjoy and appreciate simply having your company as much as anything like how great you cook, or how organized you are.

Although I do not want to take up an analysis here of the validity of Erikson's psychosocial developmental model, I do want to introduce the term *generativity*, which he uses as a marker of adult virtue¹⁸. It resonates with, and adds clarity to, the L'Arche concept of fruitfulness. Coon (1989) says that:

According to Erikson, an interest in guiding the next generation is the main source of balance in mature adulthood. This quality, called generativity, is expressed by caring about oneself, one's children, and the future... In any case, a person's concern and energies must be broadened to include the welfare of others and of society as a whole... Failure in this, is marked by a stagnant concern with one's own needs and comforts. Life loses meaning...

Moreover, McAdams (2001) argues that:

A growing body of psychological research shows that being highly generative is a sign of psychological health and maturity. People who score high on measures of generativity tend to report higher levels of happiness and well being in life, compared to people who score low. High generativity is also associated with low levels of depression and anxiety.

Jack's (an assistant) experience echoes parts of the outward shift to generativity or fruitfulness:

I realize how much of my spiritual life before had been so striving-oriented; trying to overcome my own problems. Whereas now [after being in L'Arche] I see how much spirituality there is in the nurturing side of life. In making the choice to help others, and not just focus on my own stuff all the time... It also seems to bring out good things in me.

The L'Arche redefinition of productivity as fruitfulness yields many positive outcomes for all members of the community, and certainly for the quality of care and relations that can be provided. Still, this strategy creates a number of problems for the community. L'Arche is regularly required to justify their access to government funds for care by accomplishing a set of government objectives and tasks that are based on an understanding of caregiving that is different

in certain basic ways from that of L'Arche. In making the case for their approach and values, they are required to use the terms of dominant approaches, parts of which inherently preclude some L'Arche goals. In practice, internal research shows that the increasing time spent on requisite ministry paperwork and procedures impinges on the time that L'Arche assistants have historically spent just "being with" core members and getting to know them (Lukeman 2001), as I elaborate in Chapter 7. One house assistant, Kevin, explains his frustration with this situation:

There is so much paperwork now that heads of houses have to do all this bureaucratic crap. Who wants to sit down in the evening to do paperwork when you could be sitting down to be with one of the folks? And if you choose to hang out with the folks because that is important too, then you end up having to do the other crap on your day away when you should be resting!

Internally, the prevalent notion of fruitfulness often has the effect of blurring the line between what parts of the day constitute work and those parts that are discretionary time. Although L'Arche prefers not to use the term "work" when assistants discuss this particular subject, they usually make a clear distinction between "time on" and "my time" even when they genuinely enjoy being in the house. Although some of the intentional effects of this strategy are to create commonality and solidarity, the unintentional side-effects for assistants are not always healthy. Some feel that the blurring leaves them unsure of when it is legitimate to have time for themselves. If they are continually deferring their own needs, this can lead to exhaustion and resentment, which blocks their ability to care well. Noel, a former assistant, commented on this point, saying:

The difficulty I find with the foyer model is this lack of work/home separation. Yes this feels like my home, and I like people and I grow here; but it is also my workplace, even though we are not supposed to say that; but I give baths and do interventions for health and violence prevention, and I do the dishes and—you know, having them both so close together can get very tiring and confusing. You need space.

Although most assistants find ways to create and manage boundaries for their time in order to mitigate this blurring of lines, many still reported that they perceived a constant pressure

to rescind those boundaries. This concern is not unique to L'Arche. Other research with residential direct care workers revealed the tension they experience to defer their needs in favour of the clients' needs for sociability and control (Ungerson 1999:586). Although, as an organization, L'Arche in Canada has officially conveyed to new assistants that self-care and boundaries are important, sometimes the tacit cultural messages tell them otherwise.

This problem is not just about time away—it also affects the assistants' ability to feel a sense of accomplishment and confidence about the contribution or work that they have given. When the lines between professional responsibility and personal leisure are blurred, there is the danger that the labour, concern and responsibility of the assistant will go unacknowledged. Lack of acknowledgement can be an issue for many professions, but it is particularly hard for direct-care workers, who are asked to be emotionally engaged as part of their *job*, meaning that it is often not a choice. I do not want to overstate this point, or suggest that assistants are faking their enjoyment. Yet, not all aspects of work are enjoyable, and people have bad days that make even the normally-enjoyable, relational aspects feel like a burden. This fact should not be lost in the attempt to colour all of what the assistants do with a tone of fruitfulness.

6.3.2 Revalorizing difference

The desire to revalorize difference and disability is a central theme in L'Arche. This theme is so interwoven into every aspect of what L'Arche does that many dimensions of it have already been discussed in earlier parts of this thesis. The revalorization of difference in and for relationships is also the topic of Chapter 7. However, because the L'Arche approach to revalorizing difference promotes two concepts that are anthropologically relevant, I elaborate on those concepts in detail here. The first concept is their promotion of the social value of diversity, and the second is the effort to achieve a balance of power in relationships between caregivers and people with intellectual disabilities.

To begin, I describe the case that L'Arche makes for the value of diversity, and I situate it against two other arguments for diversity that commonly appear in the literature and public sphere. Then I outline how, within their moral sub-culture, L'Arche assistants attempt to shift the power imbalance that can occur in caregiver-core member relationships by making it their responsibility to learn to recognize the value of people with intellectual disabilities on their own terms. Such a turn in the regime of recognition helps to shift the terms of what counts as valuable. This strategy can also have the unintended side-effect of devaluing qualities that are required for strong leadership among L'Arche assistants. I close this section with a discussion of some of the problems that this situation creates.

Different forms of the case for diversity

There are various ways to make a case for the value of diversity in our society. The disability field has employed many of these in its efforts to secure resources for people with intellectual disabilities, and to lobby for social policy changes in their favour. I briefly outline some of the arguments for diversity, and which one L'Arche is pioneering. L'Arche does not aim to ignore the material reality of the differences that intellectual and physical disabilities create. It does, however, attempt to change the terms on which these differences are considered. They point out that while society's dominant values promote intelligence, independence, beauty and competition, these are culturally-shaped values that contribute to feelings of despair, inadequacy and exclusion at least as often as they produce happiness, regardless of whether one has a disability or not. Vanier writes that people with intellectual disabilities tend to embody another set of values, with which they are able to teach others about an alternative way of being in the world, if people are open to them (1995, 1998). Trevor, a L'Arche director, says that people with intellectual disabilities need a particular space in which to create this openness. Thus, he explains, "L'Arche is about creating community; a place where each person, Jack the banker or Alliya the core member can find a place to be respected and valued, and can use their gifts."

In order to contextualize the L'Arche position on difference, I outline three categories of arguments that have been made in the field of caregiving to protect or value diversity that stems from disabilities. The various types of arguments overlap to some extent, and approaches like community integration draw on more than one line of reasoning. I have tried to arrange the categories in terms of the degree to which they problematize the culturally-constructed stigma of disability and difference. I show that the aim of the argument in favour of diversity is to avert the stigma associated with impairment and to decentralize its place in people's identities. Difference matters, but it is important not to trap marginalized people in their difference (Tsing 1993:18).

The *basic* case for diversity is the humanitarian argument. It asserts that being human, alone, is the basis or criterion for worthiness of being treated fairly in society, *regardless* of a person's difference or disability. In this century, this line of reasoning is reflected in early hopes to support people with intellectual disabilities to [re]enter regular life through "rehabilitation," and later normalization, and most recently the disability rights movement. Clearly, however, caring for people in spite of this fundamental aspect of who they are leaves the negative construction of difference and disability unproblematized. This basic case continues to work from a deficit model of disability, although it argues that the person's rights still supersede their disability. This position has been instrumental in generating significant gains in the material quality of life, integration and access to opportunities for people with disabilities, and has culminated in the Americans with Disabilities Act in the United States. These gains are a critical foundation for the moderate and strong cases for diversity.

The *moderate* case for diversity is reflected in parent movements, self-advocacy movements, such as People First, and many spiritual and idealistic organizations such as Camphill, or L'Arche. The moderate argument differs from the basic case for diversity in two fundamental ways. First, it aims to change the wholly negative construction of difference by

arguing that the disability or impairment need not be an insurmountable barrier to commonality or relationship. In other words, people with disabilities are about more than their disability, and have *intrinsic*, individual value beyond merely their humanness. Second, the moderate case moves toward an ecological style argument, which says that community integration creates social diversity that is good for everyone because it contributes to our long-term cultural adaptability. While this case is more hopeful, it still does not fundamentally undermine the culturally-constructed stigma tied to the impairment itself.

The *strong* case for diversity assumes and endorses the first two cases. It goes beyond them, however, to say that the difference or impairment itself has *instrumental* value to enrich and contribute to mainstream society. Thus differences and/or disabilities are not merely tolerated or accepted because tolerance will not hurt, or because it is the “right thing to do.” The strong case also aims to undermine the belief that people with impairments always wish they did not have them or find nothing redeeming in them. This is not to say that people would wish for the impairment *prospectively*, but that they can see *retrospectively* how the cognitive or physical impairment is often connected with positive characteristics they have developed.¹⁹ From this position, L’Arche asserts that it is worth the effort (and cost) to support the inclusion of people with intellectual disabilities in broader society both for their sake, as in the basic position, but also for the broader social value generated for everyone. This seems like a more promising path for promoting genuine inclusion than asking the public to be nice.

Another perspective on the intrinsic value of difference comes from an aboriginal tribe who believe that individual differences, abnormalities and “idiosyncrasies are grist for the social mill” (Jackson 1995:100). Normalization approaches are effective in many ways, but they can go too far because they begin with the unsubstantiated assumption that what is “normal” in our society is also desirable for everyone (Vanier 1995:58-9). Difference matters and it need not be

equalized or flattened in order for people to get along, if it can be seen as enriching. The local moral sub-culture that L'Arche creates is crucial for facilitating this shifted moral outlook. L'Arche socializes people to a new moral sensibility in which what counts as "value" is broadened. This encourages people to see and appreciate the value of non-traditional gifts of people with intellectual disabilities. In the next chapter, I show how L'Arche operationalizes this principle into mutually growthful relationships across difference, in which the person with a disability is often named as the teacher. In summary, the strong case for diversity tries to (re)naturalize and de-stigmatize (but not romanticize) difference and disability by showing ways in which they can be understood as a gift, not a disadvantage.

L'Arche thus makes a case for the revalorization of difference and disability, but there are further concerns. Who is responsible to make the case, and who decides whether it is convincing? I address these concerns below.

Shifting roles in the regime of recognition

Marginalized people are often required to perform for, and establish their worth to, the people who control access to resources that they need. Those with the power establish what traits are valued in what Povinelli (2001) calls the dominant "regime of recognition." People with intellectual disabilities must conform to those norms in order to access necessary resources. The dominant regime asks the marginalized group to "show us that you/your culture has value as defined and calculated on our terms," even when such terms devalue or undermine the validity of the other culture (Povinelli 2001). People with intellectual disabilities are not the only group that must adjust to such regimes. In fact, many groups do not simply adjust but choose to "protest, reinterpret and embellish their exclusion" (Tsing 1993:5). The cognitive impairments of people with intellectual disabilities, however, means that this group is less able than some other groups, such as women suffragettes or black power activists, to engage in such creative marginality²⁰.

L'Arche ideology challenges the idea that the people with disabilities should always bear the burden of change by proposing that people without disabilities also be responsible for changing and learning to understand disability differently. L'Arche creates an alternative, *local* regime of recognition through their ideas, tactics and strategies that facilitate recognition and valuing of non-traditional gifts. This local regime shifts part of the onus of proving worth or value away from the shoulders of the core members and onto the assistants, who must learn how to operate in this inverted regime of recognition. Achieving this subjective shift takes time, practice and a conscious and concerted effort on behalf of the assistant. This is clear in Adrienne's discussion of how she felt about her relationship with Patricia (a core member) during the initial stages of their relationship, and how her feelings were different once she, herself, became more open to the value of knowing Patricia. She explains:

You know we stay away from saying that these are 'staff-client relationships'. I've been staff in a group home and it is a whole different experience. It took me a long time to understand the difference here because initially I came in with this model of 'Here's this helpless, handicapped person that I'm going to help.' That is what we're raised to believe, you know? As much as I wanted to feel differently about Patricia, and I'd say things differently with my words, it wasn't different in my gut or in my heart for awhile.

Eventually Patricia just cut through all of my barriers without my realizing that I was changing. I was moved by her acceptance and over time, her trust of me. She saw all sides of me—I mean, when I lost my patience or was in a bad mood—and she still accepted me for who I was. [Adrienne]

In undertaking this moral shift in perspective and responsibility, to learn to recognize the value in others' ways of being, many assistants report an accompanying shift in their own self-concept. The daily practice of learning to seek out what is good and special in others seems to help them do the same for themselves. Hyrniuk's (2001) research with L'Arche assistants discusses how this process helps assistants through regular developmental stages of overcoming feelings of shame, guilt and insecurity. The shift in the regime of recognition is an important step towards reducing the burden of stigma associated with intellectual disability.

Side-effect issue

In the spirit of the Beatitudes and Corinthians²¹ (1:27), L'Arche intends to raise the status of the weak and to remind people that the accomplishments and trappings of the mighty do not always make them wise or happy, and do not make them *better than* the little people in the world. This is a good intention that is largely effective in helping assistants to appreciate others who have more challenges to deal with in life. There are, however, unforeseen side-effects of the strategy of revalorizing difference that deserve some consideration as they may relate to the present shortage of people who are willing to take on leadership roles within L'Arche. Some would argue that within the current body of assistants there simply are not enough people with the skills to lead, and that the talents of these people lie elsewhere. Others argue that many of these people do have the skills but are not stepping forward to accept leadership positions. I can not speak empirically to the first possibility. My observations, though, suggest the latter, and that a cultural reason might be partly responsible for their reticence.

In raising the value of non-normative characteristics and behaviours, such as those often embodied by the core members, there is often a corollary movement down the value scale for more traditional gifts and skills. Although Vanier and other L'Arche elders never explicitly endorse this corollary devaluation, it is in some ways unavoidable as it is built into the ideology. For instance, a significant part of the training, practice and theology is dedicated to promoting the virtue of leading with your heart or feelings (as people with intellectual disabilities often tend to). It is not unimaginable then, that assistants read into this a sub-text which says that leading with the head or reason is considered sub-optimal in this sub-culture. Obviously assistants do not apply such ideas unquestioned to their whole lives. If the sub-cultural norms are strong enough, however, they may be more easily convinced to acquiesce and apply them within L'Arche.

I want to be careful not to overstate this point because the effect is subtle. In fact, people do discuss their talents and skills and also apply them within. Still, in many situations, I observed

reluctance on the part of assistants to claim talents and skills, or to take the initiative to put them to use. Moreover, the “leadership crisis” as the leaders of L’Arche named the problem in the 1998 Annual Report, is evidence that this issue is widespread. A psychiatrist, who has worked extensively with L’Arche assistants, speaks to this issue, although very tentatively given her ongoing relationship with their communities. She wrote that among skilled assistants in L’Arche there is:

... a reluctance to actively use this [prior] training and formal knowledge, ... an individual and organizational ambivalence toward knowledge and/or professionalism, ... [and that] there seems to be a need to undervalue knowledge and gifts validly earned—as if this pointed to some higher spiritual state (Johnston 1987:8-9).

Many long-term assistants, who are in positions of leadership, agree that this cultural perception is part of the leadership issue. Some feel that the perception stems from a flawed interpretation of the ideology, however. As one community leader, Sam, told me:

I suppose that somehow we [leaders] need to be more clear with people that the idea of valuing the weak does not mean we want everybody to *be* weak! It is sort of like ‘each gives according to his ability’ ... You shouldn’t resent or dismiss those who *can’t* give in traditional ways, or think you are better than them, but you also aren’t supposed to feel badly that *you can* lead, or organize outings, or pay the phone bill. You see what I mean? Assistants have to be encouraged more in sharing their gifts ... Some do seem very reluctant to do so.

Sam’s position seems reasonable. Yet, assistants commonly misunderstand this message. It may, therefore, behoove the communities to begin a dialogue concerning a more appropriate interpretation of the message around skills and leadership in order to allay people’s reticence.

6.3.3 Caring for caregivers

I have outlined many ways, including the previous two strategies, in which the L'Arche philosophy and model of care are counter-cultural. In this section, I focus on a general strategy that L'Arche has developed to help support the assistants to live this atypical lifestyle. L'Arche's third key strategy in the enculturation of its caregivers is the creation of a community of support. The community of moral support acts as a space in which people can develop, test, strengthen and question their nascent counter-cultural moral and political beliefs. After discussing the merits of this strategy, I identify two side-effects it can beget; first, assistants who occasionally get stuck in the supportiveness and second, tension from the sometimes conflicting needs and rights of caregivers and people with intellectual disabilities (see also Spink 1990:185).

The definition of "community" that I rely on comes from a classic ethnography of community and relational supports in the United States:

Community is a term that is used very loosely by Americans today. We [the research team] use it in a strong sense: a community is a group of people who are socially interdependent, who participate together in discussion and decision-making, and who share certain practices that both define the community and are nurtured by it. Such a community is not quickly formed. It almost always has a history and so is also a community of memory, defined in part by its past and its memory of its past (Bellaah and et al. 1985:333).

Several other authors have useful reflections on community that add to Bellaah's definition, including a sense of belonging and being important to each other (McMillan and Chavis 1986:11) (Bazinet 1995:19), and normalizing or legitimising the norms of your group (Kingfisher 1996:43) (Fraser 1994). Caregivers have been shown to require emotional, financial and respite support from a "community of concern" (Benner 1994:43; Kittay 1999), and the relational aspects of caring practices are now being studied and revalorized (Phillips 1994:10).

Some argue that since relationships between caregivers or typical people and people with intellectual disabilities are uncommon, there are extra pressures on such relations. A "community

of resistance” can help; it is a “group of people who, among other shared interests, recognize the negative effects of common beliefs and practices on their friendships and their friends and support one another to get on with their lives” (O'Brien and O'Brien 1993:34-6). While a community of resistance also helps to contain and subvert the larger pain of stigma, they caution that it cannot remove the pain or fix everything (ibid.:35). Similarly, some anthropologists argue that by participating in “cultures of resistance,” people contribute to future possibilities for structural change (Kingfisher 1996:161; Ong 1991:300), but also, importantly, engender “a new sense of self” and alter everyday attitudes, even if they do not always achieve broader political change (Ong 1991:304-5).

Establishing the need for support

L'Arche assistants need a supportive community because what they do is counter-cultural (Bazin 1995:15) and because their lifestyle is intrinsically demanding physically, mentally and emotionally. While I discuss such constraints in chapters four and five, I want to share some of the assistants' thoughts in order to help specify the nature of the difficulties. I begin with two stories about the counter-cultural strains that impact the assistants, and which often come from external sources. Benjamin is an energetic director in Quebec, whose reflections on society generally, and on his own experience, are articulate.

There are many reasons why it's been harder for us to attract and keep assistants in the last ten years. The thing is, we're not in the 70s anymore. Sociologically you see that at that time, [1960s] these ideas of resistance and poverty were all the rage, so people had models to follow. We don't have that today. Plus religion is not seen as cool right now for a lot of people. I mean *religion* not spirituality. So L'Arche is at odds with those trends.

After my time in L'Arche, France, I came back and started thinking about my life differently. My friends had a hard time with my new 'facts of life' because they weren't in the same place, and they were all still thinking about money and 'good' jobs. When I told them I was going to turn down a great job offer at a social agency to work for L'Arche when I graduate, they were all like; 'Are you a weirdo or what?' (laughs).

Renee has been involved with L'Arche in Nova Scotia as an assistant, a director, and most recently, as a board member for over twenty years. Her husband was socially involved, as well, but he worked primarily outside of L'Arche. They faced some difficulty in straddling the two worlds. In her words:

Ever since we got involved with L'Arche, we have faced people's judgement about it. A lot of our friends are academics and they say 'Oh it's so airy fairy.' People are anti-religious, or they've been hurt by the church, so they think it must be all fake and that we're just projecting what we want on the core members. To be honest, this disharmony still bothers me. I like to fix things and I want people not to misunderstand, but I can't explain it to them because they already think that I'm going to convert them! But in my prayer and my relationships in community, I come back to what is important—like the heart of John Frusciante²² [core member] and I am happy to know him as a friend.

There are also situations and working relations that arise from within L'Arche, in which assistants report feeling pushed to their personal limits and unable to resolve the conflict on their own. In my fieldwork, I observed many of the processes and mechanisms that L'Arche has put in place to deal with this. These seem quite effective given the complexity of most cases and the shortage of resources, which means that not every issue can be dealt with well. I discuss most of these mechanisms at length in Chapter 4, and in section 6.2.1 about spatio-temporal layout. The mechanisms include: accompaniment; small and large group meetings with time and space to share personal and professional concerns and grievances; short and long retreats to reflect and rejuvenate; regular team meetings where issues can be tabled; annual personnel reviews during which assistants are, ideally, helped to understand where they are doing well and where they need to make changes in order to stay well, inclusion in most significant decisions affecting their home and the community; support for them to seek outside counselling or medical help, as needed.

Particular scenarios of support

Each assistant has different things that they need to learn and areas where they need support. They bring some issues and needs with them when they come to L'Arche, and others

emerge in the context of their particular home dynamic. Therefore, there is no formulaic approach to supporting people. In addition, people ask for support in different ways, if at all, while others resist help depending on where they are at in their capacity to face, and work through the issue. At this juncture, I want to share the thoughts of assistants who have found the support to be sufficient. Later, I share stories from those who have not. Renee explains that L'Arche has strategic reasons for supporting both the people with disabilities and the assistants. She says, "In the group homes where I *used to* work, they focused on the growth of the people with disabilities only, and not the staff's growth at all. L'Arche uses the fact that we all have problems, make mistakes, and need to grow beyond them, to create common ground between everyone."

Benjamin explains that what he found most supportive was the guidance towards honesty and clarity with himself:

L'Arche was the first time in my life where I lived and worked in an environment that allowed me, or challenged me to ask myself *real* questions about my life. And that allowed me to find, slowly, answers that would help me understand my life and purpose. Why do I want to help others? Do I believe in God? Before L'Arche, nothing challenged me in that way. It was easy. And I guess I was ready for that... I liked how their culture was to look after people's growth with accompaniment, retreats, training, praying in the home, or interactions with my head of house. All of these are part of the discourse of L'Arche and I learned from them.

Anne-Marie was in an East coast L'Arche home and Shauna was in Ontario. Both were supported by the kind of guidance that Benjamin had, but for them the guidance was connected to particular situations of conflict in their L'Arche homes. Anne-Marie found the power dynamics between assistants and the head of her house hard to handle. Shauna went through an unhealthy period with a boyfriend and substance abuse that pulled her energy outside of the house and created tension. Although both explain that the support sometimes came in the form of hard truths about themselves that are difficult to swallow, in the end they could accept others' guidance and grow from it, as they believed that it was given in a spirit of help, not judgement.

I stayed because of the core members, and because I felt at home here. And I stayed because it wasn't easy. There were a lot of challenges and still are for me... But there are people I've lived with here who've cared for me enough to be honest with me; to tell me when they thought I wasn't doing well, or to put challenges in front of me in a way that I felt okay with where the criticism was coming from ... When you choose to live community, you are saying that you will try your best to be honest with yourself, and others, and try not to hurt people. I have been in meetings where very hard things have been said, but I think the most important thing if you're going to say something, is to know exactly where it's coming from. Why am I saying it? And if I can't honestly say that it's not personal, then I shut my mouth. [Anne-Marie]

I can look back now and see how bad what I was doing was for me [boyfriend, parties]. I gained so much weight, I was always tired, and also I was incredibly distracted in the house. I was never fully there and people in the house would say to me: 'You know it seems like you're here *physically* but not *mentally*'. I was always waiting for the phone to ring and rushing the core members through their routines so I could go out for the night, or talk on the phone. It took me awhile because I am very stubborn, and there were a lot of angry words shared from both sides. But eventually I came around and I have to say looking back, it definitely helped that they kept at me about it. It felt like they cared about me, even when I was like—screw you, I don't want your help! [Shauna]

Some of the tough feedback that these assistants talk about is given in private meetings with a head of house or accompanier. As Anne-Marie explains, "In our community we assign an accompanier or friend for each new assistant; someone that has been here longer, and is good at listening to people. It is not like therapy or anything, it is more to have a confidential place that you can vent, or bring things you are struggling with, or questions. We think it helps to curb gossip too." Shauna's experience with her accompanier came at just the right time. She says, "She really took me under her wing when I was just feeling so crappy being there. I didn't get along with the other assistants in my house then... She's almost like another mom for me now." Diane became an assistant after working for a few years and she appreciated the openness in the culture, to admitting when you needed help. In her words: "I've found it is a safe enough environment that if you come up against your limits, you are able to say so, and people will usually help you

through and not make you feel like a failure. I think it is the core members that establish that tone, because they are not hiding their dependency or what they can't do... Most of them anyway.”

It is also important to note that it is not just other assistants or leaders who provide the support that people need. Assistants sometimes seek spiritual assistance or therapeutic assistance from outside the community, and core members are often an immense emotional support to assistants when they experience rough periods. I provide more extensive examples of this in Chapter 7, where I show how assistants, for various reasons, often feel safer with core members, when they are being honest about their sadness. Other research has insightfully illustrated the psychological aspects of the healing and transforming nature of this relationship in L'Arche (Hyrniuk 2001). Adam, who has been a director in L'Arche for many years, describes the potential growth in relationships between core members and assistants as follows:

I think that when it happens well, and it doesn't always, then the assistants get a taste of what it feels like to have an impact; that they can make a difference for someone. And when they experience how the core people want to trust them, I think it helps them trust themselves, too. Especially when you're young and insecure—that fundamental trust is a very significant feeling.

The ethics of care and the deferral of needs

A rich literature on the ethics of care has developed in feminist philosophy. One concern that has been raised is the need to look at who is caring for the caregivers. The disability rights movement has accomplished substantial gains on behalf of people with intellectual disability, but these ethicists also draw attention to the vulnerability of the people who are direct caregivers as well (Tronto 1993; Phillips and Benner 1994; Kittay 1999). They argue that we all need a degree of care and the direct caregivers, who are predominantly low-skilled, low-paid and women (Braddock and Mitchell 1992; Ungerson 1999:589) can be particularly disadvantaged when they engage in formal caregiver relations with people who are dependent on them. As Kittay argues, such “dependency relations” often make the caregiver feel morally bound to defer her own needs in favour of her charge's because the latter's needs are more urgent (Kittay 1999:181). Over time,

this deprives the caregiver of her own freedoms and time for self-care, which ultimately leaves her unable to be a good caregiver for others, let alone an active citizen (Kittay 1999:181). Such theories are supported by research that shows that caregivers for dependent populations tend to be devalued (Ginsburg 1989:79). One North American survey of direct care workers revealed them to be at high risk of exploitation by employers (agencies and individual clients) who regularly use guilt to push the workers beyond their contractual obligations (Ungerson 1999:595). The workers capitulate both because they care, and because they do not want to risk being fired.

The pressure to defer your own needs is a contentious issue for some people in L'Arche, and this is a leading reason why people leave earlier than they would like to. Long-term assistants who agree with the current L'Arche model talk about how important and rewarding it can be to experience putting your own needs aside in order to be of service to others. Several assistants shared compelling, and verified stories about how their most significant personal transformation [their phrase] occurred during periods where they were significantly short-staffed in a house, and they were really pushed to their limits. Some claim this even when the experience pushed them to the point of exhaustion and burnout. They do not argue that new people should be pushed that far, but they feel that if new people are not allowed/encouraged to test and explore their personal limits, they will not have the kind of stimulating experience that leads to radical change and commitment. Jack is a good example of a new assistant for whom that belief resonated. He stayed on as head of house for several extra months, even though he was struggling with it, because the community needed him. What follows is his explanation for staying during that period:

I usually go with whatever I feel like, but in the house you can't always do that— You have to be there for people. You know there are times when you don't want to be there or you're feeling a little out of it... I realized that the way I was going to grow (knowing my nature) is through commitment to others; that it would draw the best out of me, and it has.

A few long-term assistants, however, expressed degrees of concern about the long-term implications of encouraging new assistants to defer their own needs where, as they see it, L'Arche does not adequately value or support the assistants. These long-term assistants feel that the community sometimes takes advantage of the goodwill and idealism of assistants, and then, ironically, wonders why they do not stay longer. This concern touches on a larger question for any community of support: Who are you supporting? In other words, when caregivers' and core members' needs are in direct conflict, how does the ideology direct people to resolve the conflict? These are significant questions. Noel, a friend of the community and former assistant, is articulate (if bold) on the subject:

It is always approved of if you put the needs of the community first. The individual [assistant] is not seen as having needs that are as important as the community... We say to new assistants—'Here is the structure and schedule we propose. Put your needs aside for the year. 'No you can't go to the movies at night', and so on. And then after that year, we ask them to stay! But they've gotten the message that we don't really care about them having a life, we care about the core members' lives, but for assistants, just give us your service.

There are specific ways that L'Arche supports and not others. It is a bit like a relationship. When you start you are in a certain place, looking for certain things and that is good and it works well. But at a certain point, if you say, 'Wait, I am more than this; I have discovered this new thing about myself and I want to explore that.'—Well then there's trouble. If that thing doesn't fit with their ideas, they act like it ruins the symbiosis.

The need and challenge of limits with an ideology of diversity

In the passage above, Noel speaks with intentional rhetoric to make his point. Even so, he indirectly names a key challenge for L'Arche. An intentional community, by definition, is about achieving particular intentions, necessarily to the exclusion of other, often equally worthy intentions. It simply cannot accommodate every different way that people would like to live in community or it would fall apart²³. Since L'Arche is centrally concerned with valuing diversity, it is in an unusual ideological bind—which of the assistants' diverse needs, ideas and opinions can it address, and which must be put aside? How diverse is too diverse for one place? Difference, it

would seem, has its limits, even in L'Arche. I interviewed several former assistants, and heard stories about many more, who were disappointed and hurt that they did not receive the kind of support that they anticipated when they presented their divergent ideas and/or needs to their communities. At the time, they felt that their treatment was fundamentally incongruent with L'Arche's explicit ideological commitment to accepting people for who they are. Although in our interviews a few people still felt that their community should have accommodated them, most had come to terms with what had happened²⁴. Either way, all felt that the worst pain came from a sense of injustice at what they perceived to be a subjective process, lacking in clarity and directness.

The organization's inability to admit or address this discord seems to stem from a tacit, collective aversion and refusal to name the limits of their capacity, as a single organization, to accept everyone. It is as if they feel (fear) that to do so would discredit their ideology. The opposite is true. The L'Arche ideological commitment to acceptance of diversity does not specify that it must all be accomplished within its four walls. For a small organization, it already contains tremendous diversity, but it cannot, and should not, accommodate people and needs that undermine its fundamental values. That is not to say that the organization should stop listening when individuals raise tough, but important issues, nor should it be implied that L'Arche cannot accept suggestions or criticisms at all. L'Arche simply lacks a clear organizational statement about its real limits. This means that people who are not being supported to stay, or supported in the way that they expect, experience this as an intensely personal rejection, as opposed to simply a lack of fit. With a clear statement in hand, L'Arche will be able to provide assistants with an unambiguous rationale for any decisions to limit their engagement of discussion of other issues.

The side-effects of a supportive community

The final problem, which I see as being created by the ideal of a strong community of support, is that some members of the community stop looking outward—beyond the limits of the

L'Arche community—for places to direct their energy, ideas and knowledge. There are two elements to this problem. First, I noted earlier that helping people to feel safe and comfortable in L'Arche has sometimes meant that assistants become unable or unwilling to step out of that environment and take on new risks, relationships and interests, whether inside of or beyond their home and community (Johnston 1987:8). When a house assistant stops growing and accepting new challenges, they are often less welcoming of new people or other changes in the home. It can be very difficult to bring that assistant to a place of honesty about why they are not stepping up to new responsibility. Simone, a director, feels that if long-term assistants do not model this energy and risk-taking themselves, they can not expect to inspire transformation in new assistants. Sara, a long-term staff member made this insightful observation:

Watching assistants over the years, I see that when you come to L'Arche, your horizons go 'whoosh!' [widening gesture], and you are way out there, and your tunnel vision is expanded and you see everybody and everything in a totally different light. But a lot of times, you stay on and your vision starts to do this [narrowing gesture], and then you only see the L'Arche point of view. The philosophy blows you out of the water when you start, but I think after awhile you have to find other ways to keep broadening your horizons.

The second concern that arises when assistants feel reluctant to venture outwards is that the radical aims of the mission, to seek to change the conditions of oppression for people with disability, are not transmitted to the larger, non-L'Arche community. If an assistant's energy is all directed within L'Arche, they will almost certainly lose interest in the externally focused, radical socio-political aims of L'Arche that seek to change the conditions of oppression for people with disability. In her biography of Vanier, Spink briefly suggests that L'Arche has been criticized for being too personalist and conservative, and for its focus on individuals, as if change in social structure were out of reach (Spink 1990:185). Furthermore, if the assistants stop looking outside of L'Arche, they forgo the benefits of understanding their work within a broader context. Several assistants, and more than one board member whom I interviewed, noted that although they

support L'Arche 100%, they felt that many assistants became too removed from "real life." One board member, Sunil, was disheartened because he felt that L'Arche assistants sought assistance from the local community and neighbours but rarely offered reciprocal support for local community projects to help others.

There were three key points in this section on the creation of a community of support. First, to ensure the long-term success of L'Arche, the agency should consider that support of its assistants is, in fact, an aspect of their mission; one that is secondary to, but necessary for, supporting the well-being of core members. Assistants are the single most important and expensive operating resource in a direct care organization. Therefore, it makes sense to invest in them, aside from being a progressive ethical decision. Still, L'Arche needs to invest energy into clarifying what kind of support they want and are able to give to assistants, in order to mitigate the anxiety and suffering of those assistants who are not supported to stay, and those who are still there and contemplating their future with L'Arche.

6.4 Conclusion

Findings in this chapter relate to the main question of the thesis: how to motivate and enable assistants to reproduce the radical L'Arche ethic of caregiving. I named five key elements of the ideology and process of enculturation in order to illuminate both their positive outcomes and unintentional, sometimes harmful side-effects. While the ideals are important, the willingness and ability of direct caregivers to enact them was shown to be as vital to successful implementation. New approaches to care often neglect to address ways in which their goals for improving the lives of clients often involve demands of caregivers which are in direct conflict with the caregivers' own needs. It is important to provide caregivers with a reasonable ideological rationale for why they should enact the changes well, and then support the caregivers to sustain those changes even when challenging.

I described the structures and uses of space and time in L'Arche, to show how powerful it is when organizational ideals are reproduced in elements of daily life, but also how hard it is to execute. The discussion of redefining productivity to include time for relationships contributes to the importance of practice in assistants' moral transformation. Informal story-telling among caregivers about their experiences with people with intellectual disabilities, is shown to produce a sense of commonality, and to humanize perceptions of disability through emphasis on each person's particularity. The stories help to indirectly establish *what counts* in L'Arche, and helps assistants learn to recognize the unconventional gifts of people with intellectual disabilities. I also outlined the possibility of the L'Arche model of difference being translated into a more general case for the social value of diversity and inclusion of people with intellectual disabilities.

6.5 Endnotes

¹ I borrow the phrase "local, moral world" from Kleinman (1995a:96) to refer to a localized system of beliefs and behaviours in which participants develop a particular set of moral beliefs to suit their situation.

² Other research has taken up this question (see for example Pottie 2001), but confidential research done with core members exclusively, and in particular an attempt to compare the well-being of L'Arche core members with clients in other agencies would be valuable.

³ Cross-cultural research shows that this discomfort is not universal (Ingstad and Whyte 1995), suggesting that part of why it doesn't feel natural for most Canadians, is that we have already been socialized with stereotypes that shroud intellectual impairments with stigma. How we *experience* them is thus not unmediated or natural, but is rather already laden with interpretation. L'Arche tries to replace that interpretive framework with a different one.

⁴ I am aware that "authenticity" is a controversial term in current anthropology; assistants used it frequently though, to imply narrowing the gap between their values/beliefs and actions.

⁵ It is important to note that detecting their problems can be very difficult; Canadian research shows massive under-diagnosis of health issues like mental illness or depression in people with intellectual disabilities (Lunsky 2002).

⁶ An interpretive refusal (Ortner 1995: 180-90) occurs when one does not name *all* the parts of a cultural process, (here, teaching by *both* core members and assistants) for fear that doing so would discount the power of one's *desired* message, (here, that core members can teach). I believe that naming both elements here, will in fact make that main message *more* believable to sceptics.

⁷ While Young's aim is to show the questionable outcomes achieved through application of ideological techniques, my aim is to show L'Arche's use of similar techniques but for positive outcomes. See Geertz (1973) regarding how ideology as a concept has been cast unnecessarily negatively in anthropology.

⁸ Ortner urges anthropologists not to "dissolve actors" into groups or read their actions as if they were solely motivated by a single goal like resistance; ethnographies should name the multiple projects and differences among group members and include it all in analyses (1995:176-7). Agency is "the capacity of social beings to interpret and morally evaluate their situation and to formulate projects to try to enact them." (Ortner 1995:185)

⁹ After I had developed these four categories, I came across a reference in a series of lectures on narrative that suggests that the categories may be common: Fulford wrote that “Stories are how we explain, how we teach, how we entertain ourselves, and how we often do all three at once.” (1999:9)

¹⁰ Bruner suggests that good storytellers know how to create interesting variations on the same old themes and thereby make us “consider afresh what before we took for granted” (1996:140).

¹¹ Some people might feel that having assistants telling the core members’ stories smacks of paternalism or appropriation of voice. That interpretation is ungrounded for four reasons; we all tell stories about ourselves and others all the time and core members in L’Arche who can, tell their own stories, and are listened to. Second, in many cases the people there cannot tell their own story and so having the assistants perform this surrogate role is the only possibility. Third, power issues decline when the storyteller is engaged in the same life path, accountable and vulnerable to the consequences of telling the story inaccurately or dishonestly (Stoller 1994). Fourth, stories do not exist in a vacuum; assistants can test for viability of a story against the actions or silences that they observe in the core member in other settings.

¹² Rieff is discussing what was Freud’s assertion (Freud 1960).

¹³ This is a reconstruction of the conversation from memory, not a transcription

¹⁴ Jackson (1995) links human fulfilment to feeling that what you say *matters*.

¹⁵ Unless the situation was potentially harmful, of course.

¹⁶ I group their stories together because I feel that giving more particular details is potentially harmful.

¹⁷ **Productive:** producing or having the power to produce; industrial output; yielding results. **Fecund:** greatly productive, fertile; fruitfulness. **Fruitfulness:** bearing fruit in abundance; productive or prolific.

¹⁸ See Hyniuk, M. (2001) for a more extensive review of the model (Erikson 1980).

¹⁹ This thought was inspired by a conversation on Wendell’s research with narratives of pain (2002).

²⁰ But see Desjardins, M. (2000) for a strong alternative perspective.

²¹ “God hath chosen the foolish things of the world to confound the wise; and God hath chosen the weak things of the world to confound the things that are mighty” St. Paul.

²² Not his real name.

²³ Vanier recognized the need for limits early when he had to turn away some needy people (see Ch. 4)

²⁴ Most came to feel that either it was not a good fit, or that L’Arche simply was not organizationally well-equipped to deal with certain sensitive religious issues (e.g. divorce, pre-marital living arrangements, and homosexuality). This does not mean that L’Arche was right, just that people have moved on.

7.0 Negotiating Mutuality Across Difference and Inequality

7.1 Introduction

All L'Arche assistants share two things in common whether they stay or leave, and whether their experience there was nourishing or difficult. The first is their shared experience of learning to be more open to people who are very different from themselves, to appreciate, and eventually like, the endearing qualities of people with intellectual disabilities. The second is the near-universal skeptical response that assistants get from people outside of the organization or field when they say that they value and enjoy these relationships. It is very hard for people to imagine how such a relationship could really be anything other than charitable, professional or sustained by pity. People who visit the communities or meet an assistant and core member out grocery shopping will tell the assistant, "You are a saint," or "I don't know how you do it but God bless you." Assistants tend to bristle at such suggestions, and offer up some sort of corrective like "No, no. Peter's great; *he* puts up with me!" or "Hey I wouldn't do it if I didn't enjoy it."

The assistants' discomfort with the dominant view of people with disabilities (reflected in people's sympathy) is at once evidence of their subjective transformation and their subsequent naturalization of it. The capacity to get behind difference and disability to know the person is learned not natural, or at least it must be *relearned* by adult assistants who grew up learning standard stigmas about disability¹. Their new subjectivity emerges not by chance, but from

experiencing difference framed within the powerful counter-cultural L'Arche ideology. This transition often gives the assistants a sense of having grown. The tendency in L'Arche to naturalize such relations can unfortunately rob them of that feeling and dampen their initial sense of radicalism and social injustice, an otherwise potent source of motivation². These relationships *are* still unusual in our world even if they are common in L'Arche, and this should not be forgotten.

There are many important configurations of relationships in these communities, but in this chapter, I focus on the relations between caregivers and people with intellectual disabilities³. These relations are at the core of the L'Arche mission and embody their key spiritual, moral and political aims. In addition, such relations are not well understood in the literature and form an illuminating case of working with diversity⁴ (see also Pottie 2001). I evoke a sense of assistants' subjective transition in openness towards these mutual relationships. While the instrumental value of better caregiving *relations* to the "client" has been well-established (Amado 1993a, Heal 1988, Phillips and Benner 1994, Steinhoffsmith 1999; Cushing and Lewis 2002), the value to the caregivers is less thoroughly understood and I take that as my focus here.

Whenever I spend more than a few hours at the Shalom House, it is a sure thing that Frank, one of the first core members in L'Arche in Canada, will gently take his pipe out of his mouth, turn his steady, blue-eyed gaze towards me and ask, "What does your father do, Pamela?" After considering my response for a moment, he then asks me, "How long have we known each other?" No matter how many times he asks me these questions, it still makes me smile. I do not know for sure what it means to Frank to ask people these questions, but there is something direct about them that make me, and many others, feel touched that he cares to ask, and to remember. During dinner conversations where a question comes up about a former assistant, people often turn to Frank for the answer. Invariably, he recalls that name that no one else can remember.

In Chapters 5 and 6, I discussed assistants' motives for being in L'Arche and the process of enculturation for them into its alternative approach to care. These represent the individual and organizational preconditions for what kind of caregiving and relationships can transpire. Analyzing and illustrating what actually happens is the subject of this chapter. I use ethnographic examples from observation and interviews, to evoke a sense of what mutuality looks like in the actual relationships possible in a framework of care. I outline the barriers to these relationships and how people with disabilities help caregivers there to overcome some of the barriers.

There are many ways to define, conceive of, and assess the benefits of mutuality. There is some disagreement on whether it is desirable or ethical to promote mutuality between people who are different and unequal. I discuss formal and vernacular definitions of mutuality. Regarding why some caregivers (in and outside of L'Arche) want to have such uncommon relations, I share various ethnographic stories that illustrate their experiences and movements towards a new way of being and eventually to mutuality. Finally, I sketch the power dynamics inherent in these relationships, revealing the richness and challenges of negotiating mutuality in practice.

7.1.1 Themes

On a thematic level, this chapter is about three things. Fundamentally it addresses the question of what to do with difference. It does so by examining a sub-culture that revalorizes difference and creates a viable rationale for a sociology of acceptance and diversity that does not rely on the tired normative aphorisms about how people "really ought to" behave.

Second, the stories in this chapter illustrate how contingent and false the culturally-constructed stereotypes about people with intellectual disability are. As I outlined in chapters three and four, many tales have been fashioned about them that construct and then reproduce stigmatizing axes of difference, which also function to keep them marginalized and physically

separate. This ethnography illuminates an alternative reality through discussing perceptions and relations that can and have transpired under a different ideology.

Finally, this chapter is about the valuable contribution made by adding *caring about* through relationships to the *caring for* process. This is not a new assertion (see also French 1985) but I address two uncommon aspects through this case. First, caring is often argued for on the grounds of its benefit to clients (Taylor and Bogdan 1989:33; Amado 1988a, b; Phillips and Benner 1994) while I emphasize how relationality also enhances the caregivers' experience and makes them better caregivers. Second, caring is often seen as a complementary but separate, non-essential addition to the curing and technical (scientific) competence (Good and Good 1993:91; Chambliss 1996; Phillips 1994). My analysis however, suggests that while analytically distinguishable, in practice, caring relations can be integral to treatment efficacy. As Bellah put it, "The distinction needs to be drawn between caring as a sentimental psychological attitude and caring as a responsible practice, aware of its own limits" (1994:21). Although the L'Arche approach to relations is not a fully realizable prototype for most mainstream settings, where caregivers do not live in, and the caregivers and clients may not share common ground regarding community and spirituality, (see also Pottie 2001) their experience offers a challenge to dominant views of difference and the distancing practices they sanction between the people with disability and their caregivers.

7.1.2 Ethics and interpretations

Three points about the ethical delicacy of discussing stories that include people with intellectual disabilities need to be reiterated. L'Arche increasingly realizes the importance of protecting the privacy of people in their care. Thus, while I try to keep each person's unique character intact, I provide minimal particulars of their medical and personal histories. This does not compromise the value of the stories and reinforces the maxim that asks us to see them as

people first, not cases. Interpreting the meaning of non-verbal people's expressions is an uncertain and iterative process that a caregiver learns over time and through multiple indicators (Tronto 1993:137; Kittay 1999:157). Several of these scenarios involve non-verbal or verbally-limited people and I restrict interpretations of their motives to what has been deciphered with relative certainty by the caregivers involved.

7.2 Defining mutuality in caregiving relations

“Normative mutuality is a relation in which all who participate bring out the best in each other and help each other to live fully.”
(Steinhoffsmith 1999:21)

“When I say my people, I don't mean that I am their shepherd and look after them; I mean that they are written in me as I am in them; they are mine as I am theirs. There is a solidarity between us.”
(Vanier paraphrased from Spink 1990:151)

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. My discussion of mutuality is centrally concerned with caregiving relationships where difference, inequality, and professional ethics and obligations play complicating roles in how and why the relation develops, and which usually require greater effort and nurturing to be sustained.

There is no simple definition that adequately explains what is meant by mutuality in caregiving at L'Arche, so I take the next few pages to disentangle the elements of it. This basic explanation is illustrated with ethnographic examples in sections 7.4, 7.5 and 7.6 of this chapter. I also address what motivates the caregivers to be willing and able to enter into these intensive

relationships with people with disability who are, sadly, not normally considered worthy candidates of such relational engagement with typical people.

In L'Arche, mutuality is both *general and particular*. It is promoted as a general way to approach all relationships (including caregiving) in a spirit of openness and respect, especially in regards to reaching across difference and inequality. General or ideological approaches, however, can lack in depth and specificity. L'Arche leaders learned from experience and from observing many new assistants, that mutuality is most effectively developed or deepened in the particulars of specific relationships. In other words, mutual care means caring for and about a specific, unique person rather than as a category of client (see also Steinhoffsmith 1999:182-6). Charles Taylor concurs and adds that good caregiving is motivated by respect for the particular person, not just abstract ideals (1994:183; see also Phillips 1994:14-15; Thomasma 1994)⁵. Clinical experience in pastoral care convinced Steinhoffsmith that engaged, co-operative, "interested" care as mutuality is more effective than disinterested charity, which can end up condescending to the recipient (1999:184).

Caregiving relationships are invariably occasioned by the clients' need for assistance from the caregiver. It must be acknowledged then that this is always initially and fundamentally an *instrumental relationship* based on the caregiver's ability to meet the client's needs. Their relation is thus never free from the inherent imbalance of the instrumental motive, even though their mutual feelings may grow to encompass much more than that. That inherent imbalance has been the basis of debates in moral philosophy and practical medical ethics about what kind of relationship is possible, and whether it is even ethical or desirable to nurture one. The professional prohibition of relationships between therapists and their clients is a common touchstone for these debates. Hingsburger argues that when the caregiver, therapist or healer initiates a relationship with a client, the client is put in a position where they may feel unable to

refuse the friendship for fear of jeopardizing the quality of care they receive⁶ (2001a). This is an important point and the clients' freedom does need to be protected. However, in the case of people with intellectual disability who are so lacking in social contact, it is hard to see the logic in prohibiting relationships with their caregivers as well. The cure would be iatrogenic; worse than the risk or potential problem. It seems more appropriate to put checks and systems in place that monitor whether these relations are voluntary and healthy, as L'Arche does.

Philosophers who have postulated the conditions for "ideal friendships" have typically argued that instrumentality or inequality preclude the possibility for true mutuality (Aristotle 1976, Buber 1970, Lewis 1960). Feminist philosophers and psychologists would argue that these so-called ideals are not natural but rather rooted in particular, contingent values and a world-view salient for [some] privileged white males, but not the majority of people (Gilligan 1982; Jordan 1991). Those ideals assume that total autonomy (or lack of instrumental motive) is possible in life, and desirable in relations, whereas theories of the centrality and unavoidable place of relationships in our lives (Jordan 1997), and of our moral connectedness in social networks of relations (Kittay 1999; Chambliss 1996:2-4), significantly unsettle those assumptions. Instrumental motives and interdependency need not be pathologized or treated as sub-optimal ways of being. Finally, the model of mutuality at L'Arche is not even focused on such "ideal relations" but rather on the process or movement towards mutuality.

The notion of mutuality in relationships at L'Arche is concerned with the *process* or subjective shift of learning to be open to the value of difference, more so than with its ideal end product, or *outcome* which is a mutual relationship across that difference. Their books, sermons, and emphasis on daily practice all reiterate that the movement towards openness to mutuality is an end in itself. Vanier often emphasizes this daily openness as primary (Swanekamp 2000; Pottie 2001:30-32), whereas Martin Buber (1970) emphasizes the "heightened moments" of connection

possible in mutuality. There are thus degrees of mutuality (Buber 1970:178; Berry 1985:41).

Most people at L'Arche would agree if heightened moments do emerge, they are usually the fruit of the daily openness. Most stories about relationships that assistants tell informally or formally, are not about extraordinary or mystical events per se, but are rather ordinary interactions that are made more meaningful through the assistants' interpretation of them within the L'Arche-Beatitudes paradigm of "the weak" as teachers of the "strong". Since most assistants are enculturated with Western values, such interpretations are not immediately obvious or natural, but need to be re-learned.

The fourth element of this explanation of mutuality involves looking at the embedded *models of reciprocity*. Mutuality and reciprocity both refer to a flow of giving and receiving between parties and are often used interchangeably. Some have argued that reciprocity as a model for social relations can hurt marginal or disadvantaged people who cannot return what is given "in kind" and are not then "due" anything (Gewirth 1996:77). Similarly, Kittay is concerned with what counts as a "return" gesture since people with intellectual disability "cannot reciprocate the care or concern the dependency worker" gives them in an equivalent form (1999:54). Mutuality has been used to refer to systems that attempt to include a wider range of gifts (often intangible) in their notion of exchangeable units (SteinhoffSmith 1999; Carruth 1997). These analyses are progressive and thoughtful, but they still employ exchange theory, although their concern is relationships, not things.

After observing the interactions between caregivers and people with disability at L'Arche, I argue that this "exchange reciprocity" script also exists in how caregivers think and talk about what they are doing, even though they are also engaged as employees. Although the market or commodity economy legally defines these caregivers' contractual relations, much of the discourse in L'Arche reflects notions of a "gift economy" in how they talk about *giving* time,

love or extra effort for the core members over and above what might be expected or required of them based on their financial compensation. Interestingly, this discursive strategy included the paid administrative and accounting staff, who are not “community members” but still felt that they “gave” more than what was professionally required of them, out of their sense of caring and morality. French and English assistants commonly say that an attitude of mutuality involves *gratuité*, which they define as “giving without counting the cost,” or “without expectation of return”. While that is an admirable ideal, it seems inhumanly angelic, and I did not observe that to be necessarily true.

Given the low wages in this field of work (Braddock and Mitchell 1992) and also in L’Arche, many caregivers across the field resist (legitimately, I think) some requests by employers to engage in often draining *emotional labour* on top of the physical care that they are “being paid to do” (Rhodes 1993, Chambliss 1996). So when they do give more, it is not surprising that this is often accompanied by a tacit and even pre-cognitive or intuitive feeling of wanting some kind of return for their effort, even if that is just acknowledgement from the client or colleagues. At L’Arche for example, this is currently manifesting in long-term assistants’ expectation to be financially supported in retirement (Lukeman 2002).

In Parsons’ theory of the sick role, a patient could return the “favour” of the privileges of temporal liminality that a healer affords him, by complying with his role obligations to seek help, get better and be thankful (1951:436-7). “Society is willing to legitimize sickness as long as one follows culturally determined conventions of being ill, such as trying to regain health as quickly as possible, or accepting medical help in overcoming the illness.” (Christopoulos 2001:2) This model is insightful in pointing out the roles and expectations by which typical people are operating when temporary social disequilibrium is created as a result of someone getting sick⁷.

Ideally, patients and healers together restore equilibrium through compliance and treatment. However, when the patient's condition or illness is chronic—as in the case of the aged, people with severe cognitive injuries and people with intellectual disabilities—they are in a state of permanent liminality and more or less permanent dependency which does not allow them to fulfill the sick role expectations⁸. The tension arises from the unresolved imbalance created because while the caregiver is constructing her narrative using a reciprocity script, the person with intellectual disabilities is either not aware, cannot, or does not want to fulfill their tacit role in that script⁹.

This imbalance is uncomfortable for both parties over time and is why some corrective mechanism is needed. While many caregivers feel resentment or burnout from the imbalance, the care receiver can also experience his inability to give in particular ways as painful, shameful and unbearable. The power and pleasures of the *giver* have been discussed by many authors (Mauss 1954; Vanier 1998; Appadurai 1986:11-13; Silverstein 2000:141). The impact of the imbalance on the receiver was addressed in a sermon by Joe Vorstermans at a L'Arche retreat for new assistants. Joe urged them to look beyond their initial concern with the value *they provide*, to imagine how hard it must be for core members to feel that they do not have much to give that anyone wants to receive. Joe suggested they reflect on how the core members that they live with enrich their lives, or help them, and to remember to name and acknowledge that “gift” to the person directly¹⁰.

This idea serves to resolve the tension of imbalance for the caregiver in that she now has an immediate and ongoing source of reciprocity in the gift of the core member's life/presence. In this way, L'Arche has effectively created a new *unit of value* by broadening the definition of value and what counts as reciprocity to include “gifts of self” that do not require intentionality, equivalence or transfer of ownership. The unit has value only because they have invented

meaning and a need for it, but this is also true of most value assignments (Silverstein 2000). This echoes the notion of generalized reciprocity in allowing for diverse sorts of returns, but differs in that the expectation or timing of return is not deferred indefinitely (Sahlins 1972:185-195). So this model does not go beyond exchange theory, but rather accommodates it along with the clients' unusual gifts.

The fifth element of mutuality in L'Arche flows from the previous element and that is the way in which mutuality is in part a *moral, spiritual and political project of solidarity* with those who are marginalized. In daily life and interviews, L'Arche assistants described mutuality in caregiving as aiming in part to reach across difference and inequality to know (*connaître*) and support the disenfranchised person. It is a daily mode of relating to people that seeks to find and cultivate common ground to acknowledge their shared humanity. Erickson calls this sense of commonality "co-membership" (1975 in Kingfisher 1996:43). As Adam, a community leader, put it, "Mutuality is about *intentionally* staying open to the diverse people that come into our lives in community." The subjective shift towards mutuality usually takes time and effort to develop and sustain, and is more likely to last if the caregiver and person with disability have access to proper emotional, spiritual or psychological supports (Vanier 1989; see also Kittay 1999, O'Brien and O'Brien 1993, Taylor and Bogdan 1989, Pottie 2000). Empathic understanding across difference is not natural for us¹¹, requires ongoing effort (Geertz 1994), and is the basis for good relations.

Feminist psychologists such as Judith Jordan highlight how mutuality should mean respecting and supporting each other in and through differing oppressive conditions (1991:4). The myths of our "neutral" public sphere (Fraser 1994), and the fictional equality of the liberal political tradition force weak or marginal players to express and negotiate using the (hegemonic) terms of the dominant group without acknowledging the handicap that it puts on them (Bishop 1994:21; Tannen 1994; Turkle 1995). For mutuality to be present, socially constructed inequities

between people must instead be recognized. A commitment to recognizing and trying to diminish the systemic inequities of difference is a pre-condition for a relationship between people separated by difference, especially when they are operating within a normative framework, such as a care-giving relationship, which normally *reproduces* structural inequalities.

The political project of solidarity and mutual relations should not overshadow the fact that what the caregivers are doing is still *labour*, and needs to be credited as such. This work faces multiple devaluation by being classified as women's work, emotional work, "low-skilled" work and work for people with intellectual disability—none of which have been traditionally well funded. The practice or labour is inherently asymmetrical, and needs to be seen as such in order not to dismiss the critical value of caregivers' work (Kittay 1999:53-55). Thus, while "care as labour and care as relationship," are interwoven and mutually enriching (Tronto 1993:108; see also Kittay 1999:155-7), it would be wrong to conflate the relationships—the vehicles for potential mutuality—with the physical care, which is not directly reciprocated. This point is elaborated in the final section.

7.2.1 Caregivers' motives for mutual relations

Having outlined the various elements of mutuality in caregiving relations at L'Arche, I need to address the question of why caregivers are motivated to enter into such relations. Some readers may feel that the answers to this question are obvious, but in fact, research shows that social stigma against people with intellectual disabilities makes it difficult for them to make friends. The question is also salient given that what is at stake for the caregiver is significant. Being engaged in these relations involves power-sharing, openness and vulnerability and hence entails risking certain loss for uncertain gains. In teaching pastoral care, Steinhoffsmith discerned three traditional motives to "help" among pastoral care workers: self-interest (income), self-esteem (status), and altruism (sense of doing something of value by serving others) (1999:14). He

says that since these are rooted in a one-way conception of care, they often lead workers to give until they burn out. By inviting people into relations of mutuality, L'Arche is highlighting that care is two-way, or interdependent, and that both people share responsibility for well-being or healing. I follow Ortner (1984:151-3) and Geertz (1973) in assuming the need for multi-sided explanations of complex motives like this that draw on both *interest theory*, (where the motive to act is to further one's own interests) and *strain theory*, (the motive to act originates in some external source of pressure or change that requires the subject to respond). I discuss initial motives and motives that arise out of experience. Finally, lest the caregivers' degree of agency seem too muscular, I discuss how the L'Arche culture at least partially structures the emergence of these relations.

Humanitarian

The humanitarian or moral motive, which is part of most L'Arche assistants' reasons for being there, contains both *strain* and *interest* dimensions. Some argue that moral compassion and empathy almost invariably arise out of being witness to others' suffering (strain theory) and compel caregivers into supportive relations with them (Steinbock 1999; Kittay 1999). While I agree that people *can* be moved enough to enter into an engaged relationship with a person with intellectual disability in this way, it is clearly not a common occurrence, given the continuing low incidence of such relations in our society. The objective reality of care, with its limited resources, is also a powerful deterrent to any humanistic impulse the caregivers might have (Pottie 2000:140; Chambliss 1996:2), and as I discuss below, there are many other naturally occurring structural barriers to such relations.

Still, when someone begins with a moral, spiritual or humanitarian project wherein she seeks to enter into relationships with a marginalized person or group out of a desire to be in solidarity with them against their social rejection, that is clearly a strong motive for relational mutuality (Taylor and Bogdan 1989; O'Brien and O'Brien 1993). This project can be heightened

through actual experience and interaction with them. In that sense, the humanitarian motive is a response to conditions that one finds unacceptable. It also reveals North Americans' need for relationships that feel more authentic and meaningful, and thus more personally satisfying. Interestingly, Bellah found that Americans are "almost ashamed to admit that they might do anything out of altruistic motives," and so usually explain their motives in terms of individual self-interest even where there are other things at play (1994:23).

Pleasure

It is important to name motives which are not moral or serious in any sense but rather grow out of people seeking experiences that are pleasurable (interest theory). When caregivers have good, caring relations with their charges, they feel better about themselves and are more satisfied with their work (Stephenson and Coughlin 2001). Caring for people is of course what many people who entered the field wanted to do in the first place. But it is not just about caring. Angie, who was an activist for other causes for years before joining L'Arche, said that in her experience, "marginal and unusual people are simply more interesting to be with than your average person." That outlook predisposed her to be open to people with intellectual disabilities who often say and do things that are strikingly out of the norm and can be refreshing. Daniel, a director known for his humour and his good relationships with core members, describes this as their "wacky individuality." His stories reflect how he enjoys being around people who often have dramatic idiosyncrasies.

It is often people with intellectual disabilities' incomplete grasp of typical social norms that leads them to act more naturally, or as some would say, from the heart, with less social inhibition than most people (Vanier 1989; Wolfensberger 1988). In a characteristic inversion of dominant logic, Vanier writes that rather than make people with intellectual disabilities change to be "normal," we should allow ourselves to be challenged by the *dissonance* their difference creates in us (Vanier 1998 cited in Pottie 2000:19). Vanier has an uncanny way of framing

communitarian or civic goals in a way that appeals to a modernist, individualist and even self-interested sentiment. In a similar vein, Geertz wrote that while difficult and unnatural, growing beyond ethnocentrism (or here, able-centrism) is desirable because it augments our self-understanding by expanding our imaginations and mitigating our illusions about how we fit into the world (1994:460-5).

Sam, an assistant said, “When I first got here, one of the things that blew my mind was to sit there beside Deb, who gets her face right up close to yours, like really challenging you. And I would stare right back at her and just wonder what on earth she was thinking. It’s just amazing to be in a place that can handle so much difference.” For most people though, appreciating difference is “a skill we have to arduously learn, and having learnt it, always very imperfectly, to work continuously to keep alive,” (Geertz 1994:466).

Experience

There are also tensions that arise out of the lived experience of direct care for people with intellectual disabilities, which create a need to rebalance the relationship in some way (strain theory). Mauss (1954) wrote about how the act of *giving* ironically raises your status and accords you power, and new assistants usually talk about how being able to meet the urgent needs of others is a fulfilling experience. One director, Daniel, describes it as “a bodily experience of your worth as a person; so it’s more than just an abstract thought—it’s something solid.” But this part of the experience does not keep people engaged for long as it eventually feels too one-sided and imbalanced for most people. That is where the concept of non-traditional gifts of relations can be helpful. Jeff, a former assistant, said that relationships with the core members had compelled him to admit his own weaknesses, and need for others, surfacing how the “absent cry of the rich” is part of why we seek relations. Indeed, Charles, an LTA, said that upon seeing a video about L’Arche, he was struck by how absent that deep kind of relationship was in his own life: “I thought to myself—I want to learn to love like that—and *be* loved like that. I realized how much

my heart needed to grow.” Trevor, a director, averred that good relationships make the simple practices of caregiving meaningful and sustaining for assistants.

Just what we do

As noted, I do not wish to overplay the degree of activeness¹² or deliberation of these caregivers in how I describe their motivations to enter into relations with people with intellectual disabilities. While most assistants do actively *think* about these things, the behavioural environment and norms at L’Arche also influence them in imperceptible ways. Their philosophical approach to care promotes relationality as the norm and as such it becomes largely naturalized. It is, in other words, just what people do in L’Arche. As I discussed in Chapter 6, new assistants are socialized into this way of being through informal experience in practice and shared stories as much as through personal reflection and wilful agency. Research in other settings also suggests that good relationships can just happen in the right environment (Taylor and Bogdan 1989). They can be intentional as noted above, but are also part of the normal routine once you are there.

7.3 Historical attitudes to relationships and caregiving

Although feminist psychologists made their first inroads in women-specific studies of relationships (Gilligan 1982), there is increasing acceptance in the literature of the importance of relationships in many aspects of both men’s and women’s lives (Miller 1991, 1993; Jordan 1990, 1991a, b). In a caregiving setting, there is growing interest in the benefits and challenges of improving client-healer relations from both the perspective of the client and the healer (direct caregiver, doctor, nurse, rehabilitation coordinator). Relational mutuality involves the client more and thus can lighten the burden of care (Heller et al. 1997; Steinhoffsmith 1999). It can increase caregiver satisfaction (Carruth 1997) and can provide the opportunity for feedback in client responsiveness (Tronto 1993; Kittay 1999). Nurses told Chambliss that having time for caring, inter-personal interactions was what used to make the other hardships of their jobs bearable

(1996). And yet, in spite of all of these advantages, the relationship between client and caregiver remains a controversial issue in health care, often for good reasons. Here I outline the historical trajectory of this controversy, followed by barriers to relationships in the care of people with intellectual disability. These areas involve structural issues, persistent attitudes and stereotypes, and finally the real, intrinsic challenges to such relations.

7.3.1 Impersonal but fair: a paradigm shift in caregiving models

The indifference and personal detachment characteristic of late modern or post-modern citizens' ideal self is by now a well-worn cliché. In a recent article, Rimke provides evidence of this through his analysis of burgeoning self-help literature in which, as a general rule, social relations and interdependence are not just considered undesirable because they limit "freedom," but are often pathologized with labels like "co-dependency" (2000:65-7). In effect, social relationships are medicalized and formalized through the particular modern, liberal, political notion of the self as ideally autonomous and free of ties (2000:65-7). It is against this backdrop that some people are trying to bring the relational aspect back into caregiving. Feminist psychologists and moral philosophers of care are pushing for recognition of the powerful role of relationships. For example, Chambliss has shown that ethical decisions in organizational settings are most often made by networks of related people, not by the fabled individual "autonomous ethical actor" (1996:3-11). A historical overview shows how we arrived where we are now.

The professional but often impersonal system that now dominates mainstream healthcare arose in part from good intentions. While the older health care system was more personal and relationship-oriented, Phillips argues that it too fostered various injustices: sentimentality, pity-blame equations, disenfranchising certain people, paternalism, controlling caretakers, caring motivated by guilt or shame, and religious doctrines that sometimes promoted unhealthy submission and self-sacrifice (Phillips 1994:2-6). These systemic problems all lead practitioners

and patients to want a system with less room for human bias; something more “fair and just” that deals with everyone equally and protects (inherently vulnerable) patients and caregivers from those issues (Phillips 1994:2-6).

Those good intentions have accomplished much; for example, Chambliss points out that with the new system a criminal or a socially non-normative person likely gets better treatment as staff try to treat people “fairly” (1996:128). But many argue now that the changes went too far. Foucault (1973) showed the great increase in control we accepted in return for improved scientific understanding of our illnesses, and Goffman demonstrated that the iatrogenic effects of being in the impersonal institutional environment could become more harmful than the original illness (1963)! “Stripping [caregiving] relations of significance is only one radical and risky way of guarding against the ravages of personal insecurity and ambition.” (Phillips 1994:3)

In a reference to efficiency of mass production, Phillips suggests that “detached simplification” can work for inanimate objects but not for caregiving of people (1994:3-4)¹³. Other researchers have also discussed the harmful effects of the professionally-sanctioned distancing and othering strategies that health care staff often employ in their roles to avoid personal relations with clients (Murphy 1990:117; Barham 1992:77). Most current practitioners were trained to see caregiving as one-way only and to believe that distance and objectivity are necessary preconditions of therapy. They are wary of relations that cross that boundary (Benner 1994:58-9). As is often the case, the extreme version of either system presents danger, be it the distortions of partiality or the disheartening effect of depersonalization and disengagement (Phillips 1994). Ideally, we need to find a way to evolve an ideology and caregiving structure that encompasses both the fair, depersonalized system and morally-based care (Phillips 1994:6).

7.3.2 The structural privileging of technique over disposition: competence vs. caring

The classic social science debate over structure versus agency can be brought to bear on the issue of barriers that prevent mutual relations between caregivers and the cared for. Jenkins convincingly rejects structural determinism by showing how in Bourdieu's model (1977), actors can only be epiphenomena of structures, which provide no means to explain change (Jenkins 1992:17). De Certeau (1984) has built a strong case for agency in showing how people's actual tactical moves are often subjectively driven and unpredictable. Still, de Certeau believes that even as agents, people act within structurally-limited parameters, or their objective reality. As discussed earlier, de-institutionalization and community integration have not led to much improvement in the relationships of people with intellectual disabilities. So what structural factors are still inhibiting better relational opportunities for them?

One reason for the lack of opportunities for better relations that emerges frequently in the health care literature is that mainstream structures of care have not been designed to provide the time or occasions to facilitate such relationships (Lutfiya 1991; Tronto 1993; Pottie 2000:140). Resource shortages and pressure for efficiency and productivity leave staff minimal discretionary time to use for things like a caring conversation—considered “trivial” or at best a secondary priority to the science and physical aspects of care (Good and Good 1993). The chief of an emergency psychiatric unit told an ethnographer that his advice to medical interns is clear: “The closer you are to the patients, the harder it is to be good.” (Rhodes 1993:140) For this doctor, “good” is defined out of necessity (limited beds) to mean a combination light on compassion but heavy on speed and resourceful tactics for achieving patient-transfers into non-emergency assignments (i.e. emptying beds) (Rhodes 1993, 1991). This is just one example of where the structure is reproduced (via the doctor), in newly trained people to bypass relations in order to

succeed and survive. These values are exacerbated by resource scarcity and bureaucratization at L'Arche and elsewhere.

Medical historians point to the discovery of microorganisms and bacterial causes of illnesses like tuberculosis, cholera, and typhoid in the nineteenth century as how “excellence in medicine became more closely associated with rigorous scientific knowledge than empathic bedside manner,” (Lupton 1994:84 in McKay 2002; Christopoulos 2001). Anthropologists at Harvard Medical School discerned how the curriculum enculturates students in a dual discourse: caring and competence, with the latter privileged and fetishized while the former is effectively neglected through simply not being taught (Good and Good 1993:91-3). The Goods’ research shows that the production of medical knowledge is biased *a priori* in a school setting that equates science and competence with “real medicine” and relegates humanistic and affective dimensions of care to the level of afterthought (1993).

Other structural factors pull against relationships. Caregivers of all sorts¹⁴ are also, understandably, responsive to what they perceive to be what the system rewards them *personally* for. Research shows that many doctors consider themselves to be caring at heart, but they feel frustrated at a care system that “discourages the development of a close relationship between doctor and patient,” (Swaby-Ellis 1994:85; Chambliss 1996). Caregivers are consistently cited as feeling an irresolvable “conflict between the vocation to care for persons and the industry of caring for manageable parts,” (Phillips 1994:2). “Caregivers are rewarded for efficiency, technical skill, and measurable results, while their concern, attentiveness, and human engagement go unnoticed within their professional organizations and institutions.” (Phillips 1994:1) Research reveals the unintended, yet logical outcome of this narrow, if efficient, version of care: the majority of hospital nurses could not recall any *particular* stories about *specific* clients (my

emphasis); “They had become technicians doing tasks rather than practitioners engaged in care and restoration.” (Benner 1994:58)

7.3.3 Persistent negative attitudes towards difference and disability

While public and professional attitudes towards people with intellectual and physical disabilities are not as overtly derogatory as they were pre-1960s, there are indicators that underneath, things are not that different. It seems that the prevailing attitude continues to hold that relationships with people with intellectual disabilities are likely motivated and sustained by either charity, sympathy, or a desire to help. While we recall with disdain the mass popular support historically for eugenics in Canada, and across Western societies (McLaren 1990:28, 79, 91), one does not have to look far to find those ideas persisting in today’s supposedly more enlightened times, somewhat like scratching the surface of a pentimento¹⁵. Scholars like Hauerwas (1986) and Wendall Smith (2000) are concerned with the prevalence of neo-eugenic logic that is not uncommon in pre-natal genetic counseling, and bioethics reflections on who deserves to live. An extreme example of this is controversial Cambridge press ethicist Peter Singer’s “utilitarian” position that people with disabilities are not fully human, do not deserve the social resources they require, and should all be aborted at diagnosis or killed at birth (1979:127-38). It is not solely a problem of the policy-makers, however, as many expecting parents, after an amniocentesis revealing Down syndrome, hemophilia or other disabilities, are making the individual choice to terminate the pregnancy (Jones 1998; Hauerwas 1982)¹⁶.

Relationships and integration are inhibited by a fairly one-sided focus in popular and professional accounts on what people with intellectual disabilities *can not do*, and what support they *need from society*. This is often called a deficit or deviance model of difference (Pottie 2001:125-7; Taylor and Bogdan 1989). Such negative slants and stereotypes not surprisingly curtail typical people’s interest in having relationships with people with intellectual disabilities

(Barham 1992; Taylor and Bogdan 1989; Bercovici 1983), not to mention exacerbate discrimination and their socio-economic isolation (Hanna and Ragovsky 1991; Lutfiya 1991). The socially constructed stigma even inhibits some people with disabilities from wanting relationships with each other¹⁷ (Epp 2000b; Hingsburger 2001a; Hauerwas 1986:171).

An attitude shift towards a greater consideration of the social benefits of enhanced social diversity through inclusion and attending to different people's gifts would open up relational possibilities. A few self-advocates (Epp 2000a, b) and researchers are beginning to point to this need (Amado 1988b:305; Benner 1994:59) and some parents of people with disabilities have long recognized their value (Hauerwas 1982). Others show that such relationships can happen even when one is not necessarily looking to make that happen; for example, a relationship can blossom when someone has frequent interaction with a person with disability either through family, school, professional caregiving, or other forums (Taylor and Bogdan 1989). This is probably the principal area in which L'Arche philosophy can contribute to social change because it provides a concrete, relevant and actionable system of beliefs and approaches to relations across difference in practice, not just an ideal.

7.3.4 Intrinsic difficulty of relations across difference and inequality

Any relationship across such difference and inequality is bound to be challenging and laden with uncertainty and both people need to be well supported to sustain it (Kittay 1999; Phillips 1994:8). It is important to try to understand and accept "the other", and fieldwork is a good place to learn that deep understanding usually entails relationships. Typical people are often reticent to establish any close relations with people with intellectual disabilities because of an intuition that their weakness and helplessness will touch parts of their own experience and be uncomfortable for us (Hauerwas 1986:175-6; Downey 1986:74; Vanier 1998). This is often the case and should not be downplayed; as Wuthnow has argued, helping others always requires time

and energy, and usually entails sacrifices by the caregiver (1991:105 in Bellah 1994:23). But as he says, that is also what makes it special, not token in nature.

In western cultures, relationships are often seen as antithetical to freedom, as measured in units of individual autonomy. Jackson writes that relationships and freedom are twin desires but always in tension (1995:120-6). Caregiving relationships involve what Kittay (1999) calls “moral dependency” and as such are scary for us to enter into because the dependency threatens to “undermine radical independence and self-determination,” or negative freedoms, which we have come to value (Phillips and Benner 1994:ix; Vanier 1995; Pottie 2001). These deep cultural values thus also work against the possibility of relationships across difference and inequality.

7.4 Journey of discovery

The assistants embark on a journey of sorts by opening themselves up to relationships of mutuality during their time in L’Arche. This passage or transition towards a new maturity in their moral, spiritual and social capacity to accept and live with difference is vital for the organization and profound for most of the individuals. While researchers have examined this transition (Hyrniuk 2001; Sumarah 1987), it is my sense that many communities could profit from attending more closely to new assistants who are undergoing this passage. While the long-term assistants achieved clarity and articulated the lessons this experience offered, they seem to have also experienced a sort of group amnesia about how awkward their journey to get that clarity had been. Without meaning to, they seem to have also forgotten how valuable it was for them to have that liminal time in which to make mistakes while resisting and struggling with these counter-cultural ideas; to learn through experience, rather than simply being told how to be. As Theo told me, “I recall hearing Jean say that he gets worried about any L’Arche community that doesn’t have any window-breakers!”

Bourdieu (1977) wrote that “Habitus is history turned into nature and denied as such.” Novelist Kundera reflects on the tragedy of how humans forget history as our individual memories fade (1986). In this section, I show how powerful yet delicate this phase of learning is, in order to encourage L’Arche long-term assistants to recall that all of this richness was a surprise to them, and to those who started L’Arche originally (Mosteller 1996:8). Each journey, with all its turbulence, is a special gift of consciousness and needs to be recognized, rather than naturalized.

Daily practice is vital to this transitional experience. Ideologies have their effect, but as the stories below demonstrate, deeper learning requires getting your hands dirty. Charles explained that the intense ups and downs of living in L’Arche were what finally made the gospel make sense for him: “See, I’d never actually popped the hood and worked on the car; I had really only ever read the manual!” Theo had studied and talked a lot about humanist love and justice, but he said he came to L’Arche to see if he could actually live it. Bourdieu was sceptical about whether you could really change people’s everyday dispositions, (what he called *hexis*) which were so embedded as to seem thoughtless for them (Jenkins 1992:75). However, he did allow that people’s awareness of their naturalized dispositions would increase if countered by a competing ideologies (Bourdieu 1977:164).

Through ideology and practice, L’Arche introduces a new ideology and thereby unmoors and de-naturalizes these assistants’ typical habits of thought, giving them a chance to adopt, adapt or reject new possibilities. Some leaders in L’Arche feel that perhaps the practice-intensive model of having homes is no longer viable for them due to resource constraints and that perhaps a new way of executing the charism is needed. While alternative modes are no doubt possible, my analysis shows that practice, or lived experience, was a crucial point of differentiation between those who read about, and support L’Arche, and those who live in it. Experience constructs our

subjectivity (Scott 1992b:27). Many board members, secretaries, and long-time friends of the community who strongly support the mission readily grant that the growth they felt did not approach the order of change experienced by most live-in assistants. Vanier believes that the experience of commonality radically alters the meaning of caregiving:

If one remains the helper, healer, or comforter, the other must necessarily remain the one helped, the one sick, the one comforted... When we discover the true gift of the one to be consoled, such barriers and distinctions begin to fade away. (Vanier in Downey 1986:50, 62)

Again, this subjective transition is not only serious; there can be humour and delight for the assistant amidst the moral-political shift. I asked Sam, 27, a physics graduate and artist, to be more specific about what he meant by “seeing things differently.”¹⁸

Okay, I can feel my consciousness changing being here with the guys. Like when I first met Deb, there was just awe, she just seemed so different... Later I got a bit more comfortable and I could find people’s oddities amusing—like just let it wash over me... Now, I could really tell you that I am proud to go to church with Alfred [a handsome man with profound physical impairments]. And I think it is good that we don’t just stay at our own little chapel, because out there more people can be exposed to his reality; and maybe they’ll feel uncomfortable when he yells, but that’s part of life... And I love feeling uncomfortable and uncertain and questioning things. I never really thought before about bringing a disabled man who screams to church. So it makes me think more.

Adam, a community leader, echoed this sentiment when I asked him why he feels that connecting with people with disability is different for him than being with typical friends: “Well, when you sit down for dinner regularly with people who look at the world very differently than you, it makes you feel awkward and uncomfortable because it is not natural. But for me, and I’ve seen this in many assistants, it opens something up inside you that you never knew you had. It makes life fuller.”

7.4.1 Learning to “be with”

“What counts as experience is neither self-evident nor straight-forward; it is always contested, always therefore political.” (Scott 1992b:37)

And yet, we generally do not question our normative classifications or categories of experience because we do not always realize they are contingent and political until they are revealed as such in contact with different classifications (Bourdieu 1977:164). So it is that people who come to L’Arche are not instantly able to switch over to the L’Arche system of values where “being with” people with disabilities is considered as vital to care as “doing for” them (Vanier in Downey 1986:ix; Hauerwas 1986:177). People need to learn anew what counts as experience. Mathew, a personnel director, told me, “L’Arche is a very human project—the simplest point of L’Arche is to give love, and learn to be loved.” This need not be complicated, but it does take time, and can entail hard truths of self-awareness. Simone, a homes co-ordinator, attends closely to how assistants are doing in the homes. She knows from years of living in L’Arche, that time and a certain degree of strain and hardship give richness and meaning to assistants’ time there, but she wants a balance. “Effective caregiving requires... skill, knowledge and being in relation with others in ways that foster mutuality, empowerment, and growth.” (Benner 1994:45).

Predominant negative cultural attitudes work against our collective ability to be witness to the intrinsic value of people with intellectual disability. At L’Arche, assistants get to know people with disabilities whose lives implicitly contest the discriminating, limiting stereotypes applied to them. Research shows that in safe environments, people with disabilities can reveal myriad gifts that family, caregivers and others can grow to appreciate and learn from (Taylor and Bogdan 1989; Kittay 1999; Wolfensberger 1988). Learning to “be with” people means that “Assistants in L’Arche are not there to make people with disabilities somehow ‘normal’, but to

help them to grow towards maturity... to blossom forth into freedom, to encourage her to grow and to accept herself as she is.” (Vanier 1998:27). In situations where there are substantial actual and perceived differences and inequalities, there is a greater need to be intentional in finding connections.

Sometimes their unique difference can baffle you, but then later make you smile. One night I was asked to make dinner at Asha house with Sister Helena who lived in the Cape Breton community. I was there early relaxing with core members Tom, Ashleigh and Belle who had come home after work. I had only been in the community a week, so I just knew that Tom was a gentle older Mi’kmaq man who admired Ghandi, and liked to sing along, ear to the speaker, with country classics. While I was getting the salad ready, Tom came out of the bathroom brushing his teeth aggressively. Suddenly, Tom was holding his mouth and yelling in anguish “I’m going to die—die and go to heaven—see my mom and dad.” And then he collapsed on the floor, continuing to scream and yell. Since we had just met that week, I was unsure about how seriously to take this scenario. Helena came in and all was resolved when she introduced the new concern of transportation—how will he get to heaven? Tom looked at her and said, as if it were obvious: “In an ambulance, eh? With Jim Reeves and Princess Leah.”

Catherine is a dynamic, dramatic assistant who loves to laugh and point out the humour in daily life. Now in her late 30s, she had found her experiences with family and with different jobs very hierarchical. This left her tentative about standing up for what she believed in. Her relationship with Loretta, a woman with intellectual disability, whom she lived with and cared for, has altered how she thinks about those choices. This reflects the idea that self-development is an ongoing process of growth in, for, and through relationships, not something we do in isolation (Jordan 1991:11). She and Loretta have fun together amidst their differences. Catherine explains:

Loretta is so on the edge. I love this about her. In spite of often feeling hurt or marginalized, she doesn't constantly try to fit in or apologize for who she is. She

has a sense of personal dignity despite living in a society that generally does not value her existence. You could say that she's stubborn or you could call it being determined. When Loretta wanted to shave her hair off, I counseled her against it. I thought she'd change her mind like with her rings¹⁹, but I was also scared that it would further marginalize her. She told me, 'Catherine, it is *my* head, *my* hair, *my* choice, *my* decision!' In the end, she did it and it looked great because it was so *Loretta*.

In our discussion, Catherine said that over time, incidents like these helped her to listen more closely to who Loretta was saying she was, but that it could still be hard to hold back when Loretta or other core members wanted to do something that their caregivers did not think was best for them. She talked about learning to recognize how often no intervention is needed—just a willingness to accept people for who they are.

L'Arche culture shows people how to recognize non-traditional gifts in people with disabilities. Obviously every person has particular gifts, but people who have lived in L'Arche for years also attest to certain commonalities: "People with intellectual disability often possess qualities of welcome, wonderment, spontaneity and directness. They are able to touch hearts and to call others to unity through their simplicity and vulnerability." (L'Arche 1993a) This does *not* mean that people with intellectual disabilities are simple or homogeneous, as discussed earlier.

What constitutes someone's gift at L'Arche is not always something nice or positive, as I discuss below (Vanier 1989:50-3). While Loretta's determination can be inspiring, it can also be frustrating or tiring in other situations. But in both good and contentious relationships, many caregivers believe that the core members have fewer masks, hidden agendas, and rigidity around social etiquette and they usually deal with issues in a refreshingly direct way. Many assistants report finding that this creates a relational space that allows them to be themselves too.

A former community leader and assistant for 15 years, Lisa talked to me about how she got used to being around Mary, a core member who has advanced Alzheimer's disease. While growing up, Lisa strained under high family expectations because of her talent in school, and was

reluctant to express parts of herself that did not fit the image people had of her. Mary's freedom to be herself surprised Lisa at first. "Mary is truly herself in any situation. She lives life fully without having the means that most of us rely on, since her vision and language are really limited. Like with music; whenever the music starts, she is the first person up to dance irrespective of where we are." Lisa explained how she grew to really respect how Mary seeks small, but important ways to hold onto autonomy in her life in spite of being totally dependent in terms of personal and home care. "Mary can be very clear about what she wants by using her body to demand respect around boundaries and space. She likes to be nestled in on the couch with pillows around her and the coffee table pulled up close to the couch. If you sit down beside her, she may well get up and leave you sitting by yourself if she doesn't feel like being social!"

I heard many stories about how assistants had their biggest insights about the value of just spending time being with people revealed in interactions with non-verbal people. It is usually especially difficult to know what non-verbal members want or feel, since their communications are more subtle and ambiguous. Sara, a friend and employee of the community, told me about visiting her friend Brent in the hospital and at home when he was dying. When she talked to him, she would hold his hand but he was not very responsive and so she wondered "What does he really think? He has no choice that I am here—he can't tell me to go, or not to wash his feet or whatever. But I would still communicate with him." On three different occasions, she said that when she told Brent that she was going to go, he squeezed and held her hand. "To me that was a time to realize he does know I am here and he is glad—that is what I think he was saying there."

Another assistant had a similar experience with Alfred after Alfred's mom, whom he did not see too much of, had paid a short visit and Alfred seemed to feel sad. The assistant, Raoul, sat with him quietly for a bit in his room and prayed. When he thought that Alfred wanted to be alone, he got up to leave. Alfred made a soft groaning noise, which Raoul interpreted as calling

him back, as Alfred, who often screams, had been otherwise silent. This happened several times and afterwards Raoul said that it was the first time he really understood or believed the L'Arche cliché about the importance of just spending time with people. Both of these experiences support the idea that mutually growthful relationships develop from people being connected, emotionally accessible, and vulnerable (Miller and Stiver 1991:3). In my fieldwork, I found that being open or accessible was instrumental in how quickly assistants learned to enjoy aspects of being with a core member.

Straight and on the left

Of course there are also people who never really make that transition, and I talk about them more in the final section on limits to mutuality. Some assistants are not ready or interested in the changes L'Arche prescribes, and some resist all or part of what they see as misleading or manipulative organizational beliefs. Usually, if assistants do not like it, they leave since there are not many ties holding them there, especially at the early stages. Further, there is a fairly wide range in how an assistant can interpret and live the organizational mission in the house. Some choose to lead a very relaxed life of hanging out in the house with core members, listening to music or television, and doing the basics. Others are more energetic in organizing outings or cooking special meals, and being involved in prayer groups or planning committees. I found no rigid formula for what made a good assistant, friend or leader. There seemed to be consensus that living in an intentional community required all sorts of people and that diverse styles and approaches made the whole thing more liveable (see also Vanier 1989:50-3).

Some regulation of how to "be with" core members obviously has to go on in order to ensure that assistants are working and living in a way that is respectful and reflects the philosophy of the value of diversity. The L'Arche didactic mechanisms tend to be indirect. In the Ottawa community, James, a long-term assistant from the Caribbean, asked me to set the table with Shelly, a new and non-verbal core member who was having trouble adjusting to the home, mainly

because L'Arche was trying to reduce her sedatives dosage. She tended to shriek loudly when anyone talked to her, and was otherwise vocalizing or grumbling fairly constantly. Based on my initial impression, I was surprised that Shelly would be interested in, or capable of, this task and I said as much to James. His answer and comportment seemed designed to normalize the situation and encourage, or teach, me to do the same; to not let the screaming disable me from being able to see Shelly as a capable person.

“Oh, she’s fine—just ask her to come in and get the cutlery—she knows what to do.” Seeing my quizzical look, he laughed and offered indirect guidance; “Oh, it will be fun—she is a very creative table-setter.” In this way, he conveyed to me that, “yes, you are right in what you are thinking, that she can’t set a table normally, but you are wrong in thinking that that means she shouldn’t do it anyway”. In a subtle way, he was suggesting that I change the values or standards by which I assess table-setting away from the assumption that what is normal is right, to valuing the creativity or fun involved. As she moved around the table groaning, she would pause, possibly in consideration, and then lay each utensil down in a random (to me at least) position. At first I kept correcting her placement, and then, reflecting on what James said, I came to accept that people would find their forks and knives either way and I let go of the inconsequential expectation that forks should go straight and on the left.

Stories are made of the daily things that happen between assistants and core members, or even just in the attitudinal shift of an assistant, and these stories are passed around. Seth admits, though, that even after hearing many stories and instructions, it took him a while to slow down and see that “getting tasks done” was not the only goal or product of caring labour:

What impressed me most in L'Arche was the quality of relationships; to see people finding ways to celebrate and be happy in spite of so many impairments. I liked it, but, boy, it took me time to learn—sometimes I would rush through someone’s bath trying to be efficient, and people would say to me ‘Non, non, non—pas comme ca!’ ‘You must take your time; get the temperature right, make sure the towels are good, help the person to be ready for this because it is a

vulnerable, intimate time so you must talk first to show respect.’ And really for awhile I thought—‘My God what is this place?’ But you know eventually I settled in and found there was a whole other world to discover.

You can learn to be with people through various shifts in how you think about things that they do, but those adjustments do not always work. For example, it was difficult to get used to Shelly’s screaming, which, in addition to being the result of reduced medication, seemed like a release of so much anguish. As Vanier says, when you open yourself to a person who has faced so much social rejection because of their condition, you can feel overwhelmed by the degree and urgency of their pain and needs. I have sketched here the process wherein assistants learn how to simply *be with* people, even when this creates tension. I further discuss how inequality affects these relations below in section 7.5 on power. First however, I give some examples of the way in which assistants feel that the people with disabilities that they live with are teachers for them because this also speaks to assistants’ sustained interest in the relations.

7.4.2 Lessons for life

Along with the process of learning to be with people, there are also lessons that come out of this culturally-framed, daily practice. These lessons help an assistant to be a better, more empathetic caregiver, and also to be a better person. As noted, it is common at L’Arche to say that the people with disabilities can be teachers—a notion that derives from the biblical lesson that “God chose those who are weak and foolish in the eyes of the world to confound the wise” (I Corinthians, 1:21). This idea is counter-intuitive for most people and even if they buy into the spiritual or moral ideal it represents, it is still hard to integrate into how you *actually live* and interact with people across difference and inequality. It is thus easy for stories about these lessons to seem like caricatures or even projections to people who have not experienced them. I want to

tell two stories here in detail so the reader can see that who a person with intellectual disability is, or what he does or says, can truly be a pivotal lesson.

There are three key points to bear in mind here. First, the actions and choices of core members can be intentional, (e.g. Loretta's hair style) or they can be involuntary and related to their conditions (e.g. Shelly's screaming). The distinction is often impossible to ascertain unequivocally, but what can be said is that their intentions in most scenarios are related to *their own* desires, not to *teaching* the assistant a lesson. Still, by just being themselves, the core member's "unapologetic vulnerability" can put an assistant in touch with negative feelings about their own weaknesses, and lack of self-acceptance (Frascetti 2001).

The second point follows, therefore, that when assistants at L'Arche say that a core member taught them something, they are not using "taught" in its traditional sense of intentional, directed instruction. They usually mean that they (assistants) chose to read a certain meaning or life-lesson into how the core member lives his life. As discussed, these constructed meanings are also encouraged and facilitated by the cultural beliefs and values promoted within L'Arche that revive the normally-forgotten gifts of people with disabilities.

Third and finally, the encounter(s) with the core member is not usually the only factor or influence on what the assistant learns. There is, in other words, no illusion of a single magic bolt of lightning. Usually a variety of experiences and reflections, alone or with accompaniment, have already transpired surrounding their question or personal issue. However, it is generally reported by assistants that there is something unique about the honesty, rawness, and distinctness in how people with intellectual disabilities act. This can heighten or clarify the message for an assistant in a way that a direct teaching rarely can. In other words, it is partly because the person with disabilities is not trying to teach or tell anyone how to be, that people feel more open to the message inherent in their example. When I shared this idea with Adrienne, a long-term assistant,

she agreed, adding: “Core members don’t set out to teach us—that is what makes it so accessible. It’s free of condescension and expectation—it is not preached or lectured. It is more like mirroring something to us about ourselves that often touches a deep place because it goes beyond the thinking process.” L’Arche leads the field in espousing the idea that people with disabilities are teachers and have gifts, but they are not alone in this belief. Research with *parents* of people with disabilities frequently indicates their role as teachers²⁰ (Kittay 1999:181; Hauerwas 1982:56-7; Landsman 2001).

Early on, for example, I was mildly frustrated with Donna who *seemed* uncooperative to me during her hygiene routines. It was hard to ask her to explain what was wrong as she was non-verbal, and at the time, her other means of expression were not familiar or obvious to me. I shared this at a house assistants’ meeting hoping to elicit suggestions for how to get Donna to change her behaviour, an approach that seemed logical to me. Instead, my concern was met with their stories on learning to be “in sync” with her. While empathetic, they encouraged me to spend more energy on discerning what legitimate conditions or issues might be pushing her to respond like that, such as pain, illness, sadness, or if something in her routine was out of order, rather than “change her” *per se*. Other stories gently suggested ways to change the meaning (for me) from “non-compliance” to seeing how inspiring it was that in spite of the trauma and pain she had been through in her life, she continued to grapple with articulating and insisting on her desires. This traces how I learned through others’ external cues new ways to see Donna as an agent and teacher rather than an object of care. This viewpoint relies on me believing or choosing to accept the system of belief that constructs her that way, and on me relinquishing having total authority as caregiver.

Being able to find or see the gifts in these people and relations is a learned skill. In a general way it is akin to a decoding process where an assistant learns new grooves of

understanding that can be applied to different interactions or people. But it is also highly particularistic and what one assistant learns from being around Donna might not be relevant or clear to someone else. Again this is why daily practice is so vital—it takes the idea out of the realm of cliché or truism and makes it accessible, polysemous, believable, and liveable. How someone understands the phrase “We are all broken” alters completely when he has to face his own limits or pain in the intensity of a relationship with someone who has faced similar issues but does not have the same means to mask or gloss over them as he does.

Jack came to L’Arche in his late thirties, with a strong background in various eastern philosophical beliefs and meditative practices. He knew something about these beliefs and practices was not working for him, but he was not sure what. Eventually, he said:

I admitted to myself that I can’t do this [life] on my own. There was real humility in that for me. You see with Buddhist meditation, or yoga, a lot of it is on your own. You are in a community, but you meditate alone and you have to ... And being in L’Arche has just been incredible in terms of being with the core members and realizing that Joe, Eric, the guys I live with—they live with so many limitations and yet they find joy and are great to be with. I mean they can be miserable too but just—they appreciate the spirituality of living day to day. Jean talks about how we are all broken but up until recently I was like, ‘I’m not broken—I have these struggles but I will get over them and become actualized and all that.’ That was my paradigm for a long time. In some ways it is wonderful and I still like meditation, but it is very focused on the self. Coming here I guess I have a sense now that my journey is less about me alone and more about God and other people too.

Recognizing that relationships can be good and healthy parts of life and not just restrictions on one’s independence is a liberating lesson that many caregivers in L’Arche talk about. Theo explained to me that he thinks that growing up we all learn not to admit that we need other people because that is seen as a weakness. In trying to live through some leadership issues in his community in Nova Scotia, however, he was pushed to the point of “humility and learning to let go and learning that I can’t do it all, and I need to ask for help.” Direct care workers are exposed to relational needs in a way that reveals the contingency of the myth of hyper-

individualism. As Theo put it: “People need people at least some of the time. I guess it is more poignant at L’Arche because there are people who could die if you don’t feed them, right? It’s very ‘in your face.’ But it isn’t just the case for them; I realized we all need each other.”

Adrienne discovered a similar lesson in her relationship with Rachel. In particular, she came to recognize general relational patterns she had developed which were stopping her from growing. Adrienne struggled for years to identify her own needs, and she felt that her sense of self was defined largely by helping others. While she knew that this did not feel nourishing, she was not sure how to change without feeling that she was letting others down or being selfish. While living with Rachel, a core member, who was going through some profound changes after leaving the institution (Mosteller 1996:40-49), Adrienne found the model she needed for how to help and to be helped in part by accepting her own limitations. Rachel’s gift was in how her persistent effort to overcome hardship and get what she needed could teach Adrienne and others that this was possible. Their friendship is an exemplary case of how asking for help (explicitly or implicitly) can itself be a relationship-building process (Pottie 2001) as Adrienne narrates below²¹.

When Rachel first came to our house from the institution, she spent most of her time rocking and yelling and not allowing anyone to touch her. Her history of trauma seemed to have left her uncertain about who, if anyone, she could trust to take care of her needs and so she simply did not express them to anyone other than through resistance. She also had medical problems which had contributed to chronic undernourishment, lack of energy, and physical deformity. Over time in our home, we worked to figure out what supports she needed to grow, beginning with the necessary surgery for her to eat, and trying to provide her with the constant empathetic presence of others. Slowly it seemed that she began to trust that people could respect her needs. The first indications of this were the delight she took in eating more than liquids once this was made possible. This also gave her more energy and possibly confidence. Eventually in her mid-20s she learned to literally stand on her own and walk upright despite her major back problems!

This led to additional small, but significant efforts to express what she did or did not want. For example, while still somewhat guarded about the physical touch of others, she began leading people by the hand to the sink when she wanted a glass of water, or to pull them off of the couch when she wanted to sit

there. Rachel's courage and persistence continually impressed on me that it was really possible and good for someone to learn anew to identify her needs. It has taken years, but I am learning to find and value my needs amidst those of everyone around me and I often think of Rachel's steps in that direction when I find my own faltering.

Rachel has ways of consoling and helping people out directly as well. Once, when I was hidden crying in a side room about an argument I'd had with another caregiver, Rachel came in, crawled up on the bed, put her arm around me and laughed. I was not used to letting other people help me or even see that I might need help, but for some reason I didn't mind it coming from her. In fact, I was struck by how much better it made me feel. Her courage to reach out and accept her need for some support is my constant reminder of how much relationships help me too.

Daniel looks back on 15 years in L'Arche and the changes he has undertaken and been supported through. He talks candidly about a Catholic upbringing that left him with a great sense of the importance of service for others. Still, as he put it, there can be a risky corollary to giving to others; "I learned from the women in my family to do for others and not ask for things for yourself." Looking back, he thinks that he probably hoped that living a life of service in L'Arche could somehow make up for (or hide) the other things in himself that he felt were not good enough or spiritual enough. A similar theme was present in the reflections of several assistants that I interviewed. The intensity and unavoidable intimacy of life in a small community, however, made it difficult to hide those things. That, combined with giving himself so wholly to serving others, pushed him to exhaustion²². As he tells below, the community was highly supportive, and certain core members were especially helpful in teaching Daniel to accept himself as he is.

The particular gift of many people with intellectual disabilities is that they are often irrepressibly themselves. Obviously this is more true when they are somewhere they feel it's safe to be so... I lived with Marjorie, who had her share of issues, but she had spunk, and wit and she was charming in spades. It is hard to describe—she wasn't given a lot to work with—but her family must have worked to make her feel special and that stayed with her—she loved to be special, like a grand dame of the stage. A friend of mine called her my Beatrice, as in Dante, because, in her insistence on her own importance and needs, she was a model for me²³. We [in L'Arche] need to talk more about the power of their individuality—of their just being themselves.

In the end, this is probably the biggest thing that the core members taught me—that I am okay the way I am. I don't have to become a priest, or give so much that I don't sleep to be loved in God's eyes and by other people. And it is not just accepting yourself or tolerating your flaws—it is about celebrating yourself. I learned that while I could not be or do some things, I had many other gifts and the core members helped me see them and value them in myself by holding onto me and forgiving me when I got angry or tired out. That has also been affirmed in leadership responsibilities for me here. At the end of the day, they will always be handicapped and Jean says strongly that rather than being ashamed of their lack of ability, we need to create space to help them claim their gifts. Ironically, doing so is often healing for others too.

While self-acceptance can be an illusory or never-ending project, Daniel's experience reflects how this balanced sense of self can emerge as a side-effect of loving and serving others (Vanier 1989:46). A degree of self-awareness and acceptance helps assistants to be well in caregiving or other relationships. Here we have looked at the opportunities created by L'Arche's philosophical turn towards revalorizing difference. In the next section, I introduce some of the struggles that arise as both parties learn to negotiate within the ambiguity of caring in an inherently imbalanced power relationship.

7.5 Negotiating power in caregiving relations

The L'Arche vision of care creates a rich site for exploring how people negotiate caregiving relationships across significant personal and professional differences and power inequalities. The power asymmetries intrinsic to that dependency relationship influence the flavour and parameters of it. Still, the physical tasks of care are only part of what is happening and being exchanged between the dependency worker and her charges. Through negotiating this uncertain terrain in practice for over thirty years, L'Arche has found ways to encourage relational connections while acknowledging the terms and limits of the power differential that partially structures those relations.

One question that needs to be asked is, "*What is at stake for the caregivers?*" What do they stand to lose and gain by agreeing to be open to sharing power with their charges? To avoid idealizing mutuality or how it is engendered in L'Arche, it is important to speak of the insecurities and loss that can be part of the experience of care as mutuality for caregivers. For those positioned as more powerful in any relationship, mutuality clearly means giving up some control over the conditions and outcomes of care. Also at stake are unchallenged authority and autonomy in decisions, the efficiency and simplicity that were traditionally valued, the caregiver's safe emotional distance from the deviance stigmas of illness, and any solid self-concept as the healer or hero that can inhere in traditional one-way care relations.

This approach to care replaces the one-way "power discourse in which one gives, helps, and does not learn from the other," with an ideal of mutuality (Phillips and Benner 1994:ix). It thus requires certain risk and loss in return for uncertain gains. The gains are also different for each person, and are thus hard to generalize. The L'Arche philosophical and spiritual framework broadens the caregivers' definition of professional and personal goals. Negotiating the inequality requires the powerful to share power and resist the asymmetrical, dichotomous roles that form the automatic framework within which such relations exist²⁴. Sharing power is a radical ideal in a field where elsewhere most workers are tacitly trained to value patient compliance over agency, independent thought or idiosyncratic behaviour in their charges. These relations symbolize an implicit commitment to shift the terms of power in caregiving (see also Taylor & Bogdan 1989).

Loretta now lives in L'Arche, but talks about control in the institution; "Sometimes I hit people because I was angry. I don't like the [institutional] staff tell me what to do sometimes. I stole because I feel angry. So the staff drag me in the room. I didn't like it." The definition of control is subjective and variable, and assistants continually learn to monitor their assumptions

about what is “best”, and how to support people to make decisions themselves. Vanier, says that at first he assumed that he knew what was best for the men:

I thought I had the right to tell Raphael and Philippe what to do... I didn't ask their opinion about that [attending church] or anything else. It took time for me to understand that I had to listen more and that they had their own lives, their own expectations and their own desires (Vanier 1995:19).

7.5.1 Pro-active sharing of power

Assistants in L'Arche are encouraged to share power with the core members over decisions that involve or effect them, including house and community issues. Simone, who is now a director, talks about how this is much more complicated to do than it sounds. For two years, she and her husband lived in a L'Arche home with their newborn baby. One time, Simone had to go upstairs to do something while her baby slept downstairs. She asked Jane, a core member to let her know if the baby woke up, since Jane often helped out in this regard. But when Simone came back down, the baby was crying away and Jane was peacefully doing her crossword puzzle. While giving people responsibilities is a chance for them to grow and learn, it can also jeopardize safety so the caregiver must weigh these issues carefully. As Simone explains:

Many people with disabilities have been very protected and not given much opportunity to make mistakes. I realized that as long as an assistant was there, everybody [core members] held back. They didn't answer the phone or manage the kitchen. So I felt that it was good sometimes for me to be in the background more so they could take more initiative. In so many ways you have to take leadership though, and so it's a hard thing to take it when you need to but [at the same time] encourage them to take it too... Ideally, I think we should do the dishes and cooking and stuff together because it is for both of our lives. We're learning more about this... We have put the skill emphasis somewhat differently than standard group homes. Their main thing is getting people life skills for independent living, whereas we also work on things like including people in decisions about community life, or supporting their spiritual life.

Simone's story reveals the complicated path to balancing power-sharing and being responsible. It also raises the important point that the question of what aspects of their life people

most desire power over is not self-evident or homogeneous. Skills leading toward independence may be desirable but so are opportunities for social contact and input into the workings of the home, the menu, or even how one's birthday will be celebrated²⁵. For another core member in Ottawa, Ian, the community felt that if he could learn how to use public transportation, it would increase the range of employment that he could seek. It would also provide him with a new measure of freedom and confidence to be responsible for getting to and from work himself. There were assistants who were very concerned about what could go wrong and if he could get hurt, as he had "never done that before". Ian himself did not seem to feel strongly either way, but some other assistants felt that he was ready for this growth and that the risk would be good for him.

Eventually Ian decided that he would try and he did learn how to use it and started a better job as well. But one day he did not come home on time. As his friend and long-term assistant Calvin tells the story, the assistants were all worried, but eventually learned that Ian had simply missed his stop while watching the bustling crowd with interest. Calvin exclaims, "What better example is there of why we need to keep pushing ourselves to support our people in taking the risk to grow. We have to let go of control. Then you get this stuff like Ian out there enjoying himself, having an adventure, and being his own person. His life is so much fuller riding on public buses rather than in one of our vans every day."

Ian and Simone's stories echo my earlier description of the paradox of care at L'Arche in which assistants are asked to simultaneously accept people for who they are, and encourage them to develop to their full capacity²⁶. As outlined in section 4.4.2, these aims seem contradictory but can be jointly achieved if held in tension in practice. Long-term assistants in L'Arche would say that the first priority is that the core member, or the assistant for that matter, feels valued, accepted, and eventually loved for who he is, but that this should not be a womb to hide in but rather a strong centre from which to step out of and develop as an individual. There are power

and control tropes in both scenarios. The accepting womb holds the danger of producing over-protective, controlling assistants, and the push for growth is perilous if it becomes so central that the person feels inadequate and devalued for who they are. I have two more examples that touch on these complications of power-sharing and interdependence in caregiving relations.

Loretta has lived in L'Arche for 18 years and over that time has been supported to move away from impulsive, angry reactions to things that hurt her feelings, towards trying to express why it hurt her to the person in terms that they can hear. This is still a challenge for her but she now talks in terms that reflect her sense of self-worth and dignity; "I like who I am as a woman. I'm smart. Good power I have. I don't want to be treated as a little girl." Loretta is active and participates in many downtown activities like shopping and dancing. Her experiences though, are not always pleasant. When some kids insulted her in a park, she and Sandra, the assistant with her, talked through what to do together. Loretta explains:

Some kids called me retarded. I don't like people to call me that 'cause it hurts. I got me power there with me. Sandra [caregiver] was with me and we walked. I told Sandra I hate the kids calling me that name. I talked to Sandra about the kids. I cried. She helps me [with] my control. She asked to me that I stay calm. So I stay even. Then I talked to the kids. I told the kids, 'Stop! My name is Loretta.' And I shake hands. They apologized.

Sandra says:

At first Loretta wanted to 'hit those kids in the face'. As we sat there talking it through on the bench though, she moved through her anger to a place that seemed to me to be beyond 'letting it go', a phrase she often uses to help her leave difficult things behind. The way that she gathered up her courage and risked further ridicule by going back to the kids and telling them that they had hurt her, made a lasting impression on me.

Sandra and Loretta were clearly negotiating power in the decisions of whether to go back and stand up to the teens, and how to do so. Sandra was worried about going back and said so to Loretta, but when Loretta said she was ready to stand alone, Sandra chose to stand back. Risking failure also brings the opportunity for success and the positive experience of actively making decisions. While power will inhere in any relationship, freedom can be measured by one's ability

to transgress the limits of the directives (Lamb 1995:452-55). Loretta demonstrates this freedom by choosing to go back and challenge the kids against the suggestion of Sandra.

More often, the negotiation of power-sharing transpires over much longer periods of time and in smaller, everyday kinds of choices. Often many people are involved in decisions that a core member is trying to make, which is a good check to ensure that no one person controls or decides for the core member, and also brings more wisdom to bear on the question. For example, around health issues, there is first the collective knowledge of the core member, the assistants and other core members in the home. In addition, they will consult appropriate external health care professionals like doctors, nurses, psychiatrists, physiotherapists, nutritionists and so on, as well as other long-term assistants who have lived with that person before and may have useful historical insight. Where verbal communication is limited, assistants and health professionals monitor the person's behavioural and physiological responses to a given choice to see if it is acceptable to her.

One example of this group approach to sharing power voluntarily, happened in the case of Frank, a core member who was having challenges with getting to the toilet during the night. This process occurred over a year and I was impressed with how committed the team seemed to be to taking time to find a solution that worked for, and "honoured" Frank, rather than rushing to the "control option," which would have saved them a lot of work. I was told that initially there were only occasional incidents and the nurse involved determined it was not treatable medically. In discussions with Frank, the assistants shared the options with him, which were either to wear adult protective briefs, or to be woken up for a bathroom trip at night if he felt the need. He chose the latter, which worked for awhile, but more often than not, he chose not to get up, even when it was necessary. His choices obviously resulted in significant extra clean-up work for the assistants

he lived with, and they felt he was increasingly confused, embarrassed and anxious about it. But several discussions with him about getting up did not yield any change.

In the house meeting among these assistants that I observed, they talked together with the part-time community nurse and spent substantial time trying to understand what underlying feelings or stresses on Frank could possibly be contributing to the issue. They also addressed how to help him through changes in his life and work environment and proposed new solutions that reflected empathy with Frank. They supported each other to believe that continuing to work with Frank was still the right and plausible thing to do; that there were still avenues to explore before moving to the stage of requiring him to wear protective briefs at night. I do not know how this situation was eventually resolved, but the story is a clear example of discussions that I listened to in many L'Arche homes where the assistants were committed to finding ways to pro-actively share power and decision-making, even when it added to their own responsibilities, and even when the outcome of the process was not sure to yield a better or different solution. The process itself was seen as an outcome of care in that it yielded dignity and respect to Frank and allowed him the time and space to work towards a solution in the same way that any of us would.

7.5.2 Being forced to share or use power

How power is shared and used is not only in the hands of assistants in L'Arche. There are often instances in which a core member can force the assistant either to share power in a situation where the assistant did not intend to, or to use power to enforce a decision that the core member is resisting. L'Arche is able to rely primarily on a "soft approach" to authority and power (less regulation, medication and restraints) in large part because the people with disabilities who live there are generally content and cooperative. But not all people with disabilities who come are content or co-operative all or any of the time. Scenarios involving these people provide special insight for understanding how mutuality can work because they involve greater deliberation,

frustration, confusion, and reflection on the assistants' part about what a legitimate use or sharing of power is, and when they must draw the line for legal or personal reasons. I purposefully did not put these scenarios in the next section on "limits" to mutuality because in L'Arche, long-term assistants tend to view such conflictual scenarios as still having the potential to be relationship-building and mutually growthful when handled well, as discussed below.

Such conflicts of interest are usually found in the little ways in which many core members resist a decision that an assistant has made and is trying to enact or impose on them. The most common instances of this seem to occur around when to go to bed and when to get up for work or a day program. Some core members do both on a regular schedule and seem very comfortable with this routine or rhythm to their day as are most people who work full-time. It provides a sense of control and predictability. For some people with intellectual disabilities and/or mental illnesses, a break from routine can be quite disruptive and anxiety-provoking. Others are unhappy about it almost every day and refuse to get up on time, and complain once they are up, and generally give the assistant a very hard time about it. This forces the assistant to step out of the L'Arche cultural ideal role which attempts to strive for co-operation, understanding, and equality in decisions and to use his authority in the home to prod, convince, and argue with the person to get up.

Besides simply being tiring, this so-called non-compliant behaviour challenges the assistant's self-concept as a friend, and reminds both parties of the inescapable power imbalance. Again, there is a particular, direct honesty in how people with intellectual disabilities act in the world. My interpretation of such commonplace acts of resistance or complaining is that, at some level, the core members are well aware of the ultimate, if tacit difference in authority, and more willing to admit it than the assistants who have more invested in trying to meet the L'Arche ideal of "sharing life with" as opposed to just caring for people. Indeed, the assistants are so committed

to living that ideal, that I noted regular instances like this where the assistants would ultimately privilege the core member's "right to choose" not to go to work or program. They did so even when that meant that they were then unable to attend assistant meetings or have their short afternoon break time because they had to stay at home with the core member.

While I did not think to directly ask assistants during fieldwork to say which sorts of relationships or which kinds of core members had taught them "the most," I now suspect that for many assistants, the times or people they learned the most from were the ones who were difficult to get along with; relations that were intense and ridden with conflicts of power, authority, will, values, and/or desire. Ironically, the core members who are the easiest for you personally to get along with (and this is different for different people) are often not the ones from whom you learn the most. This is not always the case, but quite often, in interviews and in daily conversations, I found that people were most excited to tell me (or each other) stories about situations that involved more conflict, complete with the drama of disagreement or moral confusion, turning points, and resolutions. These stories are not often written about in L'Arche's official literature, but I have a few stories to illustrate how fruitful this genre of conflict can be.

Sebastian was an older man who had been in Daybreak twelve years, but only after several decades in an institution that were filled with some painful experiences²⁷. While most people would agree that Sebastian loved the increased freedom and integration into the world that he got at L'Arche, there were still many ways in which he expressed anger and what was probably resentment at the years of forced custody. Sebastian had habits like swearing, tearing his clothes, and yelling at new assistants. But assistants and core members who had lived with him during his many years in L'Arche, cared about him deeply, and when he died the community came together in a colourful celebration of this rowdy character.

Many assistants talked about the intensity and frustration of trying to have a relationship with Sebastian and to co-operate with him since he often did not want to co-operate with them. It forced them to greater efforts of compassion and patience, and reflection on why he was how he was. Their efforts were aided by their understanding of the pain and abuse that he had suffered in institutions in the past, but also thwarted when he cursed them or refused to co-operate with them and insisted that another assistant help him with his routines, as if they were not good or trustworthy enough. A few assistants explained that through Sebastian they learned to speak their minds more honestly about what they need. Many were inspired that he still had so much chutzpah after the tough life that he had. Importantly, these life lessons derive directly from negative aspects of his impairments, not gifts that he had "in spite of" his impairments.

Some people with disabilities who went to live in L'Arche arrived as people with significant challenges around controlling their violence, anger, and need for affection. Their entry into L'Arche, a place that offers people greater freedom to decide how to be or behave, begins an unpredictable journey that can be overwhelming for them. The decisions they choose to make with this freedom are not always progressive and are sometimes harmful to themselves or others that they live with. Matthew is an assistant who has been in L'Arche 14 years and is a big, fun-loving, no-nonsense man. I talked about him at some length earlier in the chapter on motives as well. He told me a story that made me think about how active a role the core members play in determining how power is used and shared. It bears repeating at length. Matthew lived with Robert, a core member who had diabetes and was physically very fragile, but was in other ways very strong.

Robert would walk around the house as if he was king of the world—he had an air, a grace... an integrity that made you respect him for who he was even when he was driving you nuts. Well, as an assistant you have a lot of power, you earn that. But Rob had a way of just turning that upside down. For example, in hygiene. He just hated washing his hair but it would get to the point that you would have to make him, because you couldn't have him looking like that in

public... people would not welcome him looking like that. He'd make a huge fuss and we'd fight the whole time I was washing his stupid hair, and it made me feel like a huge ogre for making him do it. But then I'd wrap the towel around his head and then he'd walk back down the corridor with this little smile as if to say 'Didn't I put you through shit!' He would get me every time! ...

But I felt that act, that departing smirk, was a great act of forgiveness in a way... as if he was letting me know that he knew that this was a game and he understood why I had to do that, and that I shouldn't take it so seriously or feel badly.

Matthew shows here how this fragile, handicapped man could invert the normative power imbalance between them, both through his resistance, and his forgiveness, which he seemed to know that Matthew wanted. It is a good example of how we all have both the patient and the healer within us, and how a healer does well not to put so much distance between him and the patient so that he forgets that the patient is not helpless, and the healer is not devoid of needs (Guggenbuhl-Craig 1971:16-20, and 78; Steinhoffsmith 1999:75). Robert forced Matthew both to share power with him (by deferring his hair-washings) and to use his power of authority when he did not feel comfortable to (wash the hair). It is clear that out of these struggles Matthew was growing in how he understood and reflected on the meaning of their conflicts and their relationship simply as people, beyond the normative caregiving structure that was imposed on them by the situation. He had to consider deeply on what grounds he could "make" Robert wash his hair and whether he was indeed acting in a way that exhibited caring for Robert and Robert's interests.

He also talks about the capacity that Robert had to call people to prayer, even when they were rushed and even when, a year later, he experienced kidney failure. "His prayer was really putting me in touch with my own need for prayer. And my need to slow down and take time with my prayer." Their struggles continued, and fed their close connection but Matthew feels that Robert's real gift to him came in the final days of his life.

With my background and all, I do not take compliments well. I was just the worst as a young man, I did terrible things. But I could charm my way out of any trouble—and so I guess I just figured that when other people said nice things, that they were like me ... I can see now that I did not, [could not] trust what people said ... And I don't know, I wouldn't have said this at the time, but I didn't see myself as worthy of love or loving... There was a lot of self-doubt underneath although people would not have seen that, I don't think. But this thing with Robert, well it broke that open—took me to the point of seeing myself as loveable.

Robert was dying. He was in and out of the hospital and we'd [assistants] do 8-10 hour 'shifts' there to keep him company. Anyway one night, days before his death, I was there twelve hours with him. It was a bit like being by the ocean, in that I found a sense of solitude beside him that didn't bother me. Still, between that and all the rest, [at the house] I was exhausted. He was in and out of sleep and kept waking up seeing me there. [Then he just] turned to me and said 'Baphew, Go home now.' (that's what he called me), and I said 'No mate, it's okay, I'm here for you.' And we argued back and forth and then he said to me; 'It's okay Baphew, I love you.' This just blew me apart. I'm with this man who is my age, and he is dying and somehow he picked up on something that I didn't.

Again, it's like he was forgiving me for all our arguments and conflicts, saying I'm loved anyway... See, I could take that on board coming from Robert—it was so pure and raw- just no agenda. I could believe that he meant it ... in a way that I never had before. And my students did- looking back I can see that... but I never took it on board... But there was more too—this transformed me because it made me recognise how important it was to tell people I was close to, how I felt for them, and I did. It opened up possibilities in my relationships that I can't even express to you.²⁸

7.6 Conclusion: The limits of mutuality at L'Arche

Aside from the way in which striving for mutuality can produce fruitful conflicts to be resolved, there are also times when it must be admitted that mutuality has limits for one reason or another. It can be a particular response to the professional power imbalance, the fact that some things are just about dependency and not mutual or particularly meaningful. Sometimes an assistant is tired or out of sorts and only wants to undertake the task, not the relational connection. And sometimes a core member and assistant simply do not get along. There are, alas, limits to our capacity for acceptance of difference, and it is important to name those times as such, rather than forcing the issue; forced mutuality is, of course, not mutuality at all. None of us likes every

person we meet or work with and the same is true for caregivers. Rather than making blanket statements like “I love the core members”, assistants at L’Arche talk almost exclusively in particular terms, about particular people whom they enjoy, conflict with, learn from, or really do not get along with. While a decent level of professional and moral acceptance must prevail in all interactions, an assistant who is relationally engaged, is bound to like some people better than others. In other words, caring as mutuality does not mean that you have to *like* everybody equally.

L’Arche aims to transform or shape people’s hearts to be more open to relations across difference. While assistants regularly report success on that count to some degree, there is no guarantee that they will actually have such a relationship *at* L’Arche; their shift in attitude may blossom more fully elsewhere. For example, Angie says that former assistants tend to make very good parents. Reasons for not coming to mutuality at L’Arche vary. Some found themselves in a home where they did not get along with the other assistants. A few never got to the point of feeling that there was “room” for them on the proverbial stage when the core members in their home were already attached to or comfortable with existing assistants. Others do not stay long enough to find their place or to get past some of the normal awkwardness. Some people simply do not feel cut out for relations with people with intellectual disabilities.

Some folks that I interviewed suggested that there were also structural issues at L’Arche which prevented or at least slowed down the development of good relations. Kevin was frustrated with how many times he had been asked to “say yes” to helping with a need in another house, which meant that he had to move homes and start over again, leaving behind incipient relationships. L’Arche Canada undertook two surveys in the last eight years, and in both cases, long-term assistants expressed concern that increasing bureaucratization and government administrative requirements were encroaching on the time they could spend being with core members and building relations (Davis 1995; Lukeman 2001).

As has been noted earlier, some aspects of the labour of care as practiced at L'Arche and elsewhere also need to be respected as plain old dependency or physical labour. In other words, part of giving someone a bath or making them dinner, is just that. Kittay argues that while it is important to talk about the reciprocity in the relations, this should not be used to further devalue the component that is labour and needs to be rewarded as such (1999:53-5). Kittay points to the moral pressures on caregivers to continually defer and subordinate their own needs in favour of meeting their charge's (more urgent) needs (1999). This suggests some limits of mutuality and the need to recognize how these relations are irreducibly dualistic in nature, even when also mutually enriching.

Mutuality cannot be forced and there are core members who are only too aware that an assistant, however kind, fun and helpful, is still an assistant and thus not a "real friend" by some definitions. However much a researcher wants to make the definition of friends nuanced and inclusive of many configurations, people with intellectual disabilities generally see things like this in more plain terms. Sebastian, who spent decades in an institution, never rescinded his incoming understanding that caregivers belong in a particular category in relation to him. Even though he had good relations with several assistants, most people who knew him well told me that he drew a clear distinction between assistant-friends and outsider-friends, with the latter having ascendancy. Raoul and other assistants' working theory was that Sebastian was frustrated and embarrassed by his own need to depend on assistants and so for him there was freedom, or different possibilities, around people who did not look after those aspects of his life.

There are people who feel uneasy about how L'Arche advocates and interprets relations between people with intellectual disabilities and their caregivers. Noel, from Quebec, said that it was ironic how the core members, who are often focused on survival, came to the relationships with an honesty of need (even if grudgingly so) that assistants often do not or can not. He felt that

assistants sometimes want to overlook that reality because they want to believe there is a friendship there that is not just about the labour of care. Billy, a director out West, felt that as an organization, L'Arche makes an unverified assumption that the core members want relationships with assistants and see them as more than just caregivers. His community asked a handful of core members about this informally, and were surprised to find that several of the core members did not see assistants as more than caregivers.

These concerns are all legitimate and could usefully be investigated further, but it would be wrong to conclude that these cautionary notes imply a need to end all attempts at relationship. Given the paucity of opportunities for relationships of any sort for people with intellectual disabilities, disallowing them care relations would do more harm than good. Furthermore, core members are rarely passive victims of unwanted attention; many of them have effective means of resisting or avoiding people that they do not want to be with. L'Arche leadership are aware of the concern that exists in the assistants' needs, or the "absent cry of the rich" and are working out how to mitigate any negative effect that that might have.

Although my research examines assistant-core member relations, other relationship dyads are also important for assistants in L'Arche. Relations with core members have certain limitations given the assistants' inherent professional responsibilities, and the lack of shared experience in certain areas, which circumscribes some conversations. Assistants often talk about the need for other kinds of relationships, either with assistants or people outside of the community, to keep their perspective and not become overly identified with L'Arche.

7.7 Endnotes

¹ Thanks to Carl MacMillan, a L'Arche director for our conversation on this.

² Pottie noted here that assistants themselves can tire of the radical agenda at times and pull back. People have multiple projects and desires, which shift in importance (Tsing 1994; Ortner 1995).

³ Although my impression is that core members valued relationships (see Chapter 2), I did not interview them directly. I now see this as a weakness with my research and I hope to do future research to correct for it. See Cushing & Lewis (2002) for an initial effort to incorporate their perspectives.

⁴ Research is needed on the challenges of assistant-assistant relations and on core members' relations.

⁵ "Care that is carried out without a sense of the real worth of the recipient is flawed in the most profound way. Such care can produce a sense of belittlement and, so, be destructive of the person toward whom it is directed." (C. Taylor 1994:183).

⁶ This begs the question "What do core members think and feel about relationships with caregivers?"

⁷ These roles are not totalizing and research shows client agency and resistance (Friedson 1961).

⁸ Or in some cases to even be aware that such a script of role expectations exists.

⁹ Again, determining what the motive or agency is for a person with intellectual disability is a tricky business. Clearly, non-cooperation is not always intentional, but sometimes it is.

¹⁰ It is also important to note that these relations occur within the web of relationships that makes up L'Arche communities and these provide another kind of support (Pottie 2001).

¹¹ Again, as noted earlier, it is likely that we do have a natural capacity to relate to those who are different, but that we are socialized out of that capacity by the time we are adults like these caregivers.

¹² Ortner (1984) cautions against this pitfall in discussions of practice.

¹³ Of course books like Ong's *Spirits of Resistance and Capitalist Discipline* (1987) show that for the people involved in mass production, detached simplification is not generally good either.

¹⁴ In this history section, I use research that has been done with a variety of caregivers including direct care workers, doctors and nurses. I recognize that each of these careers involves very different training, experience and power, but the thread of the imbalanced organizational or systemic emphasis between caring and competence seems common throughout.

¹⁵ A pentimento is a canvas which has been painted over more than once but some of the paintings underneath show through. I borrow the metaphor from Rhodes (1993:131).

¹⁶ The question of whether this kind of choice should even be made at the level of the (often uninformed, and always, initially shocked) individual is another major ethical and biological/evolutionary question. It also begs the obvious question of where will we (as a society) draw the "moral line" on what genetic disorders we deem okay (or not) to abort for as the capacity becomes available. Finally, given the increasing sophistication of how insurance companies discern between what "problems" they will and will not cover, I wonder whether health insurers might decide not to cover parents who "choose" to have a child (i.e. to not abort) that will invariably involve substantial additional health care costs/insurance payments.

¹⁷ In most agencies the common expectation is that the people with intellectual disabilities will develop friends with "peers" (i.e. other people with disabilities), not staff.

¹⁸ This is an edited version of a longer conversation but the phrasing is intact.

¹⁹ Loretta used to buy rings then decide shortly after that she did not like them, which became costly.

²⁰ P.L.A.N. is an organization of parents and friends of people with intellectual disabilities separate from L'Arche which claims Vanier as their inspiration for an ideology and set of programs based on the belief that relationships with people with disabilities can enrich typical peoples' lives (PLAN 2001).

²¹ This passage has been edited for brevity but all ideas are Adrienne's.

²² For a psychological perspective on this kind of diminished ego experience in service, see Hyrniuk (2001) and Pottie (2001).

²³ Daniel also notes that Marjorie's confidence was double-edged. Sometimes she could be hurtful to her housemates. While that was not acceptable, her confidence still triggered his reflections.

²⁴ Note that in the broader context of the work, caregivers themselves are often powerless in relation to their employers and are frequently underpaid (Kittay 1999:49; Braddock and Mitchell 1992).

²⁵ See also Stephenson and Coughlin (2001) where the aged's main priority is not always independence.

²⁶ This can also be a tension in regular relationships, but the power and authority dimension here adds a layer of complexity with who gets to make the decision.

²⁷ Sebastian died in November 1999 while I was living in the community. Rest in Peace.

²⁸ This facet of relations across inequality in caregiving could use more attention.

8.0 Conclusion

L'Arche is a community and a caregiving organization with multiple dimensions and ideas. It holds together a substantial diversity of caregivers who have different interpretations of where L'Arche should be headed. They all agree, however, that their experiences in L'Arche touch and shape their lives in deep, inexpressible ways. A social science perspective on their experiences of becoming and being assistants in L'Arche is inescapably partial. Social sciences are grounded in the particular traditions and beliefs of rational Western thought, making them inadequate purveyors of the full import or holism of deep spiritual experiences. This study is thus limited in its capacity to evoke those deeply significant parts of assistants' experiences in L'Arche. My strategic choice to focus more on *morality* than spirituality in the communities adds to that issue. For perspective, after reviewing a chapter of this thesis, one assistant wrote:

I understand the real value of an attempt to explain L'Arche in academic language, and the analysis certainly rang true to my experience there; but at the same time, after reading it, I felt like something was missing. There are parts of L'Arche, and being an assistant that simply don't make sense- they're nonsensical if you will; I suppose it just doesn't all lend itself to *reason* or explanation.

Nevertheless, the ethnography provides insightful perspectives on many other aspects of the L'Arche world. In this conclusion, I review the key questions on which the research was based. I then discuss each of the chapters briefly. Following this, I outline the areas to which this ethnography contributes: anthropological theory, transferable ideas and approaches for the disability and caregiving fields, and, specifically, implications for the future of L'Arche. I close with a discussion outlining possible directions for future research.

8.1 Research questions

In a return to my original research questions, it should be recalled that with this inquiry I aimed at the following examination: How does L'Arche motivate and enable people to become the kind of caregivers it needs in order to carry out its radical ethic of care for people with intellectual disabilities?

I also presented three component areas of inquiry regarding the manner in which L'Arche: facilitates the personal growth of people with intellectual disabilities; revalorizes disability, difference, and inequality; and makes care-giving morally, spiritually and politically meaningful for the caregivers. I have shown that L'Arche has developed a local moral sub-culture within which it stimulates the *moral imaginations* of the assistants as part of the process of enculturation into its ethic of care and alternative approach to disability and difference.

L'Arche achieves these aims through a combination of its compelling moral and spiritual perspective on disability and caregiving with extensive opportunities for direct experience with people with intellectual disabilities. Although the ideas and ideology are powerful, knowing them intellectually is only a first step. The daily practice of caregiving is essential to assistants' development; it is transformative for them precisely because L'Arche has succeeded in imbuing it with greater moral and spiritual meaning. It is in the practice of care, and the relationships which grow out of that care, that assistants actually grow and change.

8.2 Chapter summaries

Chapter Two presents two major goals regarding relevant ethnographic methods. The first was to make the complex and variable methods of participant observation and interpretive analysis as transparent to the reader as possible. In order to accomplish this goal, its inherent strengths and weaknesses are named, in addition to limits arising from my errors or oversights. The second goal was to illuminate the complexity of the ethical conundrums involved in

performing research on people with intellectual disabilities and the need for social scientists to think through the issues involved. Issues of consent are paramount here; however, related issues of representation and voice are also critical. Anthropologists are well-positioned to contribute to this discourse given the field's extensive literature on such concerns.

In Chapter Three, I illustrate the compelling history of the cultural construction of intellectual disability as a medical category and a stigmatized social category, how these processes can not solely be blamed on caregivers or technologies of care. The technologies generally arise out of, and are reflections of, widely-held social values. I describe the progress made by the current, dominant approaches to caregiving and disability in the field, as well as ways in which they could go further to improve the conditions of life for people with intellectual disabilities. I use the literature to show that genuine social integration for people with intellectual disabilities is far from a reality in spite of their physical relocation into our communities, and that family homes and smaller care facilities do not necessarily eliminate the neglect, condescension, and abuse that have scandalized large institutions.

I suggest that one of the principal reasons that deinstitutionalization and community living have not radically altered the dominant public view of disability as a deficit is that the ideologies that they are based on have not given the public or caregivers a clear rationale for a positive valuation of disability. The L'Arche philosophy of difference and disability offers a unifying ideology for the field. Its approach to care offers strong evidence of the moral and practical value of proper supports for caregivers.

Chapter Four positions L'Arche in social-political time by demonstrating the confluence of several factors which aided its emergence. I outline the key pillars of the L'Arche philosophy and how it is distinct in the field for its revalorization of disability and its equal emphasis on relationships and independence. It is also important to clarify two things in L'Arche's history

which are often vague and sometimes intimidating for young assistants today. First, the ideas, philosophy and spirituality, that L'Arche is now famous for, evolved over time through experience, effort, prayer, and relationships. In order for new assistants to learn how to live these precepts, it is necessary that they have time and practice. Second, Jean Vanier spent many years in contemplation, service, prayer, and study before he was at the stage of personal and spiritual development from which he could give himself over to the life of an assistant. He understands that this journey takes time and feels that people should discern a path that works for them, not feel tied to a perceived L'Arche ideal. Although people tend to focus on his messages about being and belonging, Jean is also a model of *becoming* in certain areas where he continues to expose himself to new risks after almost 40 years of L'Arche. For example, he regularly agrees to speaking engagements with non-L'Arche audiences who see the world differently.

In Chapter Five, I use self-narratives of assistants and volunteers with L'Arche to lay out a multi-dimensional picture of what it means for them to be in L'Arche and why they wanted to live and work there. The language patterns they use to talk about these questions are also analyzed. My analysis points to three main themes. The first of these involves the question of whether assistants come to give or to get (i.e. altruism or self-interest) and animates much of this discussion, as is often the case with research into what motivates caregivers. It is apparent that motives reflecting the analytical concepts of altruism and self-interest appear to co-exist, overlap, and be regularly reassessed by assistants. However, what they consider to be in their self-interest often shifts substantially once they experience L'Arche. Second, for many assistants the meaning of living in L'Arche was connected with their desire for a more authentic lifestyle, or a way to live their values. The work thus held particular moral weight as an enactment or embodiment of beliefs. Finally, I seek to emphasize the degree to which assistants expressed humanitarian and

grassroots political desires as part of their motivation to join L'Arche, and the implications this has for retention of staff.

Chapter Six presents my findings on the central issue of the thesis: motivating and enabling assistants to reproduce L'Arche's radical ethic of caregiving. I examine five key, interdependent elements of the ideology and process of enculturation in order to illuminate both their positive outcomes and unintentional side-effects. Overall, I endeavour to show that, while the ideals and leadership are important, the success or failure of new ideologies of care can rest largely on the willingness and ability of direct caregivers to enact them. New ideologies often neglect to address ways in which their goals for ameliorating the lives of clients often involve demands of caregivers; demands which are in direct conflict with the caregivers' own needs. Convincing caregivers of the ideological rationale behind the need for changes, and supporting them to sustain the changes over time, is essential to achieving real change in attitudes and care.

By describing in detail the structures and uses of space and time in L'Arche, I show not only the powerful effect of reproducing organizational ideals in elements of daily life but also the real challenges with executing such radical ideals. The discussion of redefining productivity to include time for relationships contributes to the importance of practice in assistants' moral transformation. Among caregivers, informal story-telling about their experiences with people with intellectual disabilities is shown to produce a sense of commonality and to humanize perceptions of disability through emphasis on each person's particularity. The stories help to indirectly establish *what counts* in L'Arche; they help assistants learn to recognize the unconventional gifts of people with intellectual disabilities. Finally in Chapter Six, I show how the L'Arche model can be translated into a more general case for the social value of diversity and inclusion of people with intellectual disabilities.

One of the most difficult tenets of L'Arche to understand, for people new to the field, is the belief that rich relationships of mutual growth are possible with people with intellectual disabilities. In Chapter Seven, I examine this aspect of L'Arche directly, including why such relationships are considered unusual in the first place. I begin by laying out a six-part vernacular definition of mutuality as it is broadly understood in L'Arche, in order to clarify what they do and do not mean by the term. They are, for example, not claiming that what is given by each person in a relationship is equal, but of an incomparable quality. Caregivers' physical labour is not reciprocated in kind but L'Arche assistants feel that they are enriched or compensated by the core members in other ways. I present diverse stories of the relationships that have developed; the kinds of lessons the assistants feel that they have learned from being near to the core members and how they have learned to recognize the core members' prophetic capacity. I also emphasize, however, that the daily process of learning to be open to these relationships, across difference and inequality, is perhaps just as vital. This process transforms assistants' basic attitudes towards difference and continues after they have left L'Arche.

Rather than focus only on the positive side of these relationships, I also discuss how difficult they can be in practice. I show how much energy is required of the caregivers as they constantly try to negotiate the relationships across substantial difference and inequality in power and capacity. I demonstrate that assistants and core members continually and actively renegotiate the possibility of relationship in the daily life of the home, particularly in situations where their needs, desires, or responsibilities conflict. Growth can emerge from the conflicts as well as from the enjoyable times, when they are interpreted and experienced through the lens of the L'Arche philosophy.

8.2.1 Contributions to knowledge / anthropology

In this ethnography, I have primarily attempted to use anthropological theory to illuminate the local moral world of L'Arche, rather than the opposite. However, it is important to indicate the ways in which this ethnography, and the L'Arche experience, contributes to the field of anthropology. There are six relevant contributions that I identify.

This ethnography presents a strong case for the cultural construction of perceptions of people with intellectual disability and the significant degree to which the constructions determine how people with disabilities are understood and treated. The contingency of the deficit model of disability from which those ideas work is dramatically revealed in the fact that L'Arche has achieved such a shift in attitudes and relational possibilities between people with and without intellectual disabilities. Related to this is the contribution that this ethnography makes to the anthropological project of heightening cross-cultural respect and awareness. I achieve this by articulating the way in which L'Arche represents and enacts a strong case for the social value of diversity. This concept moves beyond cultural relativism or liberalism to show how worthwhile it is for both parties to build bridges across the cultural divide between people with and without intellectual disabilities.

My analysis of the negotiation of power-sharing across inequality in the relationships in L'Arche provides a compelling case for an organization that is attempting to make the rhetoric of "patient empowerment" a reality. It reveals two things; the regularly neglected fact that this approach requires the power to come from, and be given up by, someone else, namely the caregivers; and how L'Arche is attempting to compensate them in innovative ways.

Another contribution of this ethnography to anthropology is the analysis of the process of enculturation and how people experience that process as transformative. Humans are all enculturated from childhood into a given cultural belief system. However, the L'Arche case is

particularly interesting because it seeks to teach adults an *alternative* set of beliefs, parts of which conflict with their existing set. This case contributes to the anthropological interest in facilitating cross-cultural understanding and how to assist people in integrating into new cultural settings. My emphasis on moral aspects of the enculturative process makes the case relevant to a variety of scenarios involving ethical differences.

Narrative theory has been a growing area of interest for anthropologists as we examine more deeply our analytical methods which often involve narratives of various sorts. In this ethnography, I discuss how self-narratives are framed and shaped by the particular organizational culture in which people find themselves. Principally, however, I present a detailed examination of the productive and didactic power of informal narratives told among caregivers about people with intellectual disabilities. These stories shape the construction of knowledge and health care in L'Arche by putting a human face on disability and difference. In this account, individualized, nuanced stories emerge as a powerful counter-point to the typical homogenizing, deficit-focused conceptions of disability. I also talk about the issues with narratives as a primary enculturative tool, given their ambiguity and covert cultural biases.

This thesis also contributes to the study of work and, in particular, the meaning that some people place on being a caregiver. While the discussion of L'Arche assistants' motivations and beliefs about their work is not fully generalizable to mainstream care, there are likely several overlaps in substance, if not degree.

8.2.2 Contributions to the disability field

Overall, the thesis shows that while the L'Arche model in its entirety is not a universal solution for the disability field, aspects of it could be highly useful in helping move the mainstream care organizations further in their goal of promoting the well-being of people with intellectual disabilities. Below, I outline five key lessons for mainstream care providers that the experience of L'Arche suggests.

The primary lesson that I hope to illuminate for mainstream readers is that a secularized version of the radical L'Arche approach to disability and difference could provide a strong foundation for uniting several contemporary movements. It could heighten their effectiveness by providing a compelling ideological route out of the deficit model of disability that dominates the public imagination, that reproduces a devalued social role for them, and that considers them primarily as a cost and a social burden. A modified version of the L'Arche revalorization of difference would help mainstream agencies to speak more effectively to the sociological imagination of the public through its rationale of the social value of people with intellectual disabilities.

Second, the L'Arche example demonstrates that in order for deinstitutionalization and community integration and living to be effective, leaders and advocates in the disability field need to make a special effort to bring about a cultural shift; to teach the public and caregivers how to unlearn old stereotypes about disability, and to learn to appreciate and like people with intellectual disabilities. This appears to require the use of a "pull strategy," which would *create* interest, in opposition to the typical "push strategy," which transfers people with intellectual disabilities from institutions into communities without attending to the strong, if latent, public will to keep them out. There is certainly enough evidence now that it will take more than physical

relocation of bodies to convince the public that they ought to change how they view people with intellectual disabilities.

Third, L'Arche's approach provides several tools such as alternative uses and priorities of space and time in congregate care. It also promotes informal story-telling among caregivers, which, as noted above, could be employed in the process of shifting attitudes. This could be accomplished by altering the framework within which caregivers interpret their experience of people with disabilities.

Fourth, the tools provided by L'Arche pave the way for a heightened emphasis on promoting better relationships between caregivers and those receiving care. Independence has reigned as a sacred value in mainstream care since the early 1970s. However, because the data increasingly shows how lonely many people are who live independently or in small care facilities, some practitioners are shifting to a promotion of "autonomy", which includes a sense of the importance of relationships. Without a shared home life the relations possible in mainstream care would not likely be as deep or common as in L'Arche, but could still move in a positive direction. It is possible to create an ethos in which caregivers are given serious training in ideological and practical tools that would help them to open up to an *appreciation* of the unique and unconventional character of people with intellectual disabilities; to see them as individuals who share the same kind of hopes and needs as the caregivers. Clearly, with any vulnerable population like this, there would need to be checks in the system to prevent abuse; however, this is not an insurmountable issue. In order to not burn-out meeting others' relational needs, caregivers would also need to be supported to place limits around the relationships.

Fifth, this work provides valuable evidence in support of claims by feminist philosophers and psychologists about the importance of articulating an ethic of care that would reflect the particular experiences and moral pressures faced by people who do "dependency work." L'Arche

is an example of an attempt, albeit an imperfect and evolving one, to *care for the caregivers* in a way that enables them to do their work well, on a sustaining basis, without them all becoming run-down and personally depleted in the process. Programs that seek to improve the quality of care provided, without considering what supports the direct providers of that care will need in order to give more of themselves, are bound to fall short of expectations.

Finally, in the discussion of research ethics, I highlight the importance of bringing researchers and practitioners together with people with intellectual disabilities in order to work out a set of research ethics for dealing with people with intellectual disabilities; a set of ethics that is more specific and prescriptive than what is currently available¹. The complexity of the issue and the tough questions that are involved has meant that most researchers have avoided clarity in their consent process; whether the caregiver or client was answering the questions and on what basis s/he did so. Ideally, some set of guidelines could be set up as a standard. Researchers could, in the future, discuss ways in which they might adhere to the standard or vary from it for valid reasons. At the very least, standardized guidelines would provide a minimum expectation of respect and consent.

8.2.3 Contributions to L'Arche specifically

“The punishment of wise men who refuse to take part in the affairs of government, is to live under the government of unwise men.”
(Plato 360 B.C.)

In L'Arche, I had the privilege of seeing new assistants learn from compassionate, skilled leaders. They learned to think about difference and disability in new ways. It was an honour to watch as the moral imagination of young people was ignited, brought to life, and enriched. This shift in moral perspective, and the mutual relationships it fosters, is discussed at length in the thesis, as are some of the issues with the organizational culture. These discussions offer specific and lengthy suggestions for L'Arche. A synthesis of these findings follows, accompanied by an

examination of how they inform the key questions about the mission and the revitalization of the organization that the L'Arche communities are currently considering. I propose a re-radicalization and re-politicization of the organization by calling forth the energy of *all* community members and friends towards a shift in how the mission is being lived.

Here, I extend the argument which has been alluded to throughout the thesis. I believe there is an imbalance in how the communities are currently living out the L'Arche mission. The dual mission of L'Arche involves two radical goals: 1) creating homes and relationships with people with intellectual disabilities, and 2) being thereby a sign of hope to the world for the social value of diversity. Taken alone, neither aim is necessarily radical: creating homes can become simply reformist, and simply signalling or talking about diversity can become merely liberal. Sharing life with people with intellectual disabilities in the homes, assistants are intimately exposed to individuals' experience of dependency and suffering. Without this, the L'Arche message would be flattened and diluted for the assistants and the public. Most long-term assistants agree with this. I contend that the radicalism of life *inside* the homes is also diminished when it becomes severed from the reality of its society. When assistants are not taught, and regularly reminded of the unusual nature of their lives in the homes, their work also suffers a loss of broader meaning, energy, and moral significance.

The two elements of the mission are radicalized when they are combined because assistants' experiences in the homes can galvanize an understanding and compassion that can fuel sincere, grounded efforts for social and political change. Vanier noticed early that the pain of rejection faced by people with impairments or other stigmatized differences often felt worse than their physical suffering. In a radical framework, assistants feel that the energy spent on creating homes is not merely an amelioration of the quality of care for a few people with intellectual disabilities. Rather, they feel it is an important component of the broader effort to change the

conditions that produce the stigma and rejection of people with disabilities in the first place. I do not mean to imply that what is done in the homes is unimportant or less important than externally-oriented efforts. Indeed, the homes are the central place from which these grassroots efforts would need to come. But in my interpretation of the mission, L'Arche was not meant to *only* help those inside of it; they wanted the example of their relationships to inspire broader change in how our society perceived and treated those who were different from them. In order for this to happen, other people need to become aware of those relations.

Over time, the "homes" element of the mission has grown to be more central than the "sign of hope" element; the former utilizes most of the resources of the communities. There are, no doubt, good reasons for why this happened. Perhaps the organizational tasks of managing growing communities were more complicated than originally expected. Alternatively, L'Arche leaders may have thought that mainstream care agencies had already gotten the message since they had planned big changes in the 1970s. It is now obvious that those changes have helped but that much remains to be done. In North America, where the normalization ideology was very strong, L'Arche was not always well-received by those agencies, possibly because of its refusal to make independent living, instead of relationships, its primary rehabilitative goal. The most significant reason for the homes emphasis however, was probably that while the founders wanted to create broader social change, this goal was likely in constant tension with factors which pulled the energy and focus of assistants and leadership inwards to the pressing, practical, daily concerns of the homes.

L'Arche tries to keep both elements in play for assistants. However, my research suggests that, in reality, the broader, symbolic vision is often sidelined by the urgent and compelling concerns of daily life in the homes, as well as by the operational and spiritual value placed on the importance of the little, daily things, over grandiose claims. This cultural belief is grounded in

experience, an experience that has shown that living out this new paradigm of care is difficult, requires an ability to focus in the present and take comfort in the small consolations that are offered, rather than hoping for major changes. As valid as that belief is, it inherently diminishes the perceived importance of unpopular, and politically challenging, moves and thereby discourages interest in them. But the two elements are interdependent and each is essential to the force of the other.

The problem is that the two elements, homes and signs, seem to suggest conflicting priorities and courses of action. I argue however, that L'Arche needs to work harder at holding the two aims in tension rather than continuing to leave the "sign of hope" element underdeveloped. Radical activism² becomes unworkable and dogmatic when unmoored from the urgency of daily life. However, reformist action, that disregards critical reflection on its broader purpose, lacks energy, direction, and conviction. The communities need to think about how to create opportunities in order for the two aims of the mission to be realized together. For example, the homes could be encouraged and trained to develop, as a team, practices which would have the core members and assistants *connect with* the broader public, rather than just *being in* public places. This is not an easy task, but my research indicates why L'Arche should make this effort; it would be helpful to society as a whole, the assistants and their caregiving, and L'Arche as an organization.

The world still needs L'Arche to pursue the "sign of hope" element for the benefit of people with intellectual disabilities. The public, and many caregivers, still need to hear the kind of message that L'Arche espouses about the value of people with intellectual disabilities. The social and economic conditions of life did not change for people with intellectual disabilities as much as hoped after deinstitutionalization. Stigma and social isolation continue to be a reality, in spite of some improvements in these people's legal rights and material quality of life. Having been

located in communities has not automatically or naturally led to changes in how the public truly feels about them. The L'Arche philosophy is well-suited to address these attitudinal issues. It offers and enables a new interpretive framework for understanding people with intellectual disabilities on their own terms, rather than forcing them to conform to standards of normal set by other people. Inclusion, contingent upon marginalized people performing as normal, is not an acceptance of difference at all; rather, it is a continued enforcement of sameness. By making grassroots efforts to extend awareness of that philosophy, L'Arche could contribute to changing social conditions for all people with intellectual disabilities, not just those within its homes.

Amplifying the energy spent engaging more often with the broader society would likely improve the satisfaction and motivation of assistants in L'Arche as well. Although assistants often indicate that working towards socio-political change is one of their motives for going to L'Arche (see Chapter 5), they rarely use such politicized language in their everyday conversations once they are there. The internal accent on spiritual life tends to transcend or even preclude the more political features of their mission. In addition, assistants' priorities shift in the short-term because the immediate needs of the homes and core members pull their focus inwards. Over time, however, the ultimate meaning of the role fades; without regular contact with people and approaches of other agencies for comparison, what occurs in the homes is naturalized.

In short, L'Arche assistants lose sight of the radical nature of what they are living. The relationships and the spiritual life continue to be enriching and enjoyable but the connection between their activities and a social justice framework grows more ambiguous for most. This is unfortunate because knowing more about the L'Arche history, how its approach compares with the field, would lend greater significance to people's activities.³ Most assistants want a chance to exercise more than simply their home-oriented skills. My research indicates that when some assistants do not have those opportunities, they become restless and tend to move on. Creating

opportunities to bring forth these other energies found in L'Arche assistants enhances their growth or "becoming" goals and prevents stagnation, self-satisfaction, and boredom. Repoliticizing L'Arche represents a pushing of assistants to think of small ways in which the house activities could be more visible and engaged with the public. It could also mean giving assistants the support to attend meetings of professional caregiving and disability associations in order to learn about other approaches and share stories about L'Arche with them.

Providing these opportunities for assistants would also be good for L'Arche itself and for the core members. Improved job satisfaction of direct caregivers in other organizations has been shown to result in a higher quality of care and longer caregiver tenure (see Chapter Six). Tenure and quality of care are two important priorities for the community. My research indicates that L'Arche assistants, who *are* aware of, and develop their understanding of, the moral and spiritual significance of L'Arche's message for society and the disability field, feel more satisfied with their daily tasks and are willing and able to stay longer in the role. A few communities encourage this already, and many others have made initial efforts to do so, but it could be more effective as an organization-wide effort. Communities could share ideas and success stories with each other. Opportunities to step outside of the L'Arche culture and observe other agencies would help to disrupt the routinization and naturalization of what assistants do in L'Arche. It would also revitalize their sense of wonder about their work and remind them that what they are doing is unusual. They should not stop asking, "Why does L'Arche have to exist?"

8.3 Directions for future research

This ethnography is somewhat evocative of life as an assistant in L'Arche; it does not achieve a detailed sense of the flow of life for particular assistants or core members over a period of time. Rather, I have shown mainly snapshots of their lives, beliefs, and behaviours through the use of stories, observations, or quotations from them. Given the initial sensitivity in the

community about my presence as a live-in researcher, I do not think that it would have been acceptable to them for me to track particular lives in complete detail. As a result, I do not have the data to produce a rich micro-ethnography such as Abu-Lughod (1993) or Brody (1981). Relationships are of such importance in L'Arche that I think the ethnography I have written suffers somewhat for this; it does not adequately provide a sense of the ebbs and flows of an individual's day, week or year; nor does it adequately represent the rich interrelations which animate the communities and are a vital part of why people enjoy being there. As a newcomer to L'Arche I may not have been able to achieve this goal; however, it would be a good project for someone who has lived there and who has established trusted relationships with people willing to participate in the endeavour.

The second limitation to the ethnography involves a lack of space to include a discussion of the cultural construction of health and illness for assistants at L'Arche. Burn-out, serious fatigue, and sometimes depression are common in L'Arche and the caregiving field generally, a field which can be emotionally, physically, and psychologically demanding. I originally intended to use medical-anthropological approaches to examine these idioms of illness in L'Arche: how they are shaped by the community's central metaphors of service and relationship in ways that are not always healthy for assistants. As one long-term assistant explained: "It is sometimes seen as a good thing in L'Arche to show that you are giving of yourself to others; so, if you are so tired that you become burnt out, it sort of shows that you gave *so* much of yourself. But it's not healthy for us." More work is needed to interpret how particular illnesses in L'Arche may be an indirect way of communicating other messages of distress that are not culturally legitimate (Lock and Scheper-Hughes 1990). Although I address various sources of this issue in Chapters Six and Seven, space limitations preclude me from linking those findings in a coherent statement of the issue.

As mentioned above, I have put greater emphasis on the moral principles and perspectives involved in the L'Arche approach than on their religious origins. This was strategic, in the sense that I aimed to produce a document which would speak to the secular audience of academics and practitioners as well as the L'Arche community. However, it is clear that by stripping the discussion of some of the spiritual language and sensibility, my representation of L'Arche itself is partially obscured. Other academic analyses of the spirituality of L'Arche round out the picture well (Downey 1986, Hyrniuk 2001, Mellis 2002, Sumarah 1996).

With a complex organization like L'Arche, there are many possibilities for future research that could bring new perspectives and disciplines to bear on illuminating and evaluating what L'Arche does. It is more important than ever for L'Arche to think about building a case for the value of its unique approach; the cost-cutting agendas of several provincial health ministries have already led to threats of amalgamation and standardization of care agencies.

The most obvious research direction related to my work is a *comparative* analysis between caregivers in L'Arche and those in mainstream agencies, regarding their experiences of caregiving, capacity to provide good care, and attitudes towards people with intellectual disabilities. While current L'Arche research indicates that it would likely render a positive view of the L'Arche approach, this has not been compared directly or empirically. Demonstrating greater caregiver satisfaction could assist L'Arche in its recruitment of good people. It could also be used as indirect proof of quality of care, given other similar research studies⁴.

It would also be valuable for L'Arche to commission research directly with the core members. Empirical research that assesses the core members' perceptions of their quality of life, and the quality of care provided in L'Arche, would give voice to what core members are feeling as a group and establish what opportunities for improvement are available from the core members' perspectives. Given issues with power imbalance and prophetic interviewing noted in

Chapter Two, it would be important for this research to be performed with outside help, from people who are not perceived by the core members to be friends of their caregivers. If this research could be conducted using measures and interview questions that resemble those used in current research on the same issues in the field (for example Brown 1997), it would provide a basis on which to compare L'Arche against other agencies and residential options for people with intellectual disabilities in these areas. This kind of comparative research could help L'Arche in building a case for the efficacy of its unusual approach.

Comparative research on L'Arche from a financial perspective could show whether it is a cost-effective service provision option relative to others available. Preliminary assessments from the Vancouver community indicates that L'Arche would stand up well in this kind of comparison. A human resources perspective could examine the various techniques and processes that L'Arche has developed in regard to consensus-based decision making, a process that includes core members in community decisions and conflict management in a co-operative paradigm.

There are often discrepancies between what assistants expect to give and learn and what L'Arche expects. It may not only be a difference in expectations but in ability as well. L'Arche should conduct research with people before they arrive, after a few months of residence, and even at their exit interviews. Again, in order to elicit candid responses to sensitive questions, outside researchers would be essential. The findings could illuminate how assistants negotiate between the two sets of expectations, and what they are willing or able to give.

L'Arche has undergone many changes in its long tenure in Canada and there are no thorough historical accounts covering the entire period. Many of the Canadian founders are still in contact with the communities and most communities have written and audio-video artefacts still on hand from their founding periods. A solid history, using secondary historical sources and interviews, could thus be constructed.

8.4 Endnotes

¹ Subsequent to submission, I learned of an attempt at ethics guidelines by Cam Crawford, Roehrer Inst.

² The discussion of radical and reformist approaches to a problem was inspired by my discussion with Professor Harvey Feit (McMaster University) about Herzfeld's (2001) use of Escobar's (1991, 1995) critical analysis of the anthropology of development, and development anthropology along these lines. Discussions with J. Pot, Pottie, Hyrniuk, and Silverstein helped me work through the idea.

³ Habitat for Humanity is a good example of an organization that actively maintains a connection in its volunteers' minds between their work on home construction for the poor, and the people who they are serving, by having those people there with them, helping them work.

⁴ Braddock and Mitchell (1992) for example, established such a link.

Bibliography

AAA

1999 Ethical Guidelines. Chicago: American Anthropological Association

AAMR

2001 Guidelines to Professional Conduct. USA: American Association on Mental Retardation

AAMR

2002a Fact Sheet: Frequently Asked Questions About Mental Retardation

http://www.aamr.org/Policies/faq_mental_retardation.shtml American Association on Mental Retardation:
July 31 2002

AAMR

2002b Changing the name of the association: Letter to Membership <http://www.aamr.org> American Association on Mental Retardation: July 31 2002

AAMR

2002c Definition of Mental Retardation [Intellectual Disability] <http://www.aamr.org> American Association on Mental Retardation: July 31 2002

Abbott, W.M. (ed.)

1966 The Documents of Vatican II. London and New York

Abu-Lughod, Lila

1990 The romance of resistance: Tracing transformations of power through Bedouin women. *American Ethnologist* 17: 41-55.

Abu-Lughod, Lila

1991 Writing Against Culture. In: R. Fox (ed.), Recapturing Anthropology; pp. 137-162. New Mexico: School of American Research Press

Abu-Lughod, Lila

1993 Writing Women's Worlds: Bedouin stories. Berkeley and Los Angeles: University of California Press

ACDD

2002 Federal Definition: developmental disability <http://www.acdd.org/definition.htm> Alabama Council for Developmental Disabilities: July 31 2002

Acker, Joan, et al.

1983 Objectivity and Truth: Problems in doing feminist research. *Women's Studies International Forum* 6: 423-35.

ADA

1990 Americans with Disabilities Act of 1990: EEOC Technical Assistance Manual and Resource Directory. [S.l.]: UMI ProQuest Direct

Albrecht, Gary

1992 The Disability Business : Rehabilitation in America. Newbury Park: Sage Publications

Alexander, D.

1998 Prevention of Mental Retardation: Four Decades of Research. *Mental Retardation and Developmental Disabilities Research Reviews* 4: 50-58.

Amado, Angela Novak

1988a Controversies Concerning the Deinstitutionalization and Community Integration Movement. In: Laird W. Heal, Janell I. Haney and Angela Novak Amado (eds.), Integration of Developmentally Disabled Individuals into the Community; pp. 283-298. Baltimore: Paul H. Brookes

Amado, Angela Novak

1988b A Perspective on the Present and Notes for New Directions. In: Laird W. Heal, Janell I. Haney and Angela Novak Amado (eds.), Integration of Developmentally Disabled Individuals into the Community; pp. 299-305. Baltimore: Paul H. Brookes

- Amado, Angela Novak (ed.)
 1993a Friendships and Community Connections Between People with and without Intellectual Disabilities. Baltimore: Paul H. Brookes Publishing co.
- Amado, Angela Novak
 1993b Steps for supporting community connections. In: Angela Novak Amado (ed.), Friendships and Community Connections between people with and without developmental disabilities; pp. x?x. Baltimore: Paul H. Brookes Publishing
- Amado, Angela Novak
 1993c Working on Friendships. In: Angela Novak Amado (ed.), Friendships and Community Connections between people with and without developmental disabilities; pp. 279-297. Baltimore: Paul H. Brookes
- Amato, Raphael
 1999 Ottawa Community Mandate; pp. 2. Ottawa: L'Arche Ottawa
- APA Task Force
 1994 Diagnostic and statistical manual of mental disorders: DSM-IV. Washington, D.C.: American Psychiatric Association. [4th ed.]
- APA Task Force
 2000 Diagnostic and statistical manual of mental disorders: DSM-IV-TR. Washington, DC: American Psychiatric Association. [4th , text revision. ed.]
- Appadurai, Arjun
 1986 The Social life of things: commodities in cultural perspective. Cambridge [Cambridgeshire] ; New York: Cambridge University Press
- Arbuckle, Gerald A.
 2001 Ensuring the Future of L'Arche. *Letters of L'Arche* 107: 21.
- ARC, Michigan
 2001 Definition of Developmental Disability <http://comnet.org/arcww/1507.html> The ARC of Western Wayne County, Michigan: *Aug 1 2002*
- ARC, The
 2001 Introduction to Mental Retardation: Frequently asked questions <http://www.thearc.org/faqs/mrqa.html> The National Organization of and for people with mental retardation and related developmental disabilities and their families: *July 31 2002*
- Aristotle
 1976 Ethics. London: Penguin (Penguin Classics,
- Bach, M.
 1999 personal communication. In: P. Cushing (ed.). North York
- Barham, Peter
 1992 Closing the Asylum: The mental patient in modern society. Uk: Penguin
- Barrett, Stanley
 1996 A Student's Guide to Theory and Method. Toronto: University of Toronto Press
- Bauman, Andrea
 2001 Commitment and Care: the benefits of a healthy workplace for nurses, their patients and the system. Hamilton and Toronto: McMaster University, University of Toronto
- Bazinet, Jean-Claude
 1995 Communal Journeys: A phenomenological inquiry into the experience of living and working in L'Arche. [Unpubl. Masters of Arts, University of British Columbia]
- Bellah, Robert
 1994 Understanding caring in contemporary America. In: Susan S. Phillips and Patricia E. Benner (eds.), The Crisis of Care; pp. 21-35. Washington: Georgetown University Press
- Bellah, Robert, and et al.
 1985 Habits of the Heart : Individualism and commitment in american life. Berkeley and Los Angeles: University of California Press
- Benner, Patricia E.
 1994 Caring as a way of knowing and not knowing. In: Susan S. Phillips and Patricia E. Benner (eds.), The Crisis of Care; pp. 42-62. Washington: Georgetown University Press

- Bercovici, Sylvia M.**
1983 Barriers to Normalization: The restrictive management of retarded persons. Baltimore: University Park Press
- Berger, Peter, and Thomas Luckman**
1966 The Social Construction of Reality: A treatise in the sociology of knowledge: Penguin
- Bernard, H. Russell**
1994 Research Methods in Anthropology: Qualitative and quantitative approaches. Thousand Oaks, CA: Sage Publications. [second ed.]
- Berry, Donald**
1985 Mutuality: The vision of Martin Buber. Albany: State University of New York Press
- Bettelheim, Bruno**
1974 Home for the Heart. London, UK: Thames and Hudson
- Biklen, D., and C. Moseley**
1988 "Are you retarded?" "No, I'm Catholic": Qualitative methods in the study of people with severe handicaps. *Journal of the Association for Persons with Severe Handicaps* 13: 155-62.
- Bishop, Anne**
1994 Becoming an Ally. Halifax: Fernwood Books
- Bogdan, Robert**
1996 The Social Construction of Freaks. In: R. Thomson (ed.), Freakery: Cultural Spectacles of the Extraordinary Body; pp. 23-37. New York: New York University Press
- Bogdan, Robert, and Steven J. Taylor**
1992 The Social Construction of Humanness: Relationships with severely disabled people. In: P. Ferguson, D. Ferguson and Steven J. Taylor (eds.), Interpreting Disability: A Qualitative Reader; pp. 275-94. New York: Teachers College Press
- Borofsky, Robert (ed.)**
1994 Assessng Cultural Anthropology. USA: McGraw-Hill, Inc.
- Bourdieu, Pierre**
1977 Outline of a theory of practice. Cambridge ; New York: Cambridge University Press (Cambridge studies in social anthropology ; 16,
- Braddock, David, and Dale Mitchell**
1992 Residential Services and Developmental Disabilities in the United States: A national survey of staff compensation, turnover, and related issues. Chicago: American Association on Mental Retardation (AAMR special publications,
- Bradley, Valerie J.**
1978 Deinstitutionalization of Developmentally Disabled Persons: A conceptual analysis and guide. Baltimore: University Park Press
- Brody, Hugh**
1981 Maps and Dreams: Indians and the British Columbia Frontier. Vancouver: Douglas & McIntyre
- Brown, Ivan**
2002a What Do We Mean by Developmental Disabilities in Ontario? In: Ivan Brown and Maire Percy (eds.), Developmental Disabilities in Ontario; pp. Chapter 2. Toronto:: The Ontario Association on Developmental Disabilities
- Brown, Ivan**
2002b personal communication. In: P. Cushing (ed.). Burlington
- Brown, Ivan, and Maire Percy (eds.)**
2002 Developmental Disabilities in Ontario. Toronto: The Ontario Association on Developmental Disabilities
- Brown, Ivan, D. Raphael, and R. Renwick (eds.)**
1997 Quality of Life- Dream or Reality? Life for people with developmental disabilities in Ontario. Toronto: Centre for Health Promotion, University of Toronto
- Bruiniks, R., M. Kudla, C. Wieck, and F. Hauber**
1980 Management Problems in community Residential Facilities. *Mental Retardation* 18: 125-30.
- Bruner, Edward**

- 1986 Ethnography as narrative. In: V. Turner and E. Bruner (eds.), The Anthropology of Experience; pp. 139-156. Urbana: University of Illinois Press
- Bruner, Jerome S.**
1986 Actual minds, possible worlds. Cambridge, Mass.: Harvard University Press
- Bruner, Jerome S.
1987 Life as Narrative. *Social Research* 54: 12-32.
- Bruner, Jerome S.
1996 The Narrative Construal of Reality. In: Jerome Bruner (ed.), The Culture of Education; pp. 130-149. Cambridge: Harvard University Press
- Buber, Martin**
1970 I and Thou. New York: Charles Scribner's Sons
- Burke, Kenneth**
1962 A Grammar of Motives. Cleveland: Meridian books, The World Publishing Company
- Busselle, Rebecca**
1989 An Exposure of the Heart. New York: W.W. Norton & Co.
- CACL**
1997 The Power of Language: Handbook on plain language writing. Toronto: The Rocher Institute-Canadian Association for Community Living
CACL
2001 What is an Intellectual Disability? <http://www.cacl.ca/english/what.html> Canadian Association for community living: August 4 2002
- CanChild**
2002 Caring for Caregivers Hamilton: McMaster University
- Card, Hollee**
2001 personal communication. In: P. Cushing (ed.). Hamilton
- Carrithers, M.**
1985 An Alternative Social History of the Self. In: M. Carrithers, S. Collins and S. Lukes (eds.), The Category of the Person: Anthropology, Philosophy, and History; pp. 234-256. New York: Cambridge University Press
- Carruth, A., U. Tate, B. Moffet, and K. Hill**
1997 Reciprocity, emotional well-being, and family functioning as determinants of family satisfaction in caregivers and elderly parents. *Nursing Research* 46: 93-100.
- Cassell, Joan**
2000 Authenticating (and Inauthenticating) Local Moral Worlds: Ethnographies of Interpersonal Experience. *American Anthropologist* 102: 615-19.
- Castel, Robert**
1991 From Dangerousness to Risk. In: Gordon Burchell and Miller (eds.), The Foucault Effect: Studies in Governmentality; pp. 281-298. Chicago: University of Chicago Press
- Certeau, Michel de**
1984 The Practice of the Everyday Life. Berkeley: University of California Press
- Chambliss, Daniel F.**
1996 Beyond Caring: Hospitals, Nurses, and the Social Organization of Ethics. Chicago: University of Chicago Press (Morality and Society)
- Christopoulos, Katerina**
2001 The Sick Role in Literature and Society. *Journal of Medical Anthropology* 285: 93.
- Clarke, Bill, S.J.**
1974 Enough Room for Joy: Jean Vanier's L'Arche; A message for our time. Toronto: McClelland and Stewart Limited
- Clifford, James**
1986 Introduction: Partial Truths. In: James Clifford and George Marcus (eds.), Writing Culture: The Poetics and Politics of Ethnography. Berkeley: University of California Press
- Clifford, James, and George Marcus (eds.)**

- 1986 Writing Culture: The poetics and politics of ethnography. Berkeley: University of California Press.
(School of American Research Advanced Seminar)
- Cohen, Raymond**
2001a Calling for Action: An interview with David Lepofsky, Ontarians with Disabilities Act committee, abilities; pp. 18-19
- Cohen, Raymond**
2001b Action for Ontarians with Disabilities? Interview with Cam Jackson, abilities; pp. 20-1
- Coon, Dennis**
1989 Introduction to Psychology: Exploration and application. St. Paul: West Publishing company
- Cooper, Matthew**
1994 Spatial Discourses and Social Boundaries: Re-imagining the Toronto Waterfront. *City and Society* Annual review: 93-117.
- Coppersmith, E. I.**
1984 A special 'family' with handicapped members: One family therapist's learnings from the L'Arche community. *Family Therapy Collections* 11: 150-59.
- CSCDD**
2002 Federal Definition of Developmental Disability http://www.scdd.ca.gov/fed_definition.htm California State Council on Developmental Disability: July 31 2002
- Cushing, Pamela**
1996 Gendered Conversational Rituals on the Internet: An effective voice is based on more than simply what one is saying. *Anthropologica?*: 47-80.
- Cushing, Pamela**
1997a The Outward Bound Approach: Experiential, Holistic Pedagogy. *Trumpeter Journal of Ecosophy* 14: 86-9.
- Cushing, Pamela**
1997b *Exploring the Cultural Dimensions of Transformation on Outward Bound Courses: Golden Feathers*. [Unpubl. Master of Arts, McMaster University]
- Cushing, Pamela**
1998 Completing the Cycle of Transformation: Lessons in the rites of passage model. *Pathways Ontario Journal of Outdoor Education* 9: 7-12.
- Cushing, Pamela**
1999 Translating Transformation into Something Real. *Pathways Ontario Journal of Outdoor Education* 12: 26-28.
- Cushing, Pamela**
2002 *Story-telling it like it is: How Narratives Teach*. Narratives of Disability, Disease and Trauma, University of British Columbia, 2002; pp. 15. Peter Wall Institute for Advanced Studies.
- Cushing, Pamela , and Tanya Lewis**
2002 Negotiating Mutuality and Agency in Care-giving Relationships with Women with Intellectual Disability. *Hypatia Journal of Feminist Philosophy* 17: 137-160.
- Davis, Marni**
1995 North American Long-Term Assistant Survey: A Way of Life; pp. 14. Vancouver, Canada: L'Arche North American Zone Council
- Day, Peter**
1981 Social Work and Social Control. London: Tavistock
- DeJong, Gerben**
1979 The Movement for Independent Living : Origins, ideology, and implications for disability research. Mass.: University Centers for International Rehabilitation: Brandeis University
- DeLauretis, Teresa**
1990 Eccentric Subjects: Feminist Theory and Historical Consciousness. *Feminist Studies* 16: 115-150.
- Desjardins, Michel**
1998 *La Rééducation Sociale Comme Système de Significations Culturelles: Le Cas de la Déficience Intellectuelle Légère*. [Unpubl. Ph.D., l'Université de Montréal]
- Desjardins, Michel**

- 2000 *Le Jardins d'Ombres: La poetique et la politique de la reeducation sociale* Universite de Montreal]
- Dillard, Annie**
1999 *For the Time Being*. Toronto, Canada: Penguin
- Downey, Michael**
1986 *A Blessed Weakness: The spirit of Jean Vanier and L'Arche*. San Francisco: Harper & Row. [1st -- ed.]
- Duneier, Mitchell**
1999 *Sidewalk*. New York: Farrar, Straus and Giroux
- Dwyer, Augusta**
1990 *A Daybreak Diary: Learning Life, Learning Love*. Equinox; pp. 49-59
- Edgerton, Robert**
1984 Anthropology and Mental Retardation: Research, approaches and opportunities. *Culture, Medicine and Psychiatry* 8: 25-48.
Edgerton, Robert (ed.)
1984 *Lives in Process: Mildly retarded adults in a large city*. Washington, D.C.: American Association on Mental Deficiency. (Monograph no. 6)
Edgerton, Robert
1990 Quality of Life from a Longitudinal Research Perspective. In: Robert L. Schalock (ed.), *Quality of Life: Perspectives and issues*. Washington, D.C.: American Association on Mental Retardation
Edgerton, Robert
1993 (1967) *The Cloak of Competence, Revised and Updated*. Berkeley and Los Angeles: University of California Press
Edgerton, Robert, and Marcia Gaston (eds.)
1991 "I've seen it all!" *Lives of older persons with mental retardation in the community*. Baltimore: Paul H. Brookes Publishing
- Egan, Joe**
2002 *The Disability Field: Our hopes and challenges for the future*; pp. 20. Richmond Hill: Ontario Association for Developmental Disabilities
- Eliot, T. S.**
1950 *The Cocktail Party: A Comedy*. London: Faber and Faber
- Enns, Ruth**
1999 *A Voice Unheard : The Latimer case and people with disabilities*. Halifax, Nova Scotia, Canada: Fernwood Publishing
- Epp, Tim**
2000a Disability: Discourse, Experience and Identity. *Disability Studies Quarterly* 20: 134-144.
Epp, Tim
2000b Embodied Identity and Hidden Disability. *Disability Studies Quarterly* 20: 334-338.
- Erikson, Erik H.**
1980 *Identity and the Life Cycle*. New York: W.W. Norton
- Erikson, Frederick**
1975 Gatekeeping and the melting pot: Interaction in counselling encounters. *Harvard Educational Review* 45: 44-70.
- Escobar, Artruro**
1991 Anthropology and Development Encounter: The making and marketing of development anthropology. *American Ethnologist* 18: 658-82.
Escobar, Artruro
1995 *Encountering Development: The making and unmaking of the third world*. Princeton: Princeton University Press
- Escrader, Anne**
2002 *The Pedagogy of L'Arche: A school for the heart*. [Unpubl. Masters, University of Western Ontario]
- Fabian, Johannes**
1990 *Power and Performance: Ethnographic Explorations Through Proverbial Wisdom and Theatre in Shaba, Zaire*. Madison, WI: The University of Wisconsin Press

Favaro, Pat

2000 Together We Are Better: Sharing and sustaining our life in the Western Prairie region; pp. 6. Calgary: L'Arche Prairie Region

Feit, Harvey A.

1985 Legitimation and Autonomy in James Bay Cree Responses to Hydro-Electric Development. In: Noel Dyck (ed.), Indigenous Peoples and the Nation-State: Fourth World Politics in Canada, Australia and Norway; pp. 27-66. St. John's: Memorial University of Newfoundland; Institute of Social and Economic Research

Fellowship for Intentional Community (ed.)

1994 Directory of Intentional Communities. Evansville, IN: Fellowship for Intentional Community Publications Cooperative; <http://www.ic.com>

Ferguson, Philip M.

1994 Abandoned to their Fate: Social Policy and Practice toward Severely Retarded People in America, 1820-1920. Philadelphia: Temple University Press (Health, Society, and Policy,

Findley, Timothy

1977 The Wars. London: MacMillan

Fine, Michelle, and Adrienne Asch

1988 Disability Beyond Stigma: Social Interaction, Discrimination, and Activism. *Journal of Social Sciences* 44: 3-21.

Foucault, Michel

1965 Madness and Civilization: A history of insanity in the age of reason. New York.: Vintage Books (Random House)

Foucault, Michel

1973 The Birth of the Clinic : An Archaeology of Medical Perception. New York.: Vintage Books (Random House)

Foucault, Michel

1990 The Use of Pleasure, The History of Sexuality. New York: Vintage

Fox, Nicholas

1994 Postmodernism, Sociology and Health. Canada: University of Toronto Press

Fraschetti, Clara

2001 personal communication. In: P. Cushing (ed.). Hamilton

Fraser, Nancy

1994 Rethinking the Public Sphere: A contribution to the critique of actually existing democracy. In: H. Giroux and P. McLaren (eds.), Between Borders: Pedagogy and the politics of cultural studies; pp. 74-100. New York: Routledge

Freidson, Eliot

1961 Patients' views of medical practice; a study of subscribers to a prepaid medical plan in the Bronx. New York: Russell Sage Foundation (Russell Sage Foundation. M[onograph] 6,

French, Marilyn

1985 Beyond power: On women, men and morals. New York: Ballantine

Freud, Ernst L. (ed.)

1960 Letters of Sigmund Freud. New York

Freund, Peter

1982 Introduction: Social Control and Health. In: P. Freund (ed.), The Civilized Body: Social Domination, Control and Health; pp. 3-15. Philadelphia: Temple University Press

Fulford, Robert T.

1999 The Triumph of Narrative: Story-telling in the age of mass culture. Toronto: Anansi Press (Massey Lectures,

Geertz, Clifford

1973a The interpretation of cultures: selected essays. New York: Basic Books

Geertz, Clifford

1973b Ideology as a cultural system, The Interpretation of Cultures; pp. 193-233. New York: Basic Books Harper Collins

- Geertz, Clifford**
1973c Religion as a Cultural System, The Interpretation of Cultures; pp. 87-125. New York: Basic Books
Harper Collins
- Geertz, Clifford**
1994 The Uses of Diversity. In: Robert Borofsky (ed.), Assessing Cultural Anthropology; pp. 454-66.
USA: McGraw-Hill
- Gennep, Arnold van**
1960 The Rites of Passage. Chicago: University of Chicago Press
- Gewirth, Alan**
1996 Community of Rights. Chicago: University of Chicago Press
- Gilligan, Carol**
1982 In a Different Voice: Psychological theory and women's development. Cambridge: Harvard
University Press
- Ginsburg, Faye**
1989 Dissonance and Harmony: The symbolic function of abortion in activists' life stories. In: Personal
Narratives Group. (ed.), Interpreting Women's Lives; pp. 59-83. Bloomington: Indiana University Press
- Goffman, Erving**
1963 Stigma: Notes on the Management of Spoiled Identity. New Jersey: Spectrum (Prentice Hall)
- Goldstone, Anthony, and Jack Spence (eds.)**
2000 World Desk Reference. London: Dorling Kindersley Ltd.
- Good, Byron, and Mary-Jo DelVecchio Good**
1993 "Learning Medicine": The constructing of medical knowledge at Harvard medical school. In: Shirley
Lindenbaum and Margaret Lock (eds.), Knowledge, Power and Practice; pp. 81-107. Berkeley: University
of California Press. (Comparative studies of health systems and medical care)
- Guggenbühl-Craig, Adolf**
1971 Power in the helping professions. Dallas, Tex.: Spring Publications
- Habermas, Jurgen**
1989 The Structural Transformation of the Public Sphere: An inquiry into a category of bourgeois society.
Cambridge, MA: The MIT Press. [Translation [1962] ed.]
- Hahn, Harlan**
1985 Toward a Politics of Disability: Destinations, disciplines, and policies. *The Social Science Journal* 22:
87-105.
- Hanna, William, and Betsy Rogovsky**
1991 Women with Disabilities: Two handicaps plus. *Disability, Handicap and Society* 6: 49-57.
- Hauerwas, Stanley (ed.)**
1982 Responsibility for Devalued Persons : Ethical Interactions Between Society, the Family, and the
Retarded. Springfield: Charles C Thomas
- Hauerwas, Stanley**
1986 Suffering Presence: Theological reflections on medicine, the mentally handicapped, and the church.
Notre Dame: University of Notre Dame Press
- Heal, Laird W., Janell I. Haney, and Angela Novak Amado (eds.)**
1988 Integration of Developmentally Disabled Individuals into the Community. Baltimore: Paul H.
Brookes
- Heber, R.F.**
1959 A manual on terminology and classification in mental retardation. *American Journal of Mental
Deficiency* 62.
- Heller, T., P. Shaver, and A. Factor**
1997 Adults with Mental Retardation as Supports to their parents: Effects on parental caregiving appraisal.
Mental Retardation 35: 338-346.
- Herzfeld, Michael**
2001a Anthropology: Theoretical practice in culture and society. Malden, Mass. ; Oxford: Blackwell
Publishers
- Herzfeld, Michael**

- 2001b Developmentalisms. In: Michael Herzfeld (ed.), Anthropology: Theoretical practice in culture and society; pp. 152-70. Malden: Blackwell
- Hingsburger, Dave**
2001a Life, Death and Disability. In: Paul Kennedy (ed.), Ideas. Toronto: CBC
- Hingsburger, Dave**
2001b Assistants Workshop on Appropriate Touch and Sexuality Concerns in Caregiving. Richmond Hill, ON: L'Arche-Daybreak
- Hyrniuk, Michael**
2001 Growth in Communion: Spiritual Transformation in the Context of L'Arche. [Unpubl. Doctorate, Emory University]
- Ignatieff, Michael**
1984 The Needs of Strangers: An essay on privacy, solidarity, and the politics of being human. U.S.A.: Penguin
- Ignatieff, Michael**
2000 The Rights Revolution. Toronto: Anansi Press (Massey Lectures, Ingstad, B., and S. R. Whyte (eds.))
- 1995 Disability and Culture. Berkeley and Los Angeles: University of California Press
- Jackson, Michael**
1995 At Home in the World. Durham and London: Duke University Press
- Jacobson, John W., Sara Burchard, and Paul Carling**
1992 Community Living for People with Developmental and Psychiatric Disabilities. Baltimore: The Johns Hopkins University Press
- Jenkins, Richard**
1992 Pierre Bourdieu. London ; New York: Routledge (Key sociologists)
- Johnston, Maridene**
1987 The Therapy of L'Arche: A professional view, Letters of L'Arche; pp. 7-9
- Jones, Deborah**
1998 Perfect Baby. *Chatelaine* 17: 34-43.
- Jordan, Judith**
1991 Do you believe that the concepts of self and autonomy are useful in understanding women? Some Misconceptions and Reconceptions of a Relational Approach, Stone Center Colloquium, 1991; pp. 4-5.
- Jordan, Judith V.**
1989 Relational development : therapeutic implications of empathy and shame. Wellesley, Mass.: Wellesley College Stone Center for Developmental Services (Work in progress / Wellesley College, Stone Center for Developmental Services and Studies ; no 39.,
- Jordan, Judith V.**
1997 Women's growth in diversity : more writings from the Stone Center. New York: Guilford Press
- Jordan, Judith V., and Stone Center for Developmental Services and Studies.**
1991a The movement of mutuality and power. Wellesley, MA: The Stone Center Wellesley College (Work in progress ; no. 53,
- Jordan, Judith V., and Stone Center for Developmental Services and Studies.**
1991b Women's growth in connection : writings from the Stone Center. New York: Guilford Press
- Kanter, R.M.**
1970 Communes. *Psychology Today* 4: 56-60, 78.
- Kanter, R.M.**
1972 Commitment and Community: Communes and utopias in sociological perspective. Cambridge, MA: Harvard University Press
- Kanter, R.M.**
1973 Communes: Creating and managing the collective life. New York: Harper & Row
- Keaney, Peggy**
2001 personal communication. In: P. Cushing (ed.). Hamilton
- Kingfisher, Catherine Pelissier**

- 1996 Women in the American Welfare Trap. Philadelphia: University of Pennsylvania Press
- Kittay, Eva Feder**
1999 Love's Labor : Essays on women, equality, and dependency. New York and London: Routledge (Thinking Gender)
- Kleinman, Arthur**
1995a Suffering and Its Professional Transformation. In: Arthur Kleinman (ed.), Writing at the Margin: Discourse between anthropology and medicine; pp. 95-10x. Berkeley: University of California Press
- Kleinman, Arthur**
1995b Writing at the Margin: Discourse between Anthropology and Medicine. Berkeley: University of California Press
- Kondo, Dorinne**
1990 Disciplined Selves. In: Dorinne Kondo (ed.), Crafting Selves : Power, gender and discourses of identity in a Japanese workplace; pp. 76-115. Chicago: University of Chicago Press
- Krishef, Curtis H.**
1983 An Introduction to Mental Retardation. Springfield, Illinois: Charles C. Thomas Publisher
- Kundera, Milan**
1986 The book of laughter and forgetting. Harmondsworth, Middlesex, England ; New York, N.Y., U.S.A.: Penguin Books
- Lamb, Andrew W.**
1995 Freedom, the Self, and Ethical Practice According to Michel Foucault. *International Philosophical Quarterly* XXXV: 449-467.
- Landsman, Gail**
2001 Too Bad You Got a Lemon: Peter Singer, mothers of children with disabilities, and the critique of consumer culture. CASCA (Canadian Anthropology Society), Montreal, Canada, 2001. unpublished paper. **Langness, L.L., and Harold G. Levine (eds.)**
1986 Culture and Retardation: Life histories of mildly mentally retarded persons in American society. Dordrecht: D. Reidel Publishing Co. (Culture, Illness, and Healing)
- L'Arche**
1993a Canada Mission and Identity Statement; pp. 1. Richmond Hill, Canada: L'Arche Canada
- L'Arche**
1993b Charter of the Communities of L'Arche; pp. 4. Cap Rouge, Canada: L'Arche International, General Assembly of the Federation
- L'Arche**
1999 Key Elements of a L'Arche Community; pp. 6. Richmond Hill, Canada: L'Arche Canada
- Lewis, C. S.**
1960 The Four Loves. London: Collins clear-type press
- Lock, Margaret, and Nancy Scheper-Hughes**
1990 A critical-interpretive approach in medical anthropology: Rituals and routines of discipline and dissent. In: T. Johnson and C. Sargent (eds.), Medical Anthropology: Contemporary theory and method; pp. 44-72. New York: Praeger
- Luckasson, R., D.L. Coulter, E.A. Polloway, S. Reiss, L.L. Schalock, M.E. Snell, et al.**
1992 Mental Retardation: Definition, classification, and systems of supports. Washington, D.C.: American Association on Mental Retardation
- Luckasson, Ruth, Sharon Borthwick-Duffy, Wil H.E. Buntinx, David L. Coulter, Ellis M. (Pat) Craig, Alya Reeve, et al.**
2002 Mental Retardation: Definition, Classification, and Systems of Supports. Washington, DC: American Association on Mental Retardation. [10th ed.]
- Lukeman, Gerald**
2001 Canadian Assistants Survey; pp. 10. Halifax: L'Arche Canada Zone Board
- Lunsky, Yona**
2002 Psychosocial Risk Factors for Mental Health Problems in Adults with Developmental Disabilities; pp. 10. Richmond Hill: Ontario Association for Developmental Disabilities
- Lupton, Deborah**

- 1994 Medicine as Culture: Illness, disease and body in western societies. London: Sage
- Lutfiya, Z.M.**
1991 A Feeling of Being Connected: Friendships between people with and without learning disabilities. *Disability, Handicap and Society* 6: 233-245.
- Lutfiya, Z.M.**
1993 When 'Staff' and 'Clients' Become Friends. In: Angela Novak Amado (ed.), Friendships and Community Connections Between People with and without Intellectual Disabilities; pp. 97-108. Baltimore: Paul H. Brookes Publishing
- MacMillan, Carl**
2001 personal communication. In: P. Cushing (ed.). Hamilton
- Marcus, George, and Michael Fischer**
1986 Anthropology as Cultural Critique. Chicago: University of Chicago Press
- Matthew**
0 A.D. Beatitudes, New Testament; chapter 5: 1-11
- Matysiak, Bettina**
2001 Interpretive Research and People with Intellectual Disabilities: Politics and practicalities, Research in Social Science and Disability; pp. 185-207: Elsevier Science Ltd.
- Matysiak, Bettina**
2002 personal communication. In: P. Cushing (ed.). Burlington, ON
- Mauss, Marcel**
1954 The Gift: Forms and functions of exchange in archaic societies. Trans. Ian Cunnison. London: Cohen & West
- McAdams, Dan**
2001 Generativity: The new definition of success, Spirituality and Health; pp. 4
- McKay, Susan**
2002 Beyond Biomedicine: Renegotiating the sick role for postmodern conditions. *Journal of Media Culture*: 1-4.
- McLaren, Angus**
1990 Our Own Master Race: Eugenics in Canada, 1885-1945. Toronto: McClelland and Stewart (Canadian Social History,
- McMillan, D. W., and D. M. Chavis**
1986 Sense of Community: A definition and theory. *Journal of Community Psychology* 14: 6-23.
- Mellis, Dana R. V.**
2001 Toward a Theology of Covenant in Jean Vanier and L'Arche: the Imago Dei and Persons with Mental Disabilities. [Unpubl. PhD, Saint Louis University]
- Miller, James**
1993 The Passion of Michel Foucault. New York: Simon and Schuster
- Miller, Jean Baker**
1991 Aren't you idealizing women? Aren't you idealizing relationships? Some Misconceptions and Reconceptions of a Relational Approach, Stone Center Colloquium, 1991; pp. 2-3.
- Miller, Jean Baker, and Irene Stiver**
1991 A Relational Reframing of Therapy. Stone Center Colloquium, Massachusetts, 1991; pp. 1-13.
- Mohanty, S.**
1989 Us and Them: On the philosophical basis of political criticism. *The Yale Journal of Criticism* 38: 1-31.
- Moore, Thomas**
1992 Care of the Soul: A guide for cultivating depth and sacredness in everyday life. New York: HarperCollins
- Morris, Jenny**
1993 Independent Lives: Community care and disabled people. London: Macmillan Press
- Mosteller, Sue, C.S.J.**
1996 Body Broken, Body Blessed : Reflections from life in community. Ottawa: Novalis
- Mosteller, Sue, C.S.J.**

- 2001 personal communication. In: P. Cushing (ed.). Hamilton
- Murphy, Robert**
1990 The Body Silent. New York and London.: W. W. Norton
- Nanda, Serena**
1994 Cultural Anthropology. Belmont, CA: Wadsworth Publishing. [fifth ed.]
- Narayan, Kirin**
1989 Storytellers, Saints, and Scoundrels: Folk narrative in Hindu religious teaching. Philadelphia: University of Pennsylvania Press
- Narayan, Kirin**
1993 How "Native" is a Native Anthropologist? *American Anthropologist* 93: 671-685.
- Newroth, Steve**
1974 *Monograph Forward*. In: Wolf Wolfensberger and Jean Vanier (eds.). Growing Together, Richmond Hill, Ontario, 1974. Daybreak Publications, Richmond Hill, Ontario.
- Nouwen, Henri J.M.**
1997 Adam, God's Beloved. Maryknoll, NY: Orbis
- O'Brien, John , and Connie Lyle O'Brien**
1993 Unlikely Alliances: Friendships and People with Developmental Disabilities. In: Angela Novak Amado (ed.), Friendships and Community Connections Between People with and without Intellectual Disabilities; pp. 9-39. Baltimore, MA: Paul H. Brookes Publishing Co.
- O'Donohue, John**
1997 Anam Cara: Spiritual Wisdom from the Celtic World. London: Bantam
- O'Murchu, Diarmuid MSC**
1997 Reclaiming Spirituality. Dublin: Gill & MacMillan Ltd
- Ong, Aihwa**
1987 Spirits of resistance and capitalist discipline: Factory women in Malaysia. Albany: State University of New York Press (SUNY series in the anthropology of work.,
Ong, Aihwa
1991 The Gender and Labour Politics of Postmodernity. *Annual Review Anthropology* 20: 279-309.
- Ortner, Sherry B.**
1984 Theory in Anthropology Since the Sixties. *Society for the Comparative Study of Society and History*: 126-166.
Ortner, Sherry B.
1995 Resistance and the Problem of Ethnographic Refusal. *Comparative Studies in Society and History* 37: 173-93.
- Parsons, Talcott**
1951 The social system. Glencoe, Ill.,: Free Press
- Peacock, James L.**
1986 The Anthropological Lens: Harsh light, soft focus. Cambridge: Cambridge University Press
- Philip's**
2000 The Pocket World Atlas. New York: Oxford University Press
- Phillips, Susan S.**
1994 Introduction. In: Susan S. Phillips and Patricia E. Benner (eds.), The Crisis of Care; pp. 1-16. Washington: Georgetown University Press
- Phillips, Susan S., and Patricia E. Benner**
1994 The Crisis of care : affirming and restoring caring practices in the helping professions. Washington, D.C.: Georgetown University Press
- PLAN**
2001 Vanier is PLAN's Inspiration: Planned Lifetime Advocacy Network, Abilities; pp. 30
- Plato**
360 BCE The Republic
- Pool, Robert**
1991 'Oh Research, very good!': On Fieldwork and Representation. In: Robert Pool (ed.), Constructing Knowledge: Authority and critique in the social sciences; pp. 59-77. London: Sage

- Porter, Beth**
1998 L'Arche Daybreak: An Example of Interfaith Ministry Among People with Developmental Disabilities. *Journal of Pastoral Care* 52: 157-165.
- Porter, Beth (ed.)**
2001 Befriending Life: Encounters with Henri Nouwen. New York: Doubleday, Random House
- Pottie, Colin**
2001 *Narrating Friendship: Reciprocal Relationships in L'Arche*. [Unpubl. Masters of Psychology, Acadia University]
- Povinelli, Elizabeth A.**
1993 Labor's Lot: The power, history, and culture of aboriginal action. Chicago: University of Chicago Press
- Povinelli, Elizabeth A.**
2001 The Cunning of Recognition: Indigenous rights and liberal force. Montreal: Canadian Anthropology Society (CASCA)
- Radford, John**
1994 Intellectual Disability and the Heritage of Modernity. In: Roeher Institute (ed.), Disability is not Measles: New Research Paradigms in Disability; pp. 9-28. Canada: Roeher Institute
- Rhodes, Lorna A.**
1991 Emptying Beds: The work of an emergency psychiatric unit. Berkeley: University of California Press (Comparative studies of health systems and medical care ; v. 27,
- Rieff, Philip**
1966 The Triumph of the Therapeutic: Uses of faith after Freud. New York: Harper & Row
- Rimke, Heidi Marie**
2000 Governing Citizens Through Self-help Literature. *Cultural Studies* 14: 61-78.
- Rioux, Marcia**
1994a Introduction: New Research Paradigms in Disability: Disability is not Measles. In: Roeher Institute (ed) (ed.), Disability is not Measles: New Research Paradigms in Disability; pp. 1-8. Canada: Roeher Institute
- Rioux, Marcia**
1994b Towards a concept of equality of well-being: Overcoming the social and legal construction of inequality. In: Roeher Institute (ed) (ed.), Disability is not Measles: New Research Paradigms in Disability; pp. 67-108. Canada: Roeher Institute
- Rioux, Marcia, and Michael Bach (eds.)**
1994 Disability is not Measles: New Research Paradigms in Disability. Toronto, Canada: Roeher Institute
- Rodman, Margaret**
1992 Empowering Place: Multilocality and Multivocality. *American Anthropologist* 94: 640-656.
- Rodman, Margaret, and Matthew Cooper**
1989 The Sociocultural Production of urban Space: Building a Fully Accessible Toronto Housing Cooperative. *City and Society* 3: 9-22.
- Roeher Institute**
1993 Social Well-being: A Paradigm for Reform. Toronto, Canada.: Roeher Institute
Roeher Institute
- 1996 Disability, Community and Society: Exploring the Links. Toronto, Canada.: Roeher
- Ryan, Gerard**
2001 personal communication. In: P. Cushing (ed.). Hamilton
- Ryan, Joanna, and Frank Thomas**
1980 The Politics of Mental Handicap. England.: Penguin Books
- Sahlins, Marshall David**
1972 Stone age economics. Chicago: Aldine-Atherton
- Saint-Exupery, Antoine de**
1943 The Little Prince. San Diego, New York and London: Harcourt Brace & Co.
- Sartre, Jean-Paul**
1964 The Words [Les Mots]. New York: Brazillien (autobiography)

- Schalock, L.L., D.L. Coulter, E.A. Polloway, S. Reiss, M.E. Snell, D.M. Spitalnik, et al.**
1994 The Changing Conception of Mental Retardation: Perspectives in change. *Mental Retardation* 32: 181-93.
- Scheper-Hughes, Nancy**
1992 Death without Weeping. Berkeley and Los Angeles: University of California Press
- Scott, Joan W.**
1992a Experience. In: Judith Butler and Joan W. Scott (eds.), Feminists Theorize the Political; pp. 22-40. New York: Routledge
- Scott, Joan W.**
1992b Experience. New York: Routledge.
- Shakespeare, Tom**
1994 Cultural Representation of Disabled people: dustbins for disavowal? *Disability and Society* 9: 283-299,
- Shearer, A.**
1976 L'Arche. Toronto: Daybreak Publications
- Sigelman, C., E. Budd, C. Spanhel, and C. Schoenrock**
1981 When in doubt, say yes: Acquiescence in interviews with mentally retarded persons. *Mental Retardation* 19: 53-8.
- Silverstein, Cory**
2000 Clothed Encounters: The Power of Dress in Relations Between Anishnaabe and British Peoples in the Great Lakes Region, 1760-2000. [Unpubl. Ph.D., McMaster University]
- Simmons, Harvey G.**
1982 From Asylum to Welfare. Downsvlew: National Institute on Mental Retardation (now Roehrer)
- Simpson, M. K.**
1998 The Roots of Normalization: A reappraisal. *Journal of Intellectual Disability Research* 42 (1):1-7.
- Sinclair, J. M.**
1994 Collins English Dictionary. Glasgow: HarperCollins. [3rd, updated ed.]
- Singer, Peter**
1979 Practical Ethics. Cambridge: Cambridge University Press
- Smith, J. David**
1997 Mental Retardation: Defining a social invention. In: R. L. Taylor (ed.), Assessment of Individuals with Mental Retardation. San Diego: Singular Publishing Group
- Smith, Wesley J.**
2000 Culture of death: The assault on medical ethics in America. San Francisco, Calif.: Encounter Books
- Sobsey, D.**
1994 Violence and abuse in the lives of people with disabilities. Toronto: Paul H. Brookes
- Spink, Kathryn**
1990 Jean Vanier and l'Arche: A communion of love. New York: Crossroad
- Spradley, James P.**
1980 Participant Observation. Fort Worth: Harcourt Brace Jovanovich College Publishers
- Stalker, K.**
1998 Some ethical and methodological issues in research with people with learning difficulties. *Disability and Society* 13: 5-19.
- SteinhoffSmith, Roy Herndon**
1999 The Mutuality of Care. St. Louis, MO: Chalice Press
- Stephenson, Peter H., and Rory C. Coughlan**
2001 Social, demographic and cultural features associated with psycho-immunology and cancer research. Canadian Anthropology Society, Montreal, 2001; pp. 1-9.
- Stoller, Paul**
1994 Ethnographies as texts/ethnographers as griots. *American Ethnologist* 21: 353-366.
- Sumarah, John**
1987 L'Arche: Philosophy and Ideology. *Mental Retardation* 25: 165-69.
- Sumarah, John**

- 1988 L'Arche from a Participant Observer's Perspective: The creation of universal community. *International Journal of Special Education* 3: 185-96.
- Sumarah, John**
1996 The Letters of Jean Vanier: Extending the Acts of the Apostles. *The Second Mile*.
- Swaby-Ellis, E.**
1994 The Caring Physician: Balancing the 3 E's: Effectiveness, efficiency, and empathy. In: Susan Phillips and Patricia Benner (eds.), *The Crisis of Care*; pp. 83-94. Washington: Georgetown University Press
- Swain, J., B. Heyman, and M. Gillman**
1998 Public research, private concerns: Ethical issues in the use of open-ended interviews with people who have learning difficulties. *Disability and Society* 13: 21-36.
- Tannen, Deborah**
1994 Talking from 9 to 5: How women's and men's conversational styles affect who gets heard, who gets credit, and what gets done at work. New York: W. Morrow. [1st ed.]
- Taylor, Charles**
1989 Sources of the Self: The making of modern identity. Cambridge, MA: Harvard University Press
- Taylor, Charles**
1994 Philosophical reflections on caring practices. In: Susan S. Phillips and Patricia E. Benner (eds.), *The Crisis of Care*; pp. 174-188. Washington: Georgetown University Press
- Taylor, Steven J., and Robert Bogdan**
1989 On Accepting Relationships between People with Mental Retardation and Non-disabled People: towards an understanding of acceptance. *Disability, Handicap & Society* 4: 21-36.
- Thomasma, D.**
1994 Beyond the ethics of rightness: The role of compassion in moral responsibility. In: Susan S. Phillips and Patricia E. Benner (eds.), *The Crisis of Care*; pp. 123-143. Washington: Georgetown University Press
- Thomson, Rosemarie Garland**
1996 Introduction: From wonder to error - a genealogy of freak discourse in modernity. In: R. Thomson (ed.), *Freakery: Cultural Spectacles of the Extraordinary Body*; pp. 1-22. New York: New York University Press
- Trent Jr., James W.**
1994 Inventing the Feeble Mind : A History of Mental Retardation in the United States. Berkeley and Los Angeles: University of California Press (Medicine and Society, 6)
- Tronto, Joan**
1993 Moral Boundaries: A political argument for an ethic of care. New York: Routledge
- Tsing, Anna Lowenhaupt**
1993 In the Realm of the Diamond Queen: Marginality in an Out-of-Way Place. Princeton, N.J.: Princeton University Press
- Tsing, Anna Lowenhaupt**
1994 From the Margins. *Cultural Anthropology* 9: 279-297.
- Turner, Victor W.**
1964 Betwixt and Between: the Liminal Period in Rites De Passage. In: William Lessa, Evon Vogt and John Watanabe (eds.), *Reader in Comparative Religion: An Anthropological Approach*; pp. 234-243. New York, N.Y.: Harper and Row
- Turner, Victor W.**
1986 Dewey, Dilthey, and Drama: An essay in the anthropology of experience. In: Victor W. Turner and Edward Bruner (eds.), *The Anthropology of Experience*; pp. 33-44. Urbana: University of Illinois Press
- Tyler, Stephen A.**
1986 Post-Modern Ethnography: From document of the occult to occult document. In: James Clifford and George E. Marcus (eds.), *Writing Culture: The poetics and politics of ethnography*. Berkeley: University of California Press. (School of American Research Advanced Seminar)
- Tylor, P., and L. Bell**
1984 Caring for the Retarded in America: A History. Connecticut: Greenwood Press
- Ungerson, Clare**

- 1999 Personal Assistants and Disabled People: An examination of a hybrid form of work and care. *Work, Employment & Society* 13: 583-600.
- Vanier, Jean**
1962 *Le Bonheur: Principe et fin de la morale Aristotelienne*. [Unpubl. Doctoral, Institute Catholique de Paris]
- Vanier, Jean
1966 *Le Bonheur: Principe et fin de la morale Aristotelienne*. Paris: Desclee de Brouwer
- Vanier, Jean
1969 *In Weakness, Strength: The spiritual sources of Georges P. Vanier, 19th Governor-General of Canada*. Toronto: Griffin House
- Vanier, Jean
1979 *Community and Growth: Our pilgrimage together*. Toronto: Griffin House
- Vanier, Jean
1989 *Community and Growth*. New York: Paulist Press. [2nd Revised Edition ed.]
- Vanier, Jean
1995 *An Ark for the Poor: The story of L'Arche*. Toronto, London, New York: Novalis/Geoffrey Chapman/Crossroad
- Vanier, Jean
1996 *The Scandal of Service: Jesus washes our feet*. London: Darton, Longman and Todd
- Vanier, Jean
1997 *Our journey home: Rediscovering a common humanity beyond our differences*. Maryknoll, N.Y.: Orbis Books
- Vanier, Jean
1998 *Becoming Human*. Toronto: Anansi (CBC Massey Lectures Series)
- Vanier, Jean
1999 *Dayspring Opening (pamphlet)*; pp. 6. Richmond Hill: L'Arche-Daybreak
- Vanier, Jean
2001 *Made for Happiness: Discovering the meaning of life with Aristotle*. Toronto: Anansi Press
- Vanier, Jean
2002 *The Founding Myth and the Evolution of Communities*; pp. 7-9. Sydney, AU
- Vorstermans, Joe**
2001 *personal communication*. In: P. Cushing (ed.). Hamilton
- Walters, Traci, and Liz Griffis**
2001 *Imagery, Individual Identity and Independent Living*, abilities; pp. 42-43
- Webb-Mitchell, B.P.**
1989 *L'Arche: An ethnographic study of persons with disabilities living in a community with non-disabled people*. [Unpubl. Doctoral, University of North Carolina at Chapel Hill]
- Weil, Simone**
1952 *The Need for Roots*. New York: Harper and Row
- Wendell, Sue**
2002 *personal communication*. In: P. Cushing (ed.). Vancouver
- Wikan, Unni**
1992 Beyond the Words: The power of resonance. *American Ethnologist* 19: 460-479.
- Wikan, Unni**
1995 The Self in a World of Urgency and Necessity. *Ethos* 23: 259-285.
- Wolfensberger, Wolf**
1972 *The Principle of Normalization in Human Services*. Toronto: National Institute on Mental Retardation
- Wolfensberger, Wolf (ed.)
1973 *A Selective Overview of the Work of Jean Vanier & the Movement of L'Arche*. Toronto: National Institute on Mental Retardation (Roehrer)
- Wolfensberger, Wolf
1975 *The Origin and Nature of our Institutional Models*. Syracuse: Human Policy Press
- Wolfensberger, Wolf

1988 Common Assets of Mentally Retarded People that are Commonly Not Acknowledged. *Mental Retardation* 26: 63-70.

Wolfensberger, Wolf, and Jean Vanier

1974 *Growing Together*. In: Daybreak & National Institute on Mental Retardation (Roehrer) (ed.). *Growing Together: Creating houses and workshops for the mentally handicapped*, Richmond Hill, Canada, 1974; pp. 47. Daybreak Publications.

WSDSHS

2002 Developmental Disabilities Last a Lifetime <http://www.wa.gov/dshs/cwofdd> Washington State Department of Social & Health Services: July 31 2002

Wuthnow, Robert

1991 Acts of compassion: Caring for others and helping ourselves. Princeton, N.J.: Princeton University Press

Young, Allan

1993 A description of how ideology shapes knowledge of a mental disorder (posttraumatic stress disorder). In: Shirley Lindenbaum and Margaret Lock (eds.), Knowledge, Power and Practice; pp. 108-128. Berkeley: University of California Press

Zablocki, B.

1980 The Joyful Community: An account of the Bruderhof. Chicago: University of Chicago Press. [rev. ed]

Zicklin, G.

1983 Countercultural Communes: A sociological perspective. Westport, CT: Greenwood Press

Zinyk, Cheryl, and Joe Egan

2001 New Assistants Survey, Ontario; pp. 3. Toronto: L'Arche

Zola, Irving Kenneth

1989 [1983] Toward Independent Living: Goals and Dilemmas. In: N. Crewe, I. Zola and & associates (eds.), Independent Living for Physically Disabled People: Developing, implementing and evaluating self-help rehabilitation programs; pp. 344-356. San Francisco: Jossey-Bass

Appendices

Appendix 2.0 -List of appendices for Chapter Two

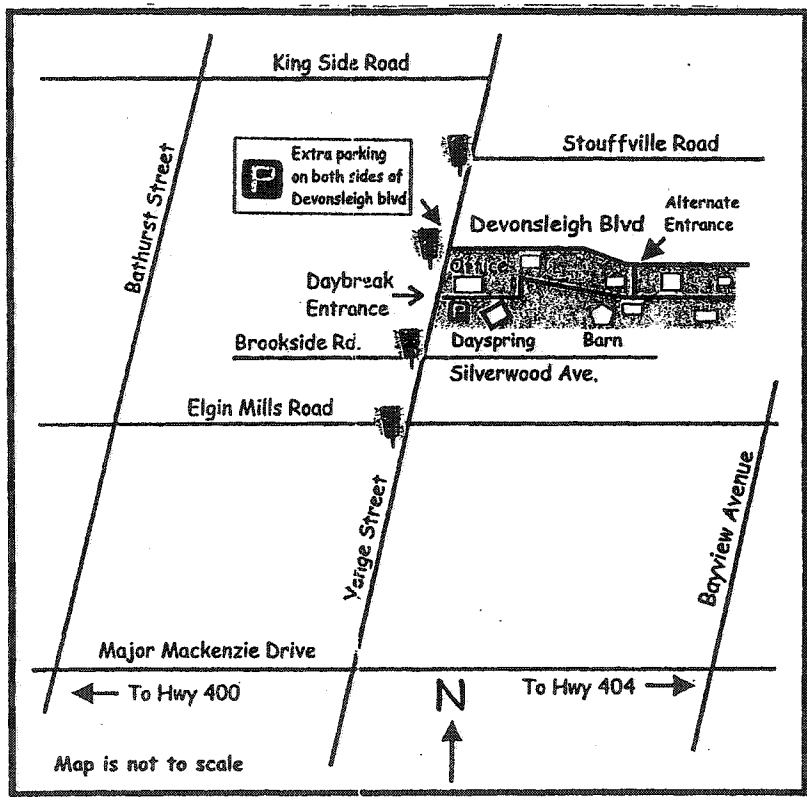
2.1 Diagram of L'Arche Daybreak community layout

2.2 Growing in the Mission survey

2.3 Summer Intern survey at Daybreak

2.4 Research participants' evaluation of anthropologist (questionnaire)

2.5 Terms and conditions agreement for research ethics



Appendix 2.2 - Growing in the Mission Survey

Opening Word for Assistants

What is this research for?

In order to help you to decide what to share in this feedback opportunity, I, (Pamela) wanted to give you a sense for why you're being asked for feedback, and what 'good' your input can do.

There are four primary areas that your input will contribute to:

- 1) To help us think about how Growing in the Mission should be next year. For this, we are interested in what was of most and least value to you, and why.
- 2) To help us decide whether we put together a follow-up week for your group next year, and what it should 'look like' if we do.
- 3) To help the human resources group to think about how to accurately explain what life at L'Arche is like for assistants, when we are doing recruiting.
- 4) To contribute to Pamela's research at L'Arche which explores what brings people to L'Arche, and why they stay or leave. [See consent forms]

Note that your responses will be kept confidential - only Pamela will read them *directly* and she will summarize them for all reports (including the thesis) in a way that obfuscates 'who' said what, (unless you wish be identified). [See consent forms] Note also, that if you wish that some, or all, of your input to be excluded from Pamela's doctoral research, (but still used for in-house reports) you need only indicate this on your form.

The committee and I are committed to sharing a summary of the results of this feedback with you. We will also give you an opportunity to review and discuss the proposed plans/steps that we come up with based on your input. If you have specific ideas for how the research results could be shared, please let me know.

Thank you

Pamela

L'Arche - Feedback Form

Growing in the Mission - Week 3

Your Basic Details:

Name:

Age:

Education:

Employment: (list only career areas or significant jobs pre-L'Arche)

Time with L'Arche: total:

Time in current community:

Community location: current:

Others:

Number of People in your Home:
Core members -

Assistants-

Your Roles in Community: (e.g. - committees, agape, etc.)

Living Environment

These questions refer to your time *during the Growing in the Mission (GIM) sessions*, and includes atmosphere, welcome, meals, and overall schedule.

1. Where did you sleep here?

2. How comfortable were you with your accommodation? (circle one)

very
dissatisfied

dissatisfied

don't
know

pretty
good

great

comments: (what was good or could be better?)

3. How did you feel about the food for the week? (circle one)

very
dissatisfied

dissatisfied

don't
know

pretty
good

great

comments:

4. How did you feel about the sharing spaces / session rooms? (circle one)

very
dissatisfied

dissatisfied

don't
know

pretty
good

great

comments:

5. How do you feel about one week per session as the length of time, in light of other commitments you have in your community or personally?

a) too long

b) too short

c) just right

comments:

Overall Assessments

1. Overall, how would you rate this week in terms of what you 'gained' on a scale of 1 -10 with 10 being the high end:

- Personal growth /reflection -
- Professionally/as a community member -
- Spiritual insight -
- Social time -

2. How do you feel about the balance of scheduled activity, and free time for solitude/reflection or hanging out with others? Would you have liked more or less of one? Please explain.

3. Below, please suggest a rough balance between the following elements (to add up to 100%) as your idea of how GIM time would ideally be structured:

• Lessons/talks		%
• Interactive workshops/discussions		%
• Solo time		%
• Free Social time		%
• Scheduled social time (movie, play etc.)		%
• Other: _____		%
	Total	100 %

comments:

4. Did you feel that the afternoon solitude was useful to you? Why or why not?
5. a) What would you think about having more structure to the 4:30 "formal" reflection time, such as suggested themes for reflection or journaling exercises?
- b) Would you say we should eliminate the 'formal' reflection time altogether? Are there better times/ways for this?
6. How do you feel about the expectation that you begin the day by worshipping in Dayspring? Is it fair to 'expect' people to do this? Why or why not?

7. a) What did you initially expect to get out of **week 3** of growing in the mission?
Try to list two or three in order of priority.
- b) Were these expectations met? If not, why not? What, if anything, could have been done differently by *you* and/or the *organizers* to meet them?
8. For this question, I need you to think back on all three weeks of GIM together. In your opinion, what are the major benefit(s) of bringing this group together (if any)?
- a) for the individuals and you in particular?
- b) for your L'Arche community?

Themes

9. We chose just five themes for Growing in the Mission out of the many possible and valuable ones. Please take a moment to reflect on the themes.
- a) Please rank them from 1 to 5 in order of value to you both personally and as a member of community (1 is most valuable).

	Personally	As a Community Member
Home Life		
Community Life		
Relationships & Personal Growth		
Spiritual Growth		
L'Arche in the World		

b) Are there any other themes that you think would be more valuable or should at least be incorporated into the other themes? (feel free to brainstorm or think outside the box here!)

10. a) Do you feel that there was sufficient or effective involvement of core members in the week?

b) How else do you think they could have been involved? (Again, feel free to think creatively)

Accompaniment

1. Were you regularly accompanied this year in your community? If not, why not? If yes, please comment on how it was valuable for you or not?

2. Was being accompanied during GIM of value to you? In what way? If you feel lukewarm about it, please help us to understand what you would have wanted.

Session Evaluations

It would be helpful to get a sense for what different value you got from the daily sessions in week 3. Below is a way to give us an idea of how each session worked for you. Thanks

Please rate each session on a scale of 1-10 (10 is high), for each of the four categories. Additional space is provided below for further comments as to why certain sessions worked well or not. Please share your thoughts there.

* Please include further comments on the daily sessions, evening events, presenters or themes below?

Session:	Presenter's Style	Subject/ Content	Personal Value	Value as a Member of Community
1. Home a) Clara b) Sue				
2. Community a) Joe E. b) Sue				
3. Relationships a) Carl b) Susan L.				
4. Spiritual Growth a) Colin M.				
5. L'A. & World a) Joe V. b) Clara				

* Please include further comments on the daily sessions, evening events, presenters or themes below?

Follow-up

1. Are you interested in a follow-up week for this group next year? (circle one)
yes / no / depends on _____

2. Do you have any recommendations for useful themes for that gathering?

3. Would you be interested in any other kinds of GIM-related follow-up through the year that would facilitate your development? If it doesn't feel right, perhaps you could explain why. [eg- a call from your accompanier; group calls between assistants; other?]

4. Would you like to be involved in helping to organize part of GIM for next year? How?

Incoming L'Arche InternsPre-Internship Discussion Questions

Since it is not feasible to get in touch with each of you before you arrive, I have put together a few questions which will help me to get a feel for where you are at, before you get here. All answers are *confidential*, meaning that only you and I, (Pamela) will have access to what you say in 'raw' format. I will be compiling a summary for the research, but answers will be disconnected from individuals. Please review and sign the attached consent form.

Note that the answers contained herein have NO evaluation function and will not effect your employment offer here; rather, they are part of the research project outlined in the accompanying letter. The people you will be living and working with at L'Arche are interested in your needs/hopes too, but more insofar as they would like your time with them to be as mutually satisfying as possible.

Basic Details:

Name:

Age:

Country:

Planned length of stay with L'Arche Daybreak:

Education:

Previous career areas:

Research questions:

1. How did you hear about L'Arche? about the Canadian branch?
2. What caught your attention *most* about L'Arche initially?
3. What were the two or three key factors which motivated you to come live in a L'Arche community at this time in your life? (*please be candid here*)
4. Was there a key event or person that was instrumental in your decision?
5. I am interested in the *expectations* you have for your time at L'Arche. Could you briefly describe what you hope 'happens' during your time here? In other words, how do you envision things happening?

6. What concerns or fears do you have about coming to L'Arche, (or a different city) if any?

7. Take a moment to think about your upcoming stay at L'Arche in Canada. Can you identify three things that you would like to get out of your time here. In other words, what would you like to 'walk away' with?

8. If you had to describe briefly what L'Arche as an organization is 'all about' to a friend who had not heard of it, what would you say? *(please use your own words.)*

9. What are you planning to do when your internship as an assistant here is through, and where will you be? If that plan is connected with coming to L'Arche, can you explain how?

10. If thinking about these questions has stimulated your thoughts or made you feel a certain way, please feel free to share any comments you want on this below. (These can be as random as you want!)

Appendix 2.4

Anonymous Anthropologist Evaluation Forms

With this form, I am asking you to give me (Pamela) some feedback to help me to continue to grow well as an anthropologist (respecting your needs and trust and generating good, open discussion). I am genuinely interested to hear your perspective, so please feel free to be candid. Use the attached paper for answers. Return in attached envelopes.

Thank you in advance for your time!

1. How honest did you feel you could, or wanted to be in our interview?
2. Were there things I did that left you feeling more or less comfortable with sharing all or part of your story?
3. Would you have appreciated/expected some kind of formal **follow-up** from me after our talk? (or would this have been awkward or overkill?)
4. Did I explain my research topic to your satisfaction? Why/not?
5. Why did you agree to do the interview?
6. Are you glad you did the interview? Why?
7. Did the interview stimulate any new thoughts about yourself, L'Arche, or the research?
8. Please comment on either the gifts, or areas of weakness of my **interview style**.
9. Did you feel that I was neutral or biased on the topics we discussed, and did that effect how you answered me?
10. When I was in your house to live or for a meal, did you and others feel that I was involved in the home life (socially and assisting) in appropriate ways? Please elaborate.
11. Did I do/say anything while there which left you, or anyone else feeling vulnerable?
12. In meetings that I observed, please comment on whether my presence felt appropriate, intrusive, awkward or otherwise and why?
13. Other general comments/insights about my conduct in your interview/home/community.

Have a great day! You can expect to see the report in early 2001.

Appendix 2.5

April 2001

L'Arche & P. J. Cushing Agreement
Anthropological Research Terms & Conditions

The following is an outline of the terms and conditions that have been agreed upon by the researcher, Pamela J. Cushing, (PJC) and the research community, L'Arche, as represented for this agreement by Daybreak, (L'Arche) the principal research site in this project. Some of these terms were laid out in other documents and informally at the beginning of the project (January, 1999), while others have been adjusted or added as the focus of the thesis has become more clear. This formalization of our agreement has become necessary now as I, (PJC) have become more familiar with the particular and vital role of individual people with disabilities in the lives of the caregivers I initially wished to understand, and also with the challenges around obtaining certain informed consent from those individuals.

1. PJC will write the thesis and subsequent publications resulting from this research using pseudonyms for all assistants and core members except where the individual expressly requests to be identified by their real name. By 'pseudonyms' I mean substituting at minimum an alternate name for the person being quoted or described. The aim of this technique is to provide the basic necessity for ensuring the research participants' and informants' right to privacy and protection from any possible ramifications of their representation in writing.
2. In most cases, PJC will not make further attempts (beyond the pseudonyms) to obfuscate the identities of the people being written about, nor to create composite 'characters'. This will allow PJC to create rich, realistic representations of community life which usually entail inclusion of certain particulars about the actors which comprise it. The community agrees that what is important is that the people incorporated in the writing are not identifiable to *outsiders*, but that it is acceptable for people to be recognizable to others within the L'Arche communities.

The exception to this approach is that where the story or quote is of a sensitive or controversial nature, PJC will make enough changes to the relevant actors' identities so that they will not be identifiable even to fellow community members (e.g. by changing the city, age, gender or other features that do not eliminate the relevance of the story) as outlined in the Consent forms that all interviewees received and signed.

3. PJC will in all cases be respectful of the core members' (people with intellectual disabilities) intrinsic right to privacy regarding sensitive issues, and will endeavor to balance this concern with the previously agreed-upon aims for the research project which involve some degree of inclusion and representation. [The same is obviously true for assistants however, I note the core members in particular given the challenges around securing genuinely 'informed consent' from many of them, which is not an issue with the assistants.]
4. PJC will provide the communities that she worked within a copy of the final draft of the thesis to review before final submission to the university for defense. The aim here is to give interviewees and other participants the opportunity to review the document and to give constructive feedback on what was written. In particular, reviewers can highlight inaccuracies, misses, and spots where more care needs to be taken to protect someone's identity. Where possible, it is hoped that I, or someone who knows the core member well, will review with them individually places where they have been discussed. While it is not standard practice in the social sciences to give any final veto to the research participants, (for reasons of scholarly and empirical rigor), I do commit to taking their concerns seriously and to reflecting on the comments in the final draft, whether I agree with them or not.

Community Representative #1

Date of Signing

Anthropologist (PJC)

Appendix 3.1: AAMR Definition of Mental Retardation (2002)

Preamble: Mental retardation is not something you have, like blue eyes, or a bad heart. Nor is it something you are, like short, or thin. It is not a medical disorder, nor a mental disorder. Mental retardation is a particular state of functioning that begins in childhood and is characterized by limitation in both intelligence and adaptive skills. Mental retardation reflects the "fit" between the capabilities of individuals and the structure and expectations of their environment.

Definition of Mental Retardation ©2002 AAMR

Mental retardation is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.

5 Assumptions Essential to the Application of the Definition

1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.
2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.
3. Within an individual, limitations often coexist with strengths.
4. An important purpose of describing limitations is to develop a profile of needed supports.
5. With appropriate personalized supports over a sustained period, the life functioning of the person with mental retardation generally will improve.

[AAMR, 2002 #625; Luckasson, 2002 #622]

Fact Sheet (paraphrased)

What is the official AAMR definition of mental retardation?

(As above, and ...) A complete and accurate understanding of mental retardation involves realizing that mental retardation refers to a particular state of functioning that begins in childhood, has many dimensions, and is affected positively by individualized supports. As a model of functioning, it includes the contexts and environment within which the person functions and interacts and requires a multidimensional and ecological approach that reflects the interaction of the individual with the environment, and the outcomes of that interaction with regards to independence, relationships, societal contributions, participation in school and community, and personal well being.

What is a disability?

A disability refers to personal limitations that represent a substantial disadvantage when attempting to function in society. A disability should be considered within the context of the environment, personal factors, and the need for individualized supports.

What is Intelligence?

Intelligence refers to a general mental capability. It involves the ability to reason, plan, solve problems, think abstractly, comprehend complex ideas, learn quickly, and learn from experience. Although not perfect, intelligence is represented by Intelligent Quotient (IQ) scores obtained from standardized tests given by a trained professional. Diagnosis of mental retardation, mental retardation is generally thought to be present if an individual has an IQ test score of approximately 70 or below; given a standard error of measurement of 5, the ceiling is 75. This score is approximately 2 standard deviations below the mean.

What is Adaptive Behavior?

Adaptive behavior is the collection of conceptual, social, and practical skills that people have learned so they can function in their everyday lives. Significant limitations in adaptive behavior impact a person's daily life and affect the ability to respond to a particular situation or to the environment. For standardized tests, significant limitations in adaptive behavior are operationally defined as performance that is at least 2 standard deviations below the mean of types of adaptive behavior: conceptual, social, or practical.

Examples of Adaptive Behavior Skills?

Conceptual Skills; Receptive and expressive language, Reading and writing, Money concepts, Self-directions

Social Skills; Interpersonal, Responsibility, Self-esteem, Gullibility (likelihood of being tricked or manipulated), Naiveté, Follows rules, Obeys laws, Avoids victimization

Practical Skills; Personal activities of daily living such as eating, dressing, mobility and toileting. Instrumental activities of daily living such as preparing meals, taking medication, using the telephone, managing money, using transportation and doing housekeeping activities.

Occupational skills, Maintaining a safe environment

What are supports?

The concept of supports originated about 15 years ago and it has revolutionized the way habilitation and education services are provided to persons with mental retardation. Rather than mold individuals into pre-existing diagnostic categories and force them into existing models of service, the supports approach evaluates the specific needs of the individual and then suggests strategies, services and supports that will optimize individual functioning. The supports approach also recognizes that individual needs and circumstances will change over time. Supports were an innovative aspect of the 1992 AAMR manual and they remain critical in the 2002 system.

Supports are defined as the resources and individual strategies necessary to promote the development, education, interests, and personal well-being of a person with mental retardation. Supports can be provided by a parent, friend, teacher, psychologist, doctor or by any appropriate person or agency.

Causes of Mental Retardation?

The causes of mental retardation can be divided into biomedical, social, behavioral, and educational risk factors that interact during the life of an individual and/or across generations from parent to child. Biomedical factors are related to biologic processes, such as genetic disorders or nutrition. Social factors are related to social and family interaction, such as child stimulation and adult responsiveness. Behavioral factors are related to harmful behaviors, such as maternal substance abuse. And educational factors are related to the availability of family and educational supports that promote mental development and increases in adaptive skills.

[AAMR, 2002 #614] (emphases mine)

Appendix 3.2: DSM-IV Definitions (1994)

Mental Disorder

Behavioral health care professionals call disorders, illnesses or diseases that have prominent emotional, behavioral, and psychological symptoms **mental disorders**. These include substance use disorders and disorders associated with physical changes or illnesses, many of which directly affect the brain. For most of these disorders, however, physical causes have not been demonstrated or are poorly understood, even though biological treatments (e.g. drugs) may be effective in treating them. They may be distinguished from, and classified separately from the **personality disorders**, or the term may be used in such a way as to include personality disorders.

Mental Retardation

This **mental disorder** is diagnosed in individuals who, from whatever cause, have **intelligence** below an arbitrary level beginning before adulthood and whose adaptive functioning is impaired in any of a variety of areas.

A. Significantly subaverage *intellectual functioning*: an IQ of approximately 70 or below on an individually administered IQ test (for infants, a clinical judgment of significantly subaverage intellectual functioning).

B. Concurrent deficits or impairments in present *adaptive functioning* (i.e., the person's effectiveness in meeting the standards expected for his or her age by his or her cultural group) in at least two of the following areas: communication, self-care, home living, social/ interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety.

C. The onset is before age 18 years.

Code based on degree of severity reflecting level of intellectual impairment:

317 Mild Mental Retardation: IQ level 50-55 to approximately 70

318.0 Moderate Mental Retardation: IQ level 35-40 to 50-55

318.1 Severe Mental Retardation: IQ level 20-25 to 35-40

318.2 Profound Mental Retardation: IQ level below 20 or 25

Mental Retardation, Severity Unspecified: when there is strong presumption of Mental Retardation but the person's intelligence is untestable by standard tests.

(emphases mine) [APA Task Force on DSM-IV, 1994 #586; APA Task Force on DSM-IV, 2000 #587; Luckasson, 2002 #622; Luckasson, 1992 #618]

Appendix 3.3: Causes of Mental Retardation & Preventative Measures [ARC, 2001 #605]

What are the causes of mental retardation?

Mental retardation can be caused by any condition which impairs development of the brain before birth, during birth or in the childhood years. Several hundred causes have been discovered, but in about one-third of the people affected, the cause remains unknown. The three major known causes of mental retardation are Down syndrome, fetal alcohol syndrome and fragile X.

- **Genetic conditions** - result from abnormality of genes inherited from parents, errors when genes combine, or from other disorders of the genes caused during pregnancy by infections, overexposure to x-rays and other factors. More than 500 genetic diseases are associated with mental retardation. Some examples include PKU (phenylketonuria), Down syndrome, Fragile X syndrome is the leading inherited cause of mental retardation.
- **Problems during pregnancy** - Use of alcohol or drugs by the pregnant mother can cause mental retardation. Recent research has implicated smoking in increasing the risk of mental retardation. Other risks include malnutrition, certain environmental contaminants, and illnesses of the mother during pregnancy, such as toxoplasmosis, cytomegalovirus, rubella and syphilis. Pregnant women who are infected with HIV may pass the virus to their child, leading to future neurological damage.
- **Problems at birth** - Although any birth condition of unusual stress may injure the infant's brain, prematurity and low birth weight predict serious problems more often than any other conditions.
- **Problems after birth** - Childhood diseases such as whooping cough, chicken pox, measles, and Hib disease which may lead to meningitis and encephalitis can damage the brain, as can accidents such as a blow to the head or near drowning. Lead, mercury and other environmental toxins can cause irreparable damage to the brain and nervous system.
- **Poverty and cultural deprivation** - Children in poor families may become mentally retarded because of malnutrition, disease-producing conditions, inadequate medical care and environmental health hazards. Also, children in disadvantaged areas may be deprived of many common cultural and day-to-day experiences provided to other youngsters. Research suggests that such under-stimulation can result in irreversible damage and can serve as a cause of mental retardation.

Can mental retardation be prevented?

During the past 30 years, significant advances in research have prevented many cases of mental retardation. For example, every year in the United States, we prevent:

- 250 cases of mental retardation due to phenylketonuria (PKU) by newborn screening and dietary treatment;
- 1,000 cases of mental retardation due to congenital hypothyroidism thanks to newborn screening and thyroid hormone replacement therapy;
- 1,000 cases of mental retardation by use of anti-Rh immune globulin to prevent Rh disease and severe jaundice in newborn infants;
- 5,000 cases of mental retardation caused by Hib diseases by using the Hib vaccine;

- 4,000 cases of mental retardation due to measles encephalitis thanks to measles vaccine; and
- untold numbers of cases of mental retardation caused by rubella during pregnancy thanks to rubella vaccine (Alexander, 1998).

Other interventions have reduced the chance of mental retardation. Removing lead from the environment reduces brain damage in children. Preventive interventions such as child safety seats and bicycle helmets reduce head trauma. Early intervention programs with high-risk infants and children have shown remarkable results in reducing the predicted incidence of subnormal intellectual functioning.

Finally, early comprehensive prenatal care and preventive measures prior to and during pregnancy increase a woman's chances of preventing mental retardation. Pediatric AIDS is being reduced by AZT treatment of the mother during pregnancy, and dietary supplementation with folic acid reduces the risk of neural tube defects.

References

- American Association on Mental Retardation. (1992). *Mental Retardation: Definition, Classification, and Systems of Supports, 9th Edition*. Washington, DC.
- Alexander, D. (1998). Prevention of Mental Retardation: Four Decades of Research. *Mental Retardation and Developmental Disabilities Research Reviews*. 4: 50-58
- Batshaw, M. (1997). *Children With Disabilities*. Baltimore: Paul H. Brookes Publishing Co.
- The Arc. (1982). *The Prevalence of Mental Retardation*. (out-of-print).

the Beatitudes of Jesus

When Jesus saw the crowds, he went up the mountain; and after he sat down, his disciples came to him. Then he began to speak, and taught them saying:

"Blessed are the poor in spirit, for theirs is the kingdom of heaven.

"Blessed are those who mourn, for they will be comforted.

"Blessed are the meek, for they will inherit the earth.

"Blessed are those who hunger and thirst for righteousness, for they will be filled.

"Blessed are the merciful, for they will receive mercy.

"Blessed are the pure in heart, for they will see God.

"Blessed are the peacemakers, for they will be called children of God.

"Blessed are those who are persecuted for righteousness sake, for theirs is the kingdom of heaven.

"Blessed are you when people revile you and persecute you and utter all kinds of evil against you falsely on my account. Rejoice and be glad, for your reward is great in heaven, for in the same way they persecuted the prophets who were before you."

(Matthew 5:1-11)



art by Thelus George of L'Arche Daybreak

Charter of the Communities of L'Arche

L'Arche began in 1964 when Jean Vanier and Father Thomas Philippe, in response to a call from God, invited Raphaël Simi and Philippe Seux, two men with mental handicaps, to come and share their life in the spirit of the Gospel and the Beatitudes that Jesus preached.

From this first community, born in France and in the Roman Catholic tradition, many other communities have developed in various cultural and religious traditions.

These communities, called into being by God, are united by the same vision and the same spirit of welcome, of sharing and simplicity.

AIMS

1. The aim of L'Arche is to create communities which welcome people with a mental handicap. By this means, L'Arche seeks to respond to the distress of those who are too often rejected, and to give them a valid place in society.
2. L'Arche seeks to reveal the particular gifts of people with a mental handicap who belong at the very heart of their communities and who call others to share their lives.
3. L'Arche knows that it cannot welcome everyone who has a mental handicap. It seeks to offer not a solution but a sign, a sign that a society, to be truly human, must be founded on welcome and respect for the weak and the downtrodden.
4. In a divided world, L'Arche wants to be a sign of hope. Its communities, founded on covenant relationships between people of differing intellectual capacity, social origin, religion and culture, seek to be signs of unity, faithfulness and reconciliation.

FUNDAMENTAL PRINCIPLES

1. Whatever their gifts or their limitations, people are all bound together in a common humanity.

Everyone is of unique and sacred value, and everyone has the same dignity and the same rights. The fundamental rights of each person include the right to life, to care, to a home, to education and to work.

Also, since the deepest need of a human being is to love and to be loved, each person has a right to friendship, to communion and to a spiritual life.

2. If human beings are to develop their abilities and talents to the full, realizing all their potential as individuals, they need an environment that fosters personal growth. They need to form relationships with others within families and

communities. They need to live in an atmosphere of trust, security and mutual affection. They need to be valued, accepted and supported in real and warm relationships.

3. People with a mental handicap often possess qualities of welcome, wonderment, spontaneity, and directness. They are able to touch hearts and to call others to unity through their simplicity and vulnerability. In this way they are a living reminder to the wider world of the essential values of the heart without which knowledge, power and action lose their meaning and purpose.
4. Weakness and vulnerability in a person, far from being an obstacle to union with God, can foster it. It is often through weakness, recognized and accepted, that the liberating love of God is revealed.
5. In order to develop the inner freedom to which all people are called, and to grow in union with God, each person needs to have the opportunity of being rooted and nourished in a religious tradition.

THE COMMUNITIES

1. *Communities of faith*

1. L'Arche communities are communities of faith, rooted in prayer and trust in God. They seek to be guided by God and by their weakest members, through whom God's presence is revealed. Each community member is encouraged to discover and deepen his or her spiritual life and live it according to his or her particular faith and tradition. Those who have no religious affiliation are also welcomed and respected in their freedom of conscience.
2. Communities are either of one faith or inter-religious. Those which are Christian are either of one church or inter-denominational. Each community maintains links with appropriate religious authorities and its members are integrated with local churches and other places of worship.
3. Communities recognize that they have an ecumenical vocation and a mission to work for unity.

2. *Called to unity*

1. Unity is founded on the covenant of love to which God calls all the community members. This implies welcome and respect for differences. Such unity presupposes that the person with a handicap is at the center of community life.

This unity is built up over time and through faithfulness. Communities commit themselves to accompany their members (once their membership

is confirmed) throughout their lives, if this is what those members want.

2. Home life is at the heart of a L'Arche community. The different members of a community are called to be one body. They live, work, pray and celebrate together, sharing their joys and their suffering and forgiving each other, as in a family. They have a simple life-style which gives priority to relationships.
3. The same sense of communion unites the various communities throughout the world. Bound together by solidarity and mutual commitment, they form a worldwide family.

3. *Called to growth*

1. L'Arche communities are places of hope. Each person, according to his or her own vocation, is encouraged to grow in love, self giving and wholeness, as well as in independence, competence and the ability to make choices.
2. The communities wish to secure for their members education, work and therapeutic activities which will be a source of dignity, growth and fulfillment for them.
3. The communities wish to provide their members with the means to develop their spiritual life and to deepen their union with and love of God and other people.
4. All community members are invited to participate, as far as possible, in decisions concerning them.

4. *Integrated in society*

1. L'Arche communities are open and welcoming to the world around them. They form an integral part of life in their localities and seek to foster relationships with neighbors and friends.
2. The communities seek to be competent in all the tasks they are called to accomplish.
3. The communities wish to enable people with a handicap to work, believing work to be an important means of integration.

4. *The communities seek to work closely with :*

- the families and guardians of people who are handicapped
- professionals
- government authorities

and with all those who work in a spirit of justice and peace for people who are handicapped.

CONCLUSION

L'Arche is deeply concerned by the distress of people who suffer injustice and rejection because they are handicapped. This concern should impel the communities of L'Arche to do all they can to defend the rights of people with a mental handicap, to support the creation of places of welcome for them and to call our society to become more just and respectful towards them.

The communities of L'Arche want to be in solidarity with the poor of the world, and with all those who take part in the struggle for justice.

*This Charter has been approved by the General Assembly of the Federation,
Cap Rouge: Province of Quebec, Canada,
May 1993*

art by Patsy Ramsey of L'Arche Daybreak

Mission and Identity of L'Arche in Canada

L'Arche in Canada is part of a world-wide network of communities inspired by the Beatitudes. At the heart of these communities are people with a developmental disability and those who share life with them.

The four fundamental aspects of L'Arche's identity in Canada are :

1. *The recognition of the unique value of person with a developmental disability* to reveal that human suffering and joy can lead to growth, healing and unity. When their gift is received, individual, social and ecclesial change occurs;
2. *Life sharing*, where person with a developmental disability and those who assist them live, work and pray together, creating a home;
3. *Relationships of mutuality* in which people give and receive love;
4. *Christian community* based on the Gospel and dependent upon the Spirit of God where faithful relationships, forgiveness and celebration reveal God's personal presence and love.

OUR MISSION IS

1. TO CREATE HOMES where faithful relationships based on forgiveness and celebration are nurtured;
2. TO REVEAL THE UNIQUE VALUE AND VOCATION of each person;
3. TO CHANGE SOCIETY by choosing to live relationships in community as a sign of hope and love.

art by Ian Thompson of L'Arche Daybreak



KEY ELEMENTS OF A L'ARCHE COMMUNITY

I- Elements

Introduction

This Zone Document on "The Key Elements of a L'Arche Community" is based on thirty years of experience and on the two fundamental texts for L'Arche in Canada: the Charter of L'Arche and our Identity & Mission Statement.

A L'Arche community grows and develops when we can identify, articulate and be accountable for the fundamental and continuing elements and gifts which define who we are and who we want to become. This will give us a dynamism which will motivate and inspire us.

We recognize the need for a continuity of common principles, goals and practices in all of our communities. The purpose of this text is to help us build our communities through its use by Coordinators, communities and boards to evaluate where a community is in its development and to set priorities for future growth. It can also be a good tool for the formation of community members and Board members.

Following are the fundamental elements expressed in simple point form under two headings linked to the Charter:

Principles : the values we want to live;

Practices : the concrete ways by which we will achieve our goals, live our values and fulfill our Mission.

More and more we are aware of the need to work together and to work diligently to build communities of L'Arche that are rooted in the following essential elements.

1. The Value of Persons with a Developmental Disability ("core members")

«The aim of L'Arche is to create communities which welcome people with a developmental disability, to reveal the particular gifts of people and give them a valid place in society. The people with a developmental disability are at the heart of a L'Arche community.»

Principles

- The life of core members has value, dignity and integrity.
- Core members have gifts which the community seeks and actively finds ways to reveal.
- Core members actively participate in all aspects in the life of a L'Arche community.
- The community wants to secure for its member's education, work and therapeutic activities which will be a source of dignity, growth and fulfilment for them.

Practices

- Core members have stable, on-going, valued relationships within the community and outside of it.
- There are clear means of communication for core members to express their dreams, desires, needs and choices.
- Each core member has a program of growth, which is reviewed annually.
- Core members participate in decisions concerning them.
- Each core member has meaningful work or daytime activity.
- Outside professionals work with the community to support the growth of core members.
- Core members have opportunities to participate in and contribute to their local neighbourhood and local community life.

2. Life Sharing

« The different members of a community are called to be one body. They live, work, pray and celebrate together, sharing their joys and suffering and forgiving each other, as in a family. They have a simple life-style which gives priority to relationships.»

Principles

- Home life is at the heart of a L'Arche community.
- Relationships are based on the attitude of "living with", which is different from "doing for".

Practices

- Core members and assistants have a place in their home and contribute to its creation.
- Priority is given to building relationships in an atmosphere of trust, security and mutual care.
- Good conditions are put in place to foster the long term commitment of assistants living in the homes and working in the day programs.
- There is a prayer life in each home.
- There is an established recognizable rhythm of life in the home, work and community.
- Core members and assistants participate in the routines, activities and traditions of their home and of the community.

3. Mutuality

« L'Arche fosters and supports relationships of mutuality in which people give and receive love.»

Principles

- People are of equal value and are bound together in a common humanity.
- Weakness and vulnerability in a person, far from being an obstacle to union with God and others, can foster it.
- Differences in people are respected and valued.

Practices

- Friendships and mutual relationships are recognized and encouraged.
- Covenant relationships are encouraged, supported, announced and celebrated.
- There are clear community traditions regarding meals, celebrations, reconciliation, worship, holidays, etc. which foster bonding between people.
- Members express what they are living in language that respects people and builds community.
- Members have a voice and decisions are made at the appropriate place.
- There are clear community traditions and policies regarding appropriate behaviour.
- Different types of accompaniment are in place for all community members.
- There is a commitment to helping members maintain their long term relationships with their families and friends.

4. Faith Community

« L'Arche communities are communities of faith, rooted in prayer and trust in God. They seek to be guided by God and by their weakest members, through whom God's presence is revealed.»

Principles

- Trust in Providence
- Welcoming and open, the community has a religious identity which is valued and respected.
- The unique spiritual journey of each person is respected and encouraged.
- The covenant is our particular spiritual path as a L'Arche community.

Practices

- Members are active in their own faith traditions and are encouraged to deepen their own spiritual life.
- The community has an obvious and active spiritual life.
- The community recognizes and lives out its ecumenical vocation.
- The community has a pastoral minister.
- There are links with local churches, synagogues, religious groups and their leaders.

5. Leadership, Management, Structures and Human Resources

« The communities seek to be competent in all the tasks they are called to accomplish »

Principles

- Each L'Arche community has the leadership, management, structures and human resources necessary for it to live the Charter and fulfill its Mission.
- Leadership and authority is exercised as a service to the community.
- There is cooperation and a partnership among Boards, community leaders, L'Arche Coordinators, pastoral ministers and long term assistants.
- There is a dynamic balance among the four fundamental functions of leadership (Gerald Arbuckle):
 - To conserve, i.e. to keep L'Arche in contact with its original founding;
 - To manage, i.e. to set up structures that allow the day to day needs of the community to be met;
 - To nurture, i.e. to respond to the legitimate needs of the members of the community.
 - To be prophetic, i.e. to be ever open to discovering new ways to live out the Charter and the Mission within a rapidly changing world.
- Subsidiary, i.e. decisions are made at the "lowest" level possible. Consensus decision making is used whenever possible.

Practices

- The community assumes its rights and responsibilities as a member community of the Federation of L'Arche. (See L'Arche Canada Membership Agreement).
- There is a functioning and competent Board of Directors which ensures the community is faithful to the Charter and that the community fulfills its Mission.
- The Board of Directors and the community understands and supports the place and vocation of assistants, particularly long term and confirmed members.
- There is an effective community leader who carries the vision and spirit of L'Arche and who ensures that the community is growing as a L'Arche community and who fosters the long term commitment and vocation of the assistants.
- There is a community constitution which defines roles, the selection process for roles, responsibilities, authority, decision making and accountability within the community.
- There is an annual review for each community member.
- There is a written policy and procedures manual.
- There is an effective and competent community council.
- There are regular and effective team meetings at all levels of the community (i.e. home, work, administration etc.)
- Membership is clearly defined in writing. The place of each member is recognized, affirmed and celebrated. Community members participate, as far as possible, in decisions concerning them.
- There are effective orientation, formation and training programs for assistants.
- There is a reasonable compensation, benefits and pension policy for all assistants and employees.
- There are financial accounting and reporting systems in place.

6. Communities integrated in society

« L'Arche seeks to offer not a solution but a sign, a sign that a society, to be truly human, must be founded on welcome and respect for the weak and the downtrodden.»

Principle

- L'Arche communities are open and welcoming to the world around. They form an integral part of life in their localities.

Practices

- The community works closely with government authorities, professionals and the families of the core members.
- The community is well integrated in its neighbourhoods, local churches and local community life.
- There is solidarity and links with other L'Arche communities.

Appendix 5.1 L'Arche research on assistants' motives

1992 Canada-USA zone survey (LTA, STA, ex-assistants)

It was determined a decade ago at the international L'Arche council meetings that they had a problem with attracting and keeping good people as long-term assistants. A survey of the Canada-USA zone probed these issues (Davis 1992) which involved 100 respondents: 30% short-term assistants (STA; less than 3 years service), 40% long-term assistants (LTA; 3 years service or more) and 30% ex-assistants. The age composition was roughly one third each for those under 30, 31 to 45, and 45 and over. The raw data for this survey no longer exist; thus I was limited to the internal report which is brief. The survey has several excellent questions, including why people came; however, unfortunately most questions are not reported at all in the summary.

One interesting discovery indicated that 75% of L'Arche assistants have a university degree and 85% have some post-secondary education. This percentage is unusually high for the field (Braddock and Mitchell 199X). Half of the STAs did *not* identify "community" as a reason for attending L'Arche but it does not say why they did. No figures are given but the report states that "a sense of call or vocation" was a major motive, especially for LTAs. Similarly, almost all respondents indicated that their attendance was motivated by spiritual reasons and/or the vision and philosophy of L'Arche¹. There is a list of what people like about L'Arche but it is not clear whether these encouraged them to come to L'Arche. This research confirms what was already known: *Intrinsic* rewards of the work and lifestyle are the central attraction in spite of the modest salary and lifestyle restrictions.

2000 Ontario regional survey (STA)

A short open-ended questionnaire was distributed in the Ontario region (8 communities) to all first year assistants (n= 54). It included three questions, the first being: "How did you hear about L'Arche?" (Zinyk & Egan 2000). The central finding for the first question was that fully 81% of new STAs noted that *word-of-mouth endorsements* from ex-assistants (36%), volunteers or friends of L'Arche were important factors. The report prescribes more effort be made to provide personal contact for candidates and, indeed, L'Arche has now prepared an information package for alumni (ex-assistants) to share with interested people. Other findings showed that books (31%) and the Internet (26%) had also been important and that public outreach, newspaper articles, and advertisements were also influential (approx. 20% each). Fully 77% of respondents listed more than one information source.

Many new assistants also cited multiple reasons for "Why did you come to work at L'Arche?" Again, a list does not explain links or relative importance of the factors, only their frequency. Each of the top four reasons was relevant in the attendance of roughly 20% of the new assistants: experience with people with disabilities; curiosity about lifestyle; faith-based community and spirituality; philosophy. Approximately 11% found community, self-knowledge and renewal, or life change relevant and approximately 5% found desire to serve, challenge/different, or meaningful work to be relevant reasons to attend.

This data provides a useful overview of common motives; however, the categories were phrased in a manner that makes their distinction from each other somewhat ambiguous. For example, the L'Arche philosophy is multi-faceted; thus "philosophy" does not clarify what part of

¹ See Wuthnow (1991:59) for a discussion of why it is difficult to make sense of research on compassion or social responsibility when people indicated several general areas as important to their decision. He suggested that this makes compassion "over-determined" or something that basically everyone agrees about is a good idea but that this no longer becomes a good way of predicting who will actually do it.

it was attractive, or whether they distinguish between philosophy and spirituality at L'Arche. As a further example, a small number cited "meaningful work" as a motive (4%) whereas, the top 4 factors could all, in fact, be construed as having some relation to finding meaning in work? The researchers note an important concern: whether STAs' expectations will match the reality of the life at L'Arche, since three out of four of the most popular motives were all idealistic and did *not* directly mention the actual labour of caregiving.

The third question was, "What helped you to come?" Assistants gave answers from concrete factors such as needing work and reading brochures or books, to values-oriented reasons such as wanting meaningful work or to do something socially or spiritually good. There are no conclusions or prescriptions indicated in the report (Zinyk & Egan 2000)

2001 Canadian national survey (LTA)

There have been several international meetings where LTAs expressed serious concerns about their willingness and ability to continue their commitment to L'Arche for the long-term without more clarity regarding some of their central issues (pensions, security, pace, and prayer life). Following this, the international council decided that each zone (Canada is now a distinct zone) should research what LTAs needed in order to stay. The L'Arche Canada board and LTA council group decided to conduct, in conjunction with the 26 Canadian communities, a lengthy 22 page survey on several areas of relevance to these questions. These included why people initially wanted to work at L'Arche. The board's main objectives for the study were related to establishing national standards and harmonizing finance and compensation-related policies. In the end, however, they were not able to analyse the qualitative data, regarding why people came and what they need to stay, other than those concerns related to finance. They did tally the results from those sections as I have discussed in chapter 5. I was allowed to review the raw (anonymous) data and I synthesized this information with my own ethnographic data to illustrate the discussion of motives in chapter 5. The tally of results to the open-ended, unranked motives question is included below:

1	community life	46%
2	spiritual journey	31
3	people with disability	27
4	Vanier's books	23
5	L'Arche's vision	16
6	relationships with the poor, marginal	8.5
7	interpersonal relationships	7.4