A New Model for Care: A Case Study in Creating Community among Persons With and Without Intellectual Disabilities

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ABSTRACT

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Sarah Parisio

Traditional models of care as experienced by persons with intellectual disabilities tend to be unidirectional and create a power relationship between caregiver and patient. The relatively new theoretical concept of mutual care provides a way of breaking down the existing power relation between caregiver and patient to make way for a more integrative model, namely care as partnership. In this ethnography, I examine the relationships between conventional caregivers and patients in the context of L'Arche, a community of people with and without intellectual disabilities founded on the notion of mutuality in relationships across differences. Recording the varying experiences of care lived by members of the L'Arche community of *Il Chicco* in Rome illuminates the risks and benefits involved in mutual care while highlighting the numerous factors that impact the possibility and success of its application in the Italian context.

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To pretend that I have accomplished this research project alone would be to disregard a number of important people who have contributed, each in their own way, to its' realization.

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LIST OF APPENDICES

TABLE OF CONTENTS

1.0 INTRODUCTION

1.1 Care in unexpected forms

Interactions between caregiver and client – or the recipient of care – tell a great deal about the model upon which their exchanges are based. In conventional models, the caregiver is the provider of care – the powerful agent – while the client is its passive receiver (Cushing, 2003a; 2003b; Cushing & Lewis, 2002; Taussig, 1980; Illich, 2003). Such exchanges often characterize care both institutional and familial contexts in which unidirectional relationships between caregivers and clients are fostered and encouraged. The relational imbalance inherent in conventional care models is especially evident in instances when the recipients of care are indeed dependent on their caregivers for daily functioning. This is the case for people with intellectual disabilities. A relatively new notion of mutual care proposes an alternative to these conventional conceptions. It is an integrative model in which care involves exchange; care is partnership (Cushing, 2003a; 2003b; Cushing & Lewis, 2002; Horwitz et al., 1996). In this research project, I examine the relationships between caregivers and recipients of care in the context of L'Arche, a community of people with and without intellectual disabilities founded on the notion of mutuality in relationships across differences (Cushing, 2003a; 2003b; Cushing & Lewis, 2002; L'Arche, n.d.). Recording the varying experiences of care lived by members of L'Arche illuminates the risks and benefits involved in this model.

Incoming phone call prior to dinner around 7:30 p.m.: Matteo has fled his house and cannot be found. Has anyone seen him?, the caller inquires in a worried tone. Her answer *comes following a quick check around the large and open common areas including the living room, kitchen, and dining room. Matteo is nowhere in sight.*

Normally, Matteo is not the type of person who goes unnoticed in spite of his short stature. Indeed, Matteo is usually quite easy to spot since he is often absorbed in animated conversations with unseen friends, some of whom have been transformed into empty, label-less softdrink bottles and coat hangers. Almost immediately following this evening's unexpected phone call, community members in the L'Arche house where I have been given a room begin a thorough search for Matteo. Some investigate the second half of the first, the second, and the third floors of the massive home where a total of seven core members – as are called the persons with intellectual disabilities living at L'Arche – and four assisting caregivers live. Others step outside of the permanently open windows of the common spaces through which passes a cool breeze. There, they verify whether Matteo wandered around the 'back' of the home near the clothesline and official front door. Still, Matteo is nowhere in sight.

The community grounds of L'Arche Il Chicco *here in Ciampino situated just outside of Rome are a relatively secure place for core members and assistants to travel alone. A heavy duty iron fence anchored in a knee-high cement base and bordered by a row of faintly fragrant pink and white oleander bushes delimits the property boundaries. The fence is a security measure that characterizes many city homes and businesses in this area of Italy. Just over thirty years ago, the bare property was donated to the founding members who built a small family-like home for young children with intellectual disabilities. Since its humble beginning, the community has expanded and now consists of three separate homes and a* *workshop. This is where Matteo has lived since the age of six. Unlike most of those who are now looking for him, Matteo knows these grounds better than the back of his hand.*

I have now been in community for two days. Earlier today around 11 a.m., I am confronted with important news along with each of the fifty or so members present and seated in a circle at the incontro di comunità*, or community gathering. Unsure of what to expect from this gathering, I am taken by an introductory musical performance provided by a hodgepodge of nearly twenty core members and assistants from various homes and workshops. Adorned with matching blue shirts proclaiming their belonging to the* Chicco Sband *in salmon-colored writing, the musicians – or drum, bongo, didgeridoo, shakers, guitar, tambourine, bloc, triangle, and clarinet players – dutifully follow the director's instructions. Spectators clap along to the three lively tunes the* Chicco Sband *performs with energy and precision.*

Then, the news. Members from the administrative council of Il Chicco *and an external L'Arche member have come to announce that the current community leader, Elisa, whom I had been in contact with prior to my arrival, is stepping down from her role. The external L'Arche member announces the news with great sadness as others abruptly transition into a solemn mood that contrasts painfully with the joyful vibes of the preceding performance.*

I am devastated. Is it possible to go ahead with my project on mutual care in relationships at such a critical moment in time for this community? Fieldwork that failed[1] *flashes through my mind as I listen to an elaboration on Elisa's motivations for abandoning her position. From what I gather, she thinks it best both for the community and herself to step down from her role and accepts to remain as* direttore sanitario*, or healthcare director,* *for a limited time. I later discover that the role of healthcare director at* Il Chicco *is crucial for legal reasons since it is a* struttura sanitaria*, or healthcare center. Elisa is present at the gathering but does not speak. Over the past two days, I have already encountered many stories surrounding the community's current 'state of crisis' and Elisa's involvement in it, the veracity of which I do not wish to explore. What I know is what I observe. Elisa appears powerless.*

As I look around the room throughout the decidedly verbose speeches of the external member and council administrators, I notice that several community members are distracted or inattentive. Two of the men in wheelchairs moan loudly, lamenting the oppressive heat of this July morning. Several minutes into the chorus of complaints, each of the men is given cold water. Nevertheless, neither is taken out of the room. Another core member falls asleep soon after the beginning of the external member's speech. Matteo, a bongo player in the band, busily pokes at those seated next to him and evidently enjoys their bothered reactions to his nagging. At the end of the external member's speech, she admits to having spoken in such a way that may have made it difficult for some community members to follow along readily, if at all. Here, she asks whether there is anyone who would like to contribute something to what has been said, an offer that Matteo takes up first and almost exclusively.

Like all good orators, Matteo rises to an upright position with his hands clasped just below his waist and makes eye contact with his audience. I listen intently to Matteo as he speaks elegantly, pacing his speech while pausing at times to invoke gravitas*. I try – I really do – to understand his words but Matteo's speech is simply incomprehensible for me. Upon scanning the room, I note that some of the other community members appear to understand what he is saying. Toward the end of his speech, an assistant interprets Matteo's words to* *mean a request for forgiveness. Subsequently, Matteo enthusiastically embraces another core member, Antonio, who accepts his request with a large smile. Following this public demonstration, the external L'Arche member thanks Matteo for his intervention and encourages others in the room to learn from his reconciliatory gesture. I hear Matteo referred to by various community members as the* maestro *of forgiveness. At that particular moment, Matteo's performance does not seem in any way related to what has been said regarding Elisa's resignation. What, I wonder, does forgiving Antonio have to do with any of this?*

After the community gathering, core members and assistants alike resume their morning activities. There is some talk throughout the day of the implications of Elisa's resignation on the upcoming summer months. Today, we all later discover, comes to mark the beginning of an uncertain and directionless four months of community life.

I am brought back to current evening events when an assistant proclaims having found Matteo, this after fifteen minutes of searching. On the second floor of the third home here at Il Chicco*, Elisa has her own private apartment where she has been all evening since the gathering. There, Matteo and Elisa are sharing a moment together over a slice of pizza.*

Mutual care is a difficult concept to portray as the moments of encounter across differences otherwise separating persons with and without intellectual disabilities tend to result in significant changes over time rather than quantifiable immediate transformations. If care is as Daniel Engster (2005) defines it – "everything we do directly to help others meet their basic needs, develop or sustain their basic capabilities, and alleviate or avoid pain or suffering, in an attentive, responsive and respectful manner" – then who is the caregiver or the recipient of care in Matteo and Elisa's relationship (p. 55)? As previously stated, in many, if not most, institutions and private care contexts, persons such as Matteo with limited apparent communicative ability are relegated to the passive role of care recipient as a result of their intellectual disabilities. In these same contexts, Elisa – the greatest authority figure in community until her resignation – holds the most responsibility and hence decision-making power; she is the caregiver archetype.

At L'Arche, the aforementioned normative and normalizing views of disability, communication, care, and community are renegotiated – at times more successfully than others. At L'Arche in Ciampino, these renegotiations are distinct from and yet common to those experienced at L'Arche in other parts of the world. Alternative conceptions of disability in the Italian context, including a view that something can be learned from rather than taught to persons such as Matteo, are put into practice. A new understanding of communication is also is also at play, an understanding in which engagement with nonverbal[3] communication through the use of multiple senses is involved. Matteo's apparent lack of attention and comprehension of the content of what was stated during the community gathering does not preclude his grasp of how it was delivered – in other words the tone or severity of the external member's speech – and who it involved. In fact, Matteo and Antonio's embrace reveals the complexity of communication and the uncertainty of comprehension involving nonverbal messages exchanged at L'Arche.

An alternative model of care is also at play in Matteo and Elisa's interaction – a model in which the power relation between caregiver and client is broken down in order to make way for care as partnership. This model is founded on mutuality in caregiving relationships (L'Arche, n.d.). Elisa's resignation is framed as both beneficial for Elisa herself and the community whose needs she cannot or does not meet. Her resignation is an act of care. Similarly, Matteo's disappearance in order to spend time with Elisa is a reflection of the value of their relationship in spite of her official role in community. Matteo's escape is an act of care. At L'Arche, care comes in unexpected forms. Lastly, personal and collective identities are created and recreated with internal and external changes in community life. The various renegotiations evident in the scene will be further explored in the dissertation that follows.

With this research project, I address the following primary research questions: 1) **What are the experiences of care in the context of L'Arche?**, 2) **What is mutuality in caregiving relationships at L'Arche?**, and 3) **What factors determine the limits of mutuality?**

1.2 Chapter summaries

The remainder of this thesis dissertation is broken up into seven chapters, the first of which involves a thorough review of literature regarding and historical framing of disability, care, the Italian social and cultural context, and L'Arche. Chapter Two begins with a look at disability and at intellectual disability more specifically. The first part of the chapter is primarily focused on establishing a working definition of intellectual disability for use throughout the remainder of the research paper. In the subsequent sub-section, I define care and outline the four models of healthcare service delivery which include the biomedical model, the independent living model, the community-based model and the client-centered model. I do this in order to then elaborate on the relatively new mutual care model. In this section, I compare and contrast the strengths and weaknesses of each of these. I also outline the six principles of mutuality at L'Arche, one of the notable public care facilities where this model is operationalized systematically.

Next, I take a look at the Italian context in which my field research takes place. This sub-section presents some of the significant social and cultural characteristics that shape the lives of Italians including Catholicism, language, regionalism and cynicism. Because cynicism plays an important role in the relational capacities of the Italian populace, I take the time to outline the current and chronic problems that have contributed to the country's generalized state of 'depression' (Mammone & Veltri, 2008). Then, I give a brief historical overview of mental healthcare in Italy throughout the twentieth century. The historical synopsis serves to contextualize the current state of care of persons with intellectual disabilities in Italy. Finally, Chapter Two ends with a historical review of L'Arche including a brief account of its foundation and subsequent growth as well as an outline of the mission and philosophy of the organization founded by Canadian-born Jean Vanier. I conclude this sub-section of the chapter with a review of literature that addresses the mutual care model at L'Arche specifically, as well as the positive and negative implications regarding its application in such a context.

Chapter Three focuses on methodology including the theoretical framework that forms the basis of my approach to studying mutual care at L'Arche, the field site, data collection techniques, data processing and analysis, ethical considerations, and benefits and limitations to research participants of partaking in this project. In Chapter Three, I position myself as a social and cultural anthropologist among other scholars whose work touches upon one of four themes: disability, communication, care or community. The theoretical framework is crucial in that it is in this section that I make my implicit framework explicit for readers. I also address how the theories I discuss tie into the research questions I address in this project. The theories discussed in this section are referred to frequently throughout the remaining five chapters. The more practical aspects of my research methodology are also discussed in detail alongside the issues and ethical considerations I was confronted with while conducting fieldwork near Rome.

The next four chapters of this dissertation are principally ethnographic in nature and explore the four themes that repeatedly presented themselves throughout my fieldwork and in interviews with *Il Chicco* community members. Each begins with an ethnographic vignette to which I refer throughout the section. In Chapter Four, I begin by unpacking some of the dominant conceptions of disability in the Italian context. These conceptions include the disabled as machines, the disabled as *bambinoni*, or big babies, and the disabled as a menace. I demonstrate how these dominant conceptions of disability force people with disabilities into passive roles including the weak and fragile recipients of care. I subsequently contrast these dominant conceptions of disability to those proposed at L'Arche and held by many community members. Alternative conceptions include an understanding of the disabled as human first, other conceptions such as the disabled as agents or as normal, and the most radical approach, namely the disabled as teachers. Each of these alternative views is discussed at length.

In Chapter Five, I delve into communication among community members as a primary means by which relationships are created and maintained. I also take a significant part of the chapter to investigate the various forms of communication engaged in at L'Arche. This is important given that a large majority of core members at *Il Chicco* have limited or no speech capacities and hence make use of various sensory channels to transmit nonverbal messages. The forms of communication that are the most prominent among assistants and core members are health problems – or somatizing, caring and violent gestures, and the use of touch. Next, I treat the methods of interpretation used by and encouraged for L'Arche members in the context of relationships with nonverbal people. As a consequence of this type of communication, frustration and uncertainty often arise. In the following sub-section, I discuss core member as well as assistant frustration as a result of difficult communication. Then, I explore the impact of the prolonged uncertainty of comprehension by assistants on the nature of relationships and the approach to care these community members subsequently take on. Lastly, I enumerate seemingly paradoxical though successful nonverbal communications – between assistants and core members, or between core members – and verbal miscommunications that frequently take place between assistants.

Chapter Six is the most substantial in that it is here that I directly address the research questions I set out to answer. In Chapter Six, I attend to mutuality in caregiving relationships across difference as it is lived by community members at *Il Chicco*. I spend the beginning of the chapter exploring the ways in which *participation* in relationships allows community members to overcome dominant conceptions of disability and communicate in new ways, while adopting an attitude of uncertainty toward care of and for others. I also spend some time exploring the possibility of mutual well-being among persons who operationalize the mutual care model. Next, I relay the ideal assistant-core member relationships defined in literature on L'Arche. The final sections of the chapter involve presenting and demonstrating the principles of mutual care in practice at *Il Chicco*. These principles, outlined for the first time by anthropologist Pamela Cushing (2003a), are seen reflected in the lived experiences of community members. Finally, I lay out the important external factors that impact the possibility and success of mutually caring relationships at L'Arche.

The final ethnographic chapter is predominantly about identity negotiations as a product of participation in mutually caring relationships. In Chapter Seven, I explore some of the contested ideas surrounding what L'Arche is, who or what counts as community, and what individual core members interpret as their role within their immediate and extended communities. To conclude this thesis dissertation, I spend some time revisiting my initial research questions and draw general conclusions based on my fieldwork. I also demonstrate how my research project contributes to academia and anthropology generally. To end, I indicate directions for further research in the areas of disability, communication, care and community.

1.3 Glossary of terms

care	everything we do directly to help others to meet their basic needs, develop or sustain their basic capabilities, and alleviate or avoid pain or suffering, in an attentive, responsive and respectful manner
communication	the transmission of information; mediations at the kernel of subjectivity and sociality; the intersubjective grounding for any and all claims to psychological or social reality
L'Arche community	a group of people associated together for the purpose of establishing a whole way of life collectively in homes; the key elements of L'Arche communities are geographic proximity, economic sharing and common vision
culture	a shared way of being and living, which has come into existence as a result of the interaction of myriad historical forces, and that remains subject to history
disability	the restriction of normal ability that arises from an impairment
handicap	the disadvantage a person experiences because of an impairment and disability
impairment	the loss of normal function (psychological, physiological, or anatomical structure)
intellectual disability	a disability originating before the age of 18 characterized by significant limitations both in intellectual functioning [refers to general mental capacity, such as learning, reasoning, problem solving, and so on] and in adaptive behavior, which covers many everyday social and practical skills
power	an integral aspect of all human relations taking the form of fluctuating balances

2.0 LITERATURE REVIEW

2.1 Review of intellectual disability

2.1.1 Debates in disability studies

Disability has been conceptualised in a variety of ways and has covered a range of diverse meanings across cultures and ideologies through time (Grönvik, 2007, p. 751). Swedish social scientist Lars Grönvik (2007) outlines two principal approaches to understanding disability which have emerged out of debates surrounding its use as an analytical category. The first approach is characterized by a focus on individual characteristics within a single body as the site of disability, while the second views disability as a social construction produced by different types of barriers (Grönvik, 2007). In his work, Grönvik (2007) critiques these definitional approaches and the methodological consequences of these definitions by looking at how disability is understood in theory and practice and how it is used to describe empirical data.

In analyzing the classic works of disability theorists Mike Oliver, Colin Barnes, Nora E. Groce, Irving K. Zola, and Gary L. Albrecht, Grönvik (2007) highlights the issues that arise from external, internal, and stipulative definitional inconsistencies in the work of each of these authors. Grönvik (2007) postulates that external inconsistencies occur primarily when authors using definitions of disability refer to the work of other authors in which disability is differently operationalized. Internal inconsistencies, on the other hand occur when the definitions laid out by authors do not remain consistent throughout the entirety of their work. This tends to happen when stipulative definitions – or definitions that clearly articulate a "meaning-relation between some word and some object" (Grönvik, 2007, p. 754) and often take the form of ‘Disability is…’ or ‘By disability I mean…’ – are either absent from the work or in conflict with the applied definitions. In other words, there is a lack of clarity as to the author’s definition or a discrepancy between its definition and “how the concept of disability *in fact* [is] used in the studies” (Grönvik, 2007, p. 754). Grönvik (2007) states that ideally, “the stipulative definition and the applied definition should stand… [in] semantic correspondence” to one another, though this is by no means an easy task (p. 754). Such a relation between theoretical and operational definitions of disability is an aim of my project.

Throughout this dissertation, I will refer to the definition of disability proposed during the United Nations Convention on the Rights of Persons with Disabilities held in 2006. According to the Convention, disability is defined as “an *evolving* concept… that… results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (UN Economic and Social Council 2006, Preamble, emphasis added). This definition is also espoused by the American Association on Intellectual and Developmental Disabilities (AAIDD, 2013), previously referred to as the American Association for Mental Retardation (AAMR). Cushing (2003b) uses this definition but makes an important distinction between disability, impairment and handicap. She states:

> *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. (p. 73-74)

Scholars such as Devva Kasnitz (2001) and Gregor Wolbring (Cushing, 2003b) who write and speak about disability from a first person perspective, also utilize a similar definition. In an introduction to anthropology in disability studies, authors Kasnitz and Russell P.

Shuttleworth (2001) elaborate on the aforementioned concepts in the following way: "A disability may or may not be a handicap, or handicapping, dependent on management of societal discrimination and internalized oppression… and on cultural and situational views of cause and cure and of fate and fault" (p. 3). Hence, many scholars including Cushing (2003b), Cushing and Lewis (2002), Kasnitz and Shuttleworth (2001), and Wolbring (Cushing 2003b) identify disability as at least partially if not entirely socially and culturally constructed while existing in reference to ability.

2.1.2 Defining intellectual disabilities

According to the aforementioned definition, persons with disabilities have an, or several, impairment(s) that may inhibit their full and successful involvement in society on an equal basis with others. These impairments include "long-term physical, mental, intellectual or sensory impairments" (UN Economic and Social Council 2006, Article 1). Of particular interest to this study are intellectual impairments that result in restrictions of normal ability as they are characteristic of persons with disabilities living in L'Arche communities. Though explanations differ across cultures, the AAIDD provides a definition of intellectual disability that is both clear and most relevant in countries such as Italy. According to the AAIDD (2013a; 2013b):

> Intellectual disability is a disability characterized by significant limitations both in intellectual functioning [refers to general mental capacity, such as learning, reasoning and problem solving] and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18.

Intellectual disability thus differs from commonly confounded developmental disability, and mental or psychiatric illness. It is also imperative to note that the definition of intellectual disability, like that of disability, is constantly changing in reaction to public attitudes toward people with intellectual disabilities (Cushing, 2003b, p.74). Cushing (2003b) points to the AAIDD definition of intellectual disability as representative of these fluctuations; the definition has been updated ten times over the past century.

Though my point of departure assumes the social and cultural construction of disability generally, I join philosopher Eva Feder Kittay (2001; 2011; Kittay, Jennings & Wasunna, 2005) in arguing that such a position is insufficient when theorizing intellectual disability. She states: “Ensuring equal opportunity to people is admirable when people are in a position to take advantage of the opportunities on offer, but some who are disabled are not in this position” (Kittay, 2011, p. 55-56). Here, Kittay (2011) points to people with severe intellectual disabilities such as her daughter Sesha for whom “no accommodations, antidiscrimination laws, or guarantees of equal opportunity can make her self-supporting and independent” (p. 56). Instead, Kittay (2001; 2011; Kittay, Jennings & Wasunna, 2005) proposes an ethic of care that recognizes the dependencies all members of society who drift in and out of states of dependency at various moments in their lives. If intellectual disability is in part socially and culturally constructed, it also requires a paradigm shift in which interdependency rather than independence and autonomy serves as the basis for care and justice (Kittay, 2001).

2.2 Review of models of care

Care has been theorized by many scholars over the past century (Cushing, 2003a; 2003b; Cushing & Lewis, 2002; Engster, 2005; Held, 2005; Horwitz et al., 1996; Kittay, 2001; 2011; Kittay, Jennings & Wasunna, 2005; Lapierre & Hunter, 1989; Lin et al., 2012; Taussig, 1980; Vitalino et al., 2004). Definitions of care have come to encompass a wide range of caring practices, which "of course, vary among different cultural groups," (Engster, 2005, p. 56) though some such as Engster (2005) claim that the differences in form are relatively trivial compared to their common structural elements including the values that ground them. In what follows, I will define care as it will be understood throughout my research project and outline the four principal models of service delivery operationalized in both public and private rehabilitation centers. These include the biomedical, the independent living, the client-centered and the community-based models (Forster, 2007). Then, I will briefly describe the relatively new mutual care model that differs from the previously mentioned four, which are characterized attempts by healthcare professionals to remain objective and neutral in their activities and responsibilities.

2.2.1 Defining care

Care as defined by Engster (2005) is "everything we do directly to help others to meet their basic needs, develop or sustain their basic capabilities, and alleviate or avoid pain or suffering, in an attentive, responsive and respectful manner" (p. 55). Care thus encompasses a range of practices that are performed for the purposes of developing and sustaining the needs and capacities of care recipients. In his work, Engster (2005) argues that there are at least three distinct types of care that can be derived from this definition. The first type is care for the recipient of care. The second type involves securing "good care" of care recipients "by ensuring that (…) caregivers have the resources and support necessary to provide [it]" (Engster, 2007, p. 57). The second mode, though indirect, is as important as the first because it consists of providing support for caregivers whose role it is to offer it. Lastly, Engster (2007) argues that there is a third type of care that involves attending to the group rather than the individual. Engster (2007) states: "one may care for others collectively by supporting or instituting programs that directly help them to meet their needs, develop or sustain their basic capabilities, or live as much as possible free from suffering" (p. 57). This third type of care entails providing or promoting care programs, hence ensuring the well-being of the group.

Though Engster (2007) does not refer to an ethic of care, he does nominate the dual nature of care in the aforementioned definition. Philosophers Kittay (2001; 2011) and Virginia Held (2005) who theorize care make its dual nature explicit in their work.

> I think, then, of care as practice and value. The practices of care are of course multiple, and some seem very different from others (...) Yet all care involves attentiveness, sensitivity, and responding to needs. (Held, 2005, p. 39)

Both authors conceptualize care as a value or moral principle as well as a set of practices that support the principle. Care practices, as Held (2005) points out, involve responding to the needs of others while caring relationships with others "should be characterized by trust" (p. 42). Held (2005) adds that care also "builds trust and mutual concern and connectedness between persons" (p. 42). Kittay's (2001; 2011) further notes that we have a duty to care for others that is rooted in our dependency on them. She claims that ignoring the prevalence and frequency of this dependency on others does not allow for valorizing the range of human possibility. Dependency, Kittay (2001; 2011) argues, characterizes moments or extended periods of time for all persons. To disregard the prevalence and frequency of dependency is also to discard a collective responsibility of caring for others and ensuring that everyone is provided adequate care by concerned and attentive individuals (Kittay, 2001).

2.2.2 Four models of healthcare service delivery

In her doctoral thesis, Donna Marie Forster (2007) outlines four models of healthcare service delivery: the biomedical model, the independent living model, the community-based rehabilitation model, and the client-centered model. According to Forster (2007), each of these embraces a perspective that differs from the others on the nature of the problem or issue at hand, the type of relationship between the caregiver and the recipient of care required to address the issue or problem, the process of change, and the projected outcomes of the change process (p. 102). These same models are employed by healthcare professionals and caregivers in service delivery to persons with intellectual disabilities. In the following section, I will outline the distinguishing characteristics of each of these models.

The **biomedical model** of care claims to be rational and scientific in nature (Kingsley, 1996, p. 169). This impersonal model that now governs mainstream healthcare was created in order to counter the injustices engendered by older "more personal and relationship-oriented" models of care (Cushing, 2003b, p. 256). Forged with good intentions, the new biomedical model left "less room for human bias" instead making room for "something more 'fair and just' that deal[t] with everyone equally and protect[ed] (inherently vulnerable) patients and caregivers" from injustices (Cushing, 2003b, p. 257). The new model was further purged of fraudulent medicine, such as Anton Mesmer's animal magnetism (Riskin, 2009), and replaced with an empirical scientific model free of human sensory perception as a legitimate means of drawing conclusions (Barcan, 2011). Along with these changes, other important developments such as the creation of effective new drugs presented alternatives to previous treatment of ill persons (Cushing, 2003b; Fierlbeck, 2011; Lemay, 2009).

The biomedical model addresses problems in bodily functions and structures of individuals that are deemed problematic because they deviate from what is "considered normal or standard for human beings" (Forster, 2007, p. 15). Forster (2007) explains that according to the biomedical model, all individuals who live with a similar impairment or deficit experience it in the same way as each other and over time. As such, "the biomedical model facilitates the assessment and diagnosis of these impairments" because it operates within a positivistic framework where both problems and the solutions to problems can be entirely identified through an understanding of human anatomy and function (Forster, 2007, p.15). The goal of this model is to assist clients in obtaining the greatest level of functioning, hence restoring normal levels of personal and practical independence (Forster, 2007, p. 16). For persons with intellectual disabilities, biomedical rehabilitation aims to maximize the ability of persons to take part in activities of the everyday (Forster, 2007).

According to the biomedical model, change is initiated by the professional who "classifies the nature of the impairment, assesses the extent of functional loss and finally, identifies limits and restriction in activities" (Forster, 2007, p. 16). Change occurs as patients integrate, use, and practice techniques, skills and technologies supplied by professionals (Forster, 2007). Theorists such as Michel Foucault (1973) and Michael Taussig (1980) have argued that this model accords caregivers with a "great increase in control" in exchange for "improved scientific understanding of… illness" (Cushing, 2003b, p. 257). In the case of individuals with intellectual disabilities, patients are expected to adjust to their impairments and to become as independent as possible.

The second important model of care is the **independent living model**. Forster (2007) argues that it shares a heritage with the American civil rights struggles of the 1960s, consumer movements, and trends to deinstitutionalize individuals with mental health problems and intellectual disabilities. The independent living model accepts and emphasizes normality and independence. Whereas the biomedical model addresses problems located in bodily function and structure, the independent living model addresses problems which are considered to be social in origin (Forster, 2007). According to Forster (2007), the independent living model is “concerned about the impression of vulnerability and the impact this has on the ability to act as independent autonomous person” (p. 19). The goals of the independent living model are the achievement of the highest level of personal and social development and an increase in the power and control that persons have over decisions about their care. The relationship between client and professional in the independent living model is structured so that the client maintains maximum control over the care they receive including decision-making power over the needs and services believed to be needed (Forster, 2007). In this model, there is also an emphasis on the importance of other types of relationships, including peer relations.

According to the independent living model, change occurs both at the individual’s and social levels through empowering and giving control to vulnerable peoples. Forster (2007) stipulates that empowerment is achieved through “assessments… based on the needs of the client rather than eligibility criteria… giving clients increased control, choice and flexibility with regard to how health and social needs are met” (p. 19). Decisions and plans are made “with, rather than for, the service user” (Forster, 2007, p. 19). Social change occurs in the form of the removal of financial and social barriers to housing, transportation, work and participation in civil life (Forster, 2007). Individual change is promoted simultaneously through strategies that aim to increase the ability of individuals to function independently while increasing their access to human and civil rights (Forster, 2007, p. 20).

The third rehabilitation model of service delivery put forward by Forster (2007) is the **community-based model**, a “response to prescriptive, paternalistic and institutionalized approaches that have dominated service delivery in the past” (p. 20). The history of care of persons with mental illness and those with intellectual disabilities reflects this model, as seen in the move away from institutional care beginning in the 1960s in many countries such as Canada, the United States and Italy, toward community-based care involving re-insertion of individuals who had long been isolated in institutions back into the larger community (Davis, 2006; Fierlbeck, 2011; Latimer, 2005; Lemay, 2009; Dumont & Dumont, 2008; Preti et al., 2009). This form of care was seen as cost efficient for governments whose mental health spending decreased significantly. Indeed, the cost of community-based care fell increasingly on the shoulders of individuals themselves, families and women in particular (Cushing, 2003b; Escrader, 2008; Laing, 1966; Fierlbeck, 2011).

According to Forster (2007), this form of care originates in developing nations where problems are seen as the outcome of social attitudes, structures and processes, hence external to individuals. Forster (2007) argues that the goal of community-based rehabilitation for persons with intellectual disabilities is an increase in participation of persons in their respective communities. This is said to occur through the development of job skills and employability as well as the equalization of opportunity for social integration (Forster, 2007).

Furthermore, the community is encouraged to take ownership of the services that are provided to individuals with intellectual disabilities. This model thus relies on the involvement of both the individual – "who is expected to be a motivated, active and responsible member of his/her family and larger community" (Forster, 2007, p. 20) – as well as the family and the larger community. The recipient of care is as such defined broadly in order to include all members of the community.

The community-based care model stipulates that the relationship between the caregiver and the recipient of care is one of collaboration where both are expected to actively partake in goal setting and decision-making. Change is understood to occur through community development strategies including "developing, mobilizing and maintaining local and natural support systems and resources" (Forster, 2007, p. 21). Change hence begins when individuals and families utilize and integrate the suggested strategies, and is optimized when community members take ownership and leadership roles within the provided services (Forster, 2007).

Fourth and lastly, the **client-centered model** of rehabilitation defines the problem yet another way. According to this model, the process of defining the problem to be addressed itself is in the hands of clients who require the input of caregivers, such as persons with intellectual disabilities. Forster (2007) states: "the model recognizes that individuals living with disabilities experience a range of issues as they adjust to living with a disability and therefore… a range of problems" as well (p. 21). This differs a great deal from the biomedical model which views all individuals with the same impairment or illness as fundamentally the same. The client-centered model places the emphasis on "deciding what goals [of treatments or rehabilitation] should look like" (Forster, 2007, p. 21). Forster (2007) asserts that “goals should be based on outcomes which are meaningful to the client” (p. 22) as opposed to being motivated by abstract goals of care defined impersonally by those in the caregiving field. The client-centered model is concerned with the fair distribution of power between the caregiver and the recipient of care. For caregivers and healthcare professionals, this involves “active listening” as well as the integration of the “perspectives and needs of the client into all aspects of clinical decision-making” (Forster, 2007, p. 22). The role of the caregiver and healthcare professional is that of a “collaborative partner” who provides unconditional positive regard, acceptance or empathetic attitude toward the client’s worldview as well as congruence or attentiveness during clinical interactions. The relationship is hence non-directive and supportive while allowing clients full freedom in decision-making.

In her thesis, Forster (2007) argues that the client-centered model is influenced by the counseling genre of Carl Rogers. In this model, “individuals possess an innate ability to understand themselves and, given the right circumstances, to make the right choices about their situation” (Forster, 2007, p. 22). According to this model, “change occurs as individuals define their needs, develop plans to have their needs met and then, successfully meet these needs” (Forster, 2007, p. 23). In other words, change is described as self actualization – an internal rather than external process. In this way, clients shed the role of passive recipients of care in order to become actively involved in the healing process.

2.2.3 The mutual care model

The aforementioned care models operationalized in public and private settings are based on the establishment and reinforcement of a unidirectional relation in which the caregiver has power over the recipient of care. These models are inadequate because they fail to address and challenge the fundamental power relationship expected to be experienced and reproduced between those related by care. Instead, these models assume a power differential and thus foster “domination rather than caring” while ignoring the possibility of reciprocal care or partnership (Kittay, 2001, p. 576). Consequently, relationships tend to be inadequate for caregivers, who may experience dissatisfaction, burnout, or health risks caused by their role (Essex & Hong, 2005; Forster, 2007;, Hoyert & Seltzer, 1992; Jeglic et al., 2005; Lin et al., 2012; Vitaliano et al., 2004), as well as for the recipients of care who are deprived of agency and forms of autonomy (Illich, 2003; Taussig, 1980).

In contrast, a care model elaborated by Horwitz, Reinhard and Howell (1996) that differentiates itself from other models by identifying caregiving “as a process of mutual exchange” (p. 149). This model was first elaborated from a study examining the relationships of people with disabilities with their aging parents as they negotiated the parents’ growing needs (p. 149). The study highlights the awareness of people with disabilities of their parents’ growing needs and identifies the ways in which they subsequently take on additional responsibilities. Inspired by Horwitz et al. (1996), other studies have focused on mutually caring relationships between parents and their children among Dutch and immigrant families in the Netherlands (Komter & Schans, 2008), between a chronically ill patient with multiple sclerosis and her healthcare providers (Oeseburg & Abma, 2006), between people with intellectual disabilities and their elderly parents in Britain (Williams & Robinson, 2001), between elderly persons and their informal caregivers including family members and home helpers in Denmark (Lewinter, 2003), and between people with Alzheimer’s disease and those who care for and about them (Graham & Bassett, 2005). Most of these studies focus either on individual cases of relationships of care to demonstrate mutual care or reciprocal relationships within the private context of the home where care interactions tend to be driven by family ties.

It is noteworthy that unlike with private interactions, the mutual care model has been studied relatively little with respect to its counterparts in institutional or public settings where it is operationalized infrequently, if at all. One of the first applications of this model in the public setting is mutual care at L'Arche. L'Arche, in fact, became one of the first and primary loci of study of this unique model of care with John Sumarah's (1987a; 1987b) work on the importance of mutual relationships involving reciprocity among equal partners. According to Sumarah (1987b), mutual caregiving relationships at L'Arche are based on a philosophy of interdependence.

Forster (2007) also attempts to theorize the model of care seen in Vanier's L'Arche. She states that personal interactions between healthcare professionals and clients are a part of the therapeutic environment. Co-operation rather than independence is encouraged through shared leadership, while an emphasis is placed on self development and growth of persons with and without intellectual disabilities. The clinical work hence takes into account the needs of both members while encouraging power negotiations among caregiving partners (Cushing & Lewis, 2002).

In her work, Cushing (2003a) systematically outlines what she observes to be the six guiding principles of mutual relationships at L'Arche. First, L'Arche maintains that successful mutuality is general and specific (Cushing, 2003a, p. 88). In other words, mutuality is at once an approach to all relationships among community members while being recognized as upheld "in the particulars of particular relationship" (Cushing, 2003a, p. 88).

Second, Cushing (2003a) argues that an instrumental motive – persons with intellectual disabilities need assistance – serves as the basis of relationships between persons with and without intellectual disabilities, despite not always defining the entirety of these relations. Third, L'Arche recognizes the inherent value of the process involved in building relationships rather than emphasizing the outcome of said relationships. The fourth guiding principle of mutual relationships at L'Arche is recognition of reciprocity as gifts in quality rather than in kind, while the fifth principle outlines the need for moral, spiritual and political solidarity of caregivers with the marginalized people with whom they live (Cushing 2003a). Finally, mutual relationships at L'Arche are distinct from caregiving labour that is inherent asymmetrical in nature. According to Cushing (2003a), caregiving labour and mutual relationships are not to be confounded.

2.3 The Italian context

2.3.1 Italian social and cultural characteristics

Italy is a country located in the southern-most part of Europe with a population of over 60 million people. In the North, the Alps form a natural border with surrounding countries including France, Switzerland, Austria and Slovenia. Italy is constituted of a famous boot-shaped peninsula extending over 800 kilometers, and several islands including Sicily and Sardinia situated in the Mediterranean Sea. Italy was unified in Antiquity and was subsequently divided into city-states, duchies and kingdoms which remained rivals until the mid nineteenth century. Its definitive unification took place in 1861.

Despite trends toward globalization, Italy has preserved many distinctive social and cultural features. Several of these are worth discussing in further detail as they become important in some of my fieldwork observations. In this section and throughout the remainder of the thesis, I make reference to Italian culture in the sense of culture that Antonio Gramsci proposes. Kate Crehan (2011) describes Gramsci's definition of culture as follows:

> A shared way of being and living, which has come into existence as a result of the interaction of myriad historical forces, and that remains subject to history. Cultures for Gramsci, while they may seem to persist for long periods of time, are always also in flux, coming into being, undergoing transformation, passing away. (p. 276)

The Italian cultural and social features which will be highlighted here include the brand of Italian Catholicism; language; regionalism versus nationalism evidenced in the north-south divide, the nature of Italian politics, food, health, the economy, and 'Italianness' through othering, or racism; and cynicism. In the following section, I will briefly describe each of these as well as delve into the chronic problems that have played a central role in shaping the country's cynic populace.

First, **Catholicism** in Italy is widespread, and its distinctive Italian features are numerous and recurrent (Garelli, 2007, p. 2). Ethnologist Erick Castellanos (2010) describes the importance of Catholicism in Italy. He observes: “There is no denying the pervasiveness of the Catholic Church in everyday life in Italy. Whether people are believers, whether they practice, or whether they reject Catholicism, the Church impacts their lives” (Castellanos, 2010, p. 75). He goes on to describe the significance of the Catholic Church in various aspects of life. An example demonstrating the pervasiveness of its influence is the presence of churches in towns and cities of all sizes throughout the country and the association of a patron saint to each neighbourhood (Castellanos, 2010, p. 75-76). Despite having undergone state secularization, close ties still exist between the Catholic church and the Italian state and what Franco Garelli (2007) calls a “direct relationship between church and political parties on behalf of Catholic values and interests” (p. 6). In fact, Garelli (2007) goes on to point out that recent popes have praised the ‘exemplary’ nature of Italian Catholicism which is “held up as a model of the church-state relations best suited to reawaken the consciences of Christians throughout Europe and the world” (p. 4).

Second, the at once unifying nature of the Italian **language** and divisive quality it holds as it competes with local dialects is especially poignant in intergenerational and inter-regional encounters. The language now known as Standard Italian originates from archaic Tuscan that “had evolved as a prestige language… used for literary purposes and by elites” (Griffiths, 2010, p. 182). Following the country’s unification, Standard Italian became the official language; it has been taught in schools throughout the country and has been used in official documents since that time. Despite the frequency of this language’s usage particularly in northern regions and by younger generations of Italians, Castellanos (2010) notes that “Italian dialects have [nevertheless] been resilient” (p. 74); local dialects are shared by citizens whose regional affiliations are strong. Castellanos (2010) concludes that locality and dialect are intrinsically linked.

Castellanos’ aforementioned observation is related to a third characteristic of note, namely the emphasis on **regionalism** at the cost of nationalism, or local versus national affiliations. Castellanos (2010) remarks that Italians often prefer to associate with the local rather than align themselves with the nation hence identifying as *Romani* (Rome), *Bergamaschi* (Bergamasco), or *Napolitani* (Naples) rather than Italian (p. 68). Castellanos (2010) points to attitudes surrounding and use of language, politics, and food, among others, to demonstrate this phenomenon. For example, regional differences are reflected in linguistic variants mentioned above. Interestingly, Castellanos (2010) also links the rise and triumph of regionally affiliated political parties such as Lega Nord to the favoring of a regional sense of belonging over a national one. Castellanos (2010) affirms that “Without understanding the local and national dynamics of how a sense of community is created and sustained, it is difficult to discern the complex and often chaotic nature of Italian politics” (p. 77). The emphasis on regional ties is further supported by academics including Elizabeth Whitacker (2003), Paolo Malanima and Vera Zamagni (2010), and Elizabeth Krause (2001) who identify regional differences in areas of life such as perceptions of disease and health.

Regional differences are also observable in economic trends in various parts of the country. Malanima and Zamagni (2010) observe that the Italian economy is marked by this north-south divide along which disparities are structured. This is distinct from the mapping of disparities in other European countries regions where a north-south axis does not tend to characterize disparities in the same way. Malanima and Zamagni (2010) state: “The poorest regions in Italy, as from the end of the nineteenth century, have been located in the south" (p. 9). This is still true today, at a time when the economic and political precariousness of the country has reached a recent high.

Regionalism, though not inherently bad, has also lead to the stereotyping of the various Italian regions along this boot-shaped peninsula. The country's pre-unification division into three distinct realities, namely the north with Nordic influences, central Italy – or the pontifical state – and southern Italy with its North-African influences (Silverman, 1967), is in many ways still a social and cultural reality today. The stereotypes associated with these realities are also prevalent despite unification. Castellanos (2010) maintains that

> While each region has its own stereotype, the most striking division and the most widely believed stereotypes are those that run the north-south divide. The negative images of the south (…) have significantly impacted the public imagination. (p. 70)

Forms of othering through "racially-based social hierarchies" result from these perceived differences. These stereotypes are also highlighted in the media and espoused in moments of encounter between Italians from different parts of the country (Krause, 2001, p. 596).

2.3.2 Italian cynicism

One feature that plays on all of the aforementioned socio-cultural features is the cynicism of Italian citizens. Though there are various forms of cynicism as well as multiple causes, I here refer to social cynicism specifically which is characterized by a "negative view of people, a bias against some social groups, a mistrust of social institutions, and a disregard of ethical ways for achieving ends" (Li & Leung, 2011, p. 718). According to social psychologists Fuli Li and Kwok Leung (2011) and in line with the psychological contract framework, this negative perception of others, social groups and institutions is the result of a breached contract with society. Li and Leung (2011) argue that such a breach of psychological contract involves the perception of unmet obligations by the other party (p. 720). For socially cynical people, unmet obligations include "perceived undesirable societal conditions" such as a recession or elevated rates of unemployment (p. 720). Li and Leung (2011) maintain that people who frame societal conditions as undesirable are prone to perceive others as malevolent and social groups and institutions as deceitful.

Authors such as Andrea Mammone and Giuseppe Veltri (2008) attribute the cynical – or 'depressed' – state of Italian citizens to longstanding and unresolved national problems that are perceived by them as undesirable. In this section, I will explore the causes of Italian social cynicism including national problems such as the current dismal condition of Italian economic affairs, a poor national identity, growing inequalities between regions of northern and southern Italy stemming from deep regional divisions, a lack of political stability, and the presence of dramatic organized crime in addition to widespread corruption at multiple levels of society including the state and Catholic Church.

First, the Italian economic situation plays a central role in shaping the country's current cynical shadow. In an overview of the past 150 years, Malanima and Zamagni (2010) maintain that the economy – beginning in the second half of the 1990s – lags when compared to international standards. Others, including Mammone and Veltri (2008), support this claim by pointing to the numerous scholarly works that frame Italy's decline as an "incapacity of Italian capitalism to face the challenges of globalization" (p. 298). Today, the effects of such a lagging economic system are evident in elevated rates of youth unemployment and a growing national debt to the European Union. Not for the first time in recent history, Italy faces a situation in which there is much apprehension surrounding the nation's ability to reverse or regain important economic losses without seeing a state similar to that of their European counterparts such as Greece and Spain.

The struggling Italian economy fails to fully account for the persistent fatigue that markedly afflicts the Italian populace (Mammone & Veltri, 2008, p. 298). Instead, Mammone and Veltri (2008) insist that "chronic problems... which have never been seriously faced by Italian society and politics" are at the root of the 'depressed' state of citizens and the "diffuse awareness of political, economic and social decline [that] has spread throughout the... public sphere" (p. 298). One of the contributing longstanding difficulties is the country's "weak national identity" (Castellanos, 2010, p. 61) despite a heavy emphasis by government on *federalismo*, or federalism, that has long been presented as the answer to complex problems (Mammone & Veltri, 2008, p. 301). Castellanos (2010) argues that the perception of a fragmented Italian identity contrasts vividly with the perceived unity of the French and cohesion of the idealized German nation by Italians. He rightly adds that given the "instability, fragmentation and incapacity of identifying common national interests" of the Italian political system (Mammone & Veltri, 2008, p. 301), this process of nation construction through shared histories has been slow and inefficient (Castellanos, 2010). If national identity is understood to represent the image of the collective Italian 'self,' the effects of a slow and inefficient process of national federalization has invariably lead to a depressed or negative self-image. This sense of incoherence is especially stark when Italians compare themselves to the self-narratives ascribed to Germans and French.

A second chronic problem involves the growing inequalities between the country's northern and southern regions. Castellanos (2010) claims: "even before the erosion of national sovereignty, Italy wallowed in a negative self-image and deep regional divisions...

divided not only between north and south, but also into micro-communities over the whole country" (p. 61-62). For example, the pessimistic images of the south as in a constant state of emergency contribute to its negative portrayal in the media and significant divisions among Italian citizens. The disagreements or misunderstandings that result from such divisions are especially noticeable in moments of encounter when Italians from different regions diverge in their approaches to food preparation, driving methods, pronunciation of shared vocabulary, or cultural, social and historical reference points, to name a few. Once again, the lack of a collective experience and the significant divides running along a north-south axis contribute to a deep sense of division and a negative self-image of individuals particularly southern Italians. This negative valuation of themselves and other Italians subsequently inspires cynical attitudes and creates a national cynical paradigm.

A third chronic problem in addition to a weak sense of nationhood and deep regional divisions is a lack of political stability. Malanima and Zamagni (2010) suggest that a part of the larger problem of political fragmentation stems from slow, inefficient and often corrupt Italian public administration. They state that "the Italian public administration has become a real burden to the system, contributing to its overall loss of productivity and making the Italian welfare system costly and unsatisfactory" (Malanima and Zamagni, 2010, p. 17). Corruption of government members epitomized by the three-term Prime Minister and media tycoon Silvio Berlusconi also contributes to the ineffectiveness of the administration system (Ruggiero, 1994).

In addition to these rather practical problems, Mammone and Veltri (2008) also point to a failure by Italians to deeply engage in issues often discussed in public discourse. This failure results in a shared sense of unrest due to "the lack of planning.... [and] the general tendency of starting and never finishing important reforms and changes" (Mammone & Veltri, 2008, p. 302). They state: there is "a common theme of incompleteness in the attempts at applying a solution" to problems including "the lack of political reconciliation" among "quarrelling parties" and "unstable governmental coalitions" (Mammone & Veltri, 2008, p.297-298). For this reason, anthropologists, outside observers, and Italians themselves recently observe a growing "mistrust of government" among Italian people (Whitacker, 2003, p. 361). Castellanos (2010) additionally suggests that the emergence of movements across Europe that challenge the legitimacy of the central government is yet another outcome of such political fragmentation. As a consequence, Italians fail to view themselves as represented by national political authority figures, which paradoxically often leads to their misrepresentation.

Lastly, the presence of dramatic organized crime and widespread corruption in public life remains a chronic problem in Italy (Mammone & Veltri, 2008; Ruggiero, 1994). Ranging from small favours for family acquaintances to monopolies of entire industries such as the media, corruption in Italy has long been a way of life. In fact, faith in 'the system' is a rare find among Italians. Castellanos (2010) argues that "the negativity in Italian national culture is the ideological expression of self-critical individuals who tend to recognize its vices" (p. 68). In order to navigate corruption at various levels of society, many Italians feel that it is justifiable to take part in it to a certain degree in order to maintain their quality of life. Vincenzo Ruggiero (1994) sustains that corruption in Italy "entails participation of diverse social groups, and that this characteristic makes its reproduction possible, while affecting the way corruption in general is perceived" (p. 333). As a consequence, Italian rules and regulations tend to be implemented and respected at the individual's convenience rather than viewed as a general code of conduct.

2.3.3 Mental health care in Italy

Italy, as has been mentioned previously, is at once very much influenced by trends in other so-called Western countries such as Canada, the United States, and France, while remaining distinct in many ways. This is also true of the history and evolution of attitudes toward persons with intellectual disabilities throughout the twentieth century. Though the following is brief and risks underestimating the rich history that has brought about systemic change, I now outline the history of mental health care in Italy in order to contextualize the current state of care of persons with intellectual disabilities.

While mental illness and intellectual disability are not the same biologically and socially, the history of mental healthcare is shared by individuals with intellectual disabilities and those with mental illness who, for a better part of the past century, have been provided similar care. Many people with intellectual disabilities do indeed have some form of mental illness, though this is not the case for all people. Moreover, change in Italy, as in most places, has not happened uniformly or at the same rate in all geographic areas. Care is not provided in the same way by all communities, agencies and individuals. Hence, the generalized history of Italian mental health care cannot be said to encompass the experiences of all those affected by it.

Colin Pottie (2001) outlines the history and evolution of attitudes toward persons with disabilities in the twentieth century in his thesis dissertation. He states that the turn of the century was characterized by the rise of Darwinism, a theory that stipulates that the survival of the fittest is the governing law of evolution and the driving force of change. In this framework, and with the predominance of Descartes' rationalism, weak persons, such as those with intellectual disabilities, did not have a place in society (Pottie, 2001). In addition to Darwin's theory of evolution, the turn of the century was also characterized by the presupposition that rehabilitation and training was possible for persons with disabilities. These trends in thinking and other factors including a desire to create a more humane living situation for persons with mental illness and for persons with disabilities brought about the construction of institutions in many countries including Italy.

The 1904 Law in Italy led to the creation of the Italian asylum system, which would remain prominent for the first half of the twentieth century (Dumont & Dumont, 2008). Despite the aforementioned intention to make institutions humane care facilities, there were other important social promises involved in the isolation of mentally ill persons. Among the most significant in Italy was a commitment to the defense of society *from* those housed in the institutions – or *pericolosità* (Dumont & Dumont, 2008, p. 64). Mentally ill persons "created a sense of fear and alarm" (Bettoni & Benigni, 2009, p. 20). For this reason, institutions remained a place where abuse and physical restraint were permitted for the 'greater good' of Italian society. By the end of the 1950s, following the Second World War, critiques of psychiatry began to surface in intellectual circles including those frequented by Franco Basaglia (& and Dumont, 2008). Basaglia, now known as the father of psychiatric reform in Italy, soon left the academic world in order to become the director of an asylum in Gorizia, situated in Northern Italy near the border with Yugoslavia. There, he began a wider social movement along with the support of other doctors, nurses, and students toward deinstitutionalization (Dumont & Dumont, 2008). Basaglia was hence the "detonator for a movement already simmering" (Dumont & Dumont, 2008, p. 64). His resignation from Gorizia and subsequent move into psychiatric institutions elsewhere in Italy coincided with the creation of diasporas of reformers throughout various Northern Italian cities and towns, particularly relatively small cities.

After many years of instigating bottom-up reform in Italy, Basaglia was asked in 1978 to take part in shaping legislation that eventually resulted in Law 180; Law 180 served to overturn Italy's previous commitment to *pericolosità*, and affirmed the broader social movement that had gained prominence since the 1950s (Dumont & Dumont, 2008, p. 68). Authors such as Enrico Garaci (2009) affirm that "this law represented both a cultural and medical revolution in the practice of psychiatry" founding itself on goals including the preservation of dignity of mentally ill persons and the recognition and protection of their rights (p. 4). The new law mandated a gradual transfer of mental hospital patients to a network of community-based services (Dumont & Dumont, 2008). The new community care system authorized by Law 180 was intended to stand alone; Italy hence "became the first developed country to base its mental health care solely on a community network of mental health facilities" (Lora, 2009, p. 5). The definitive closure of all Italian mental hospitals took place in the late 1990s (Lora, 2009). Despite the death of Basaglia shortly after the creation of the legislation and the subsequent dissipation of the energy behind the reform movement, many have suggested that Italy was successful in phasing out all of the former mental hospitals through Law 180 (Dumont & Dumont, 2009; Preti et al., 2009). The Italian reform law has also had a far-reaching international impact. Observers such as Antonio Maone and Elisabetta Rossi (2003) claim that the quality of the services should be evaluated in relation to the care of people who suffer from severe and persistent mental illness, a measurement which would indicate that change in Italy has only begun (Bersani, 2009; Preti et al., 2009).

2.4 Historical review of L'Arche

2.4.1 A brief history of L'Arche

As large scale changes such as deinstitutionalization occurred in various parts of the world in the 1960s, a small movement prompted by Jean Vanier, son of the Canadian Governor General George Vanier, began to occur in the rural French village of Trosly-Breuil (Pottie, 2001; Spink, 2006; Vanier, 2007). There, Vanier invited two formerly institutionalized men Rafael Simi and Philippe Seux to live with him in a home (Spink, 2006; Vanier, 2007). Vanier's approach to care of persons with intellectual disabilities was initially rooted in the Christian Beatitudes (Appendix G; Currie, 2005; Cushing, 2003), and provides to this day a viable alternative to the institutional care approach. Vanier named the house L'Arche, 'the ark' in French, after the Biblical story of Noah's Ark, in the hope that the community would "provide a refuge for people with (sic) mental handicaps, who can so quickly be drowned in the waters of our competitive society" (Vanier, 1997, p. ix; Cushing, 2003b). L'Arche was a place where diversity was accepted and valued, a place where difference or what may be judged as weakness could be the source of life and of growth. Today, the L'Arche movement has grown and expanded to include 137 communities in 40 countries around the world (L'Arche, n.d.; Escrader, 2008). Though L'Arche is often equated with Vanier, a historical review such as the one provided by Cushing (2003b) highlights the fact that "Vanier's vision was nourished by several people during a long and rich developmental period" (p. 110).

L'Arche is an intentional community where a group of people are associated together for the purpose of establishing a whole way of life collectively in homes (Dunne, 1986; Elkins, 2008). Academic and L'Arche member Joe Egan (1987) who is cited in Caroline

Currie's (2005) work outlines the following three key elements of L'Arche communities: geographic proximity, economic sharing and common vision. Each of these characterizes L'Arche communities around the world. All individual L'Arche communities consist of a home or a collection of homes where people with and without intellectual disabilities live together and develop personal relationships with the community's other members. Some, such as Sonya Evelyn Brown (2003), have concluded that L'Arche is a collective of people who share similar ways of being and living: L'Arche is a culture in the Gramscian sense.

Anthropologist Anna Tsing (1993) reminds us that, contrary to many dated anthropological accounts of communities, it is necessary to refrain from understanding communities as "homogeneous form[s] of consciousness" (p. 8). Instead, she notes that it is important to listen for "shifting multistranded conversations in which there never [is] full agreement," hence challenging the idea that belonging to community self-generates solidarity and group cohesion (Tsing, 1993, p. 8). L'Arche does have theoretical ideals by which it hopes to abide in daily life, as made explicit in the organization's Mission and Identity Statements, as well as its Charter (Appendices H and G). Tsing's (1993) caution is relevant in that the interpretations and applications of the L'Arche principles vary among individual members who, together, form communities in constant transformation and subject to history in various parts of the world.

2.4.2 The mission and philosophy of L'Arche

The vision of L'Arche is to create a community where core members – persons with intellectual disabilities – and assistants or administrators are encouraged to mutually support one another while striving to respond to each other's needs (L'Arche, n.d.). L'Arche is a semi-closed community whose members engage in a lifestyle and in many cases a lifelong endeavour of care. According to Cushing (2003b), "L'Arche is both an intentional faith community and a caregiving organization for people with intellectual disabilities" (p. 110). John Dunne (1986) describes what happens at L'Arche in the following way: "In L'Arche, community is not just for or with, but essentially *through* the (sic) retarded members" (p. 43). Furthermore, the values of reciprocity, mutuality and vulnerability are deemed central to both the community narrative and the type of care experienced by community members (Bowling, 2006).

On the L'Arche International website, a L'Arche community is described as consisting of four essential components: mutual relationships, spirituality, know-how and community life (L'Arche, n.d.). Mutual relationships between persons with and without intellectual disabilities that "foster the acceptance of each person as a unique and valuable individual, whatever his or her abilities or disabilities" are at the heart of L'Arche communities (L'Arche, n.d.). In these relationships members "treat each other as of equal value" (L'Arche, n.d.). Spirituality is also central in communities which are respectful of the diversity of faith traditions and "seek to support members to deepen in their own faith experience and values, whether they situate themselves within or outside a religious affiliation" (L'Arche, n.d.). L'Arche was initially founded in the Roman Catholic tradition and has since come to incorporate the various cultural and religious backgrounds of its members throughout the world. A third important quality of L'Arche communities is know-how, which comes from "more than 40 years of experience and cooperative work with doctors, psychologists, social workers and other professionals" that "have enabled L'Arche communities to develop strong competencies and a high standard of quality in the field of care-giving" (L'Arche, n.d.). Lastly, community life emphasizes the capacities of all of its members to give, learn, and achieve. According to the vision of L'Arche, "all members of the community are responsible for the group's well-being, be it at home, in a workshop or a day program, through cooking or washing up, through a helping hand, a smile or a joke" (L'Arche, n.d.).

In sum, L'Arche's focus on mutual relationships, spirituality, know-how and community life have allowed it to flourish in various parts of the world while providing a radical alternative to dominant healthcare models and an example of a thriving intentional community. Cushing (2003) characterizes the Charter of the Communities of L'Arche (Appendix G) and the international organization's Mission and Identity Statements (Appendix H) as examples of "radical insights." She further explains:

> 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 [Vanier's spiritual leader] Père Thomas and especially through the spiritual vision and leadership of Jean Vanier. (p. 125)

2.4.3 The mutual care model at l'Arche

L'Arche operationalizes the mutual care model (Bowling, 2006; Cushing, 2003a; 2003b; Cushing & Lewis, 2002; Forster, 2007). In everyday life, dominated by L'Arche's ethic of care, members are encouraged to understand needs as universal, to counter current care models by being invited to accept care and encouraging the conventional recipients to care to provide it (Bowling, 2006). Contrary to traditional models, people's experience of care is dictated by reciprocity rather than by power. The mutual care model of L'Arche is in line with Michael Taussig's (1980) vision of care, as he poignantly states in his striking application of the concept of reification that "in so far as health care is provided, both patient and healer are providing it" (p. 10). The model serves as a direct critique of Arthur Kleinman's (1988) exercise of the "patient's definition of the problem" to "better control" the patient's experience (p. 13). Because care is central to the lives of persons involved in L'Arche, they are able to deconstruct previous identities as powerful or powerless, and are empowered to reconstruct new ones based on redefined agency, shared responsibility, and dependency on the other (Sökefeld, 2001, p. 530).

Despite its positive implications this model, like any other, is not without its challenges. Some of these include the dual task of fulfilling community responsibilities while remaining accountable to statutory services, a move toward person-centered care in opposition to community-centered care, and stress or exhaustion due to "difficult, intense relationships" (Vanier, 2004, p.101-102). The overwhelmingly positive representations of L'Arche by both insider and outsider scholars have been problematized by authors such as Cushing (2003a) who states that though the L'Arche model is indeed unique in its content and application, "mutuality in care also has costs" (p. 86). Furthermore, though each L'Arche community adheres to the L'Arche approach of mutual relationships and shared decision-making, it would be faulty to assume that these qualities have not changed over time nor been shaped by the cultural contexts particular to those individual L'Arche communities. In fact, Cushing (2003a) argues that these principles have been promoted without a clear understanding of how their meanings have evolved over time. This trend is problematic because L'Arche unity is largely due to self-narrative rather than individual community similarity. In other words, L'Arche communities experience difficulties in applying these principles when past examples of successful operationalizations do not work in their contexts, and so are faced with reinterpreting the practical applications in every community.

In light of observations of this care model, the goal of my study will be to interpret the significance, value, and consequences of the institutional practice of mutual care and its implication in the lives of those who live L’Arche in Rome.

3.0 RESEARCH METHODOLOGY

3.1 Theoretical framework

Like anthropologists before me, I am interested in the study of humanity and more specifically in the forms human ways of life take, the reasons they take on these forms, and the meaning those engaged in them draw from conducting them in this way (Welsch & Endicott, 2006; Bailey, 2007). The type of qualitative research I conducted for this project was interpretive in nature, premised on the "ontological belief (…) that there is no objective social reality but instead multiple realities" (Bailey, 2007, p. 53). I hence made close observations of social relationships while looking at the ways in which individual members navigated and fashioned their social environments.

Within the broader anthropological discipline, my research aligns itself with the subfields of social and cultural anthropology, characterized by ethnographic fieldwork as a primary means of data collection (Amit, 2000). As Vered Amit (2000), who writes about ethnographic fieldwork, notes "Much as fieldwork is the most commonly cited defining criteria of anthropology, intensive participant observation in turn is frequently treated as defining anthropological fieldwork" (p. 1): indeed, I utilized participant observation, in addition to various other methods including archival work and interviews, as my primary tool method of inquiry. Because most of the people I worked with at L'Arche did not make use of language, participant observation was an essential tool for communicating with and understanding the lived experiences of care of persons with intellectual disabilities at L'Arche. As noted by Amit (2000), "the strength of participant observation is the access it provides to lived experiences which incorporate but transcend language" (p. 12). This aspect of anthropological work was essential to my research.

The ethnographic fieldwork I undertook incorporated travel away from my ordinary place of residence or 'home' in Montreal to a 'field site' in Rome, Italy (Amit, 2000). In this sense, my research fits the description of traditional anthropological fieldwork. However, the seemingly obvious distinction between my field site and home is quickly problematized by my previous experience living and making a home for myself in Northern Italy while only having lived in Montreal less than a year at the time of my fieldwork. Furthermore, L'Arche was at once for me an old and new undertaking: my family's involvement with L'Arche in Canada rendered the reality of community life familiar while introducing an entirely new dimension – the international one – to my knowledge of the organization. Though I had an extensive knowledge of Italian prior to my arrival in Rome, I lacked many of the colloquial Roman and dialectal expressions. I also lacked technical terms to express some of the theoretical concepts I was grappling with at the time. Moreover, despite knowledge of both English and Italian, translation of social or cultural references was at times challenging.

Ethnography is at once my empirical approach to research in the field and the product of my research itself in the form of this dissertation (Jackson, 2008, p. 667; Marcus & Cushman, 1982). In this thesis, I focus my attention on the lived experiences of members of the L'Arche community of *Il Chicco*. Though the narratives and analyses are largely separate in this work, they are not mutually exclusive (Eriksen, 2006) nor are personal experiences distinct from theory (Jackson, 1989). Instead, the theories that I discuss relating to disability, communication, care and community are grounded in the experiences that community members and I relay orally or through actions, and states of being described throughout the vignettes. The primary theories that serve to illuminate or illustrate the trends that I noted during my fieldwork will be briefly discussed below. These theories form the basis of the theoretical framework with which I approach the experiences of people with and without intellectual disabilities at L'Arche.

3.1.1 Disability

My approach to disability begins with social and cultural theories of disability construction. These theories are reflected primarily in the works of first person disability theorists such as Kasnitz and Shuttleworth (2001) and Wolbring (Cushing, 2003a; 2003b) who recognize the handicapping aspects of disability as a product of deeply rooted social and cultural views. These authors also affirm that disability stands in reference to ability. I refer to these theories primarily in an attempt to challenge the negative constructions of disability and the realities to which those constructions limit people. My effort to highlight faulty reasoning involved in dominant constructions is meant to provoke a shift in actual circumstances, including knocking down some of the barriers that prevent people with intellectual disabilities from partaking fully in social life. I am also motivated by a belief in the possibility of changing realities through changing minds. Intellectual disability, when not viewed as a negative and all-consuming attribute of persons, can become less handicapping with a shift in perception by members of society.

Such a shift in perception with regards to physical disability has already begun to take place. Significant gains including surmounting some environmental and attitudinal barriers have been attained by disability theorists and activists who note important changes like newly accessible public places to persons in wheel chairs or the visually impaired. Thanks to physical environmental changes such as the construction of ramps and elevators, people with restricted mobility who make use of wheel chairs or whose gait is impeded have greater access to opportunities they are able and ready to take advantage of. Their disabilities hence become less handicapping and they are able to participate more fully and effectively in society on an equal basis with others (UN Economic and Social Council, 2006). Advances such as these are significant, though limited to people with physical disabilities.

In the case of intellectual disabilities, on the other hand, social and cultural theories do not suffice because they do not propose ways of accessing full inclusion to a person who is incapable of being self-sufficient and of making independent and autonomous choices. Social and cultural theories of disability construction must instead be supplemented by a critique of the poor socio-cultural value associated with dependency. Here, I make use of Kittay's (2001; 2011; Kittay, Jennings & Wasunna, 2005) argument against the overvaluation of independence. Kittay (2001; 2011) argues that dependency should not be viewed as problematic; rather dependence on others must be recognized as a quality of life – or of periods of time – for all members of society. Kittay (2001) maintains that the goals of care should change in order to include people with intellectual disabilities. She thus proposes that the goals of care be replaced with interdependence and cooperation.

3.1.2 Communication

Because communication is so vital in relationships of all types, it is important for me to clarify the framework within which I operate when I refer to it. Anthropologist John Jackson (2008) notes that cultural anthropologists variously understand communication in one of the three following ways: "as the transmission of information, as mediations at the kernel of subjectivity and sociality, or as the intersubjective grounding for any and all claims to psychological or social reality” (p. 665). In this thesis, I initially make reference to the first interpretation including a series of messages – whether verbal or nonverbal – that are sent by someone with intention and/or perceived by a receiver as meaningful (Brown, 2003, p. 15). Messages may take on various forms and are often communicated more successfully when they involve engagement of multiple sensory channels (Howes, 2003; Howes & Classen, 1991). The forms and channels become particularly relevant when attempting to represent communication between people with and without intellectual disabilities.

I also make reference to the second and third definitions proposed by Jackson (2008). Here, communication is the series of negotiations that form the base of human subjectivity and sociality as well as the grounds upon which communicating partners can reach agreement regarding psychological or social reality. However, my standpoint involves a further step: communication does not guarantee understanding or comprehension in the conventional sense as a necessary outcome. By this, I mean that understanding does not involve intellectual beholding of facts or ‘truth’ about what has been communicated (Jackson, 1989, p. 15). Instead, understanding – or knowledge claims as a result of verbal and nonverbal interactions – is “created” and “caused” by those who engage (Meyer, 2001, p. 109-110). In this sense, knowledge involves “being-together-with” the one with whom one communicates in a shared moment of lived-experience (Jackson, 1989, p. 8).

3.1.3 Care

Much has been written on care in various settings including rehabilitative and long-term living settings such as L’Arche (Cushing, 2003; Cushing & Lewis, 2002; Engster, 2005;

Held, 2005; Horwitz et al., 1996; Lapierre & Hunter, 1989; Lin et al., 2012; Taussig, 1980; Vitalino et al., 2004). For many theorists, care is defined as a set of practices alone while others, including Engster (2005), Cushing (2003b), Held (2005) and Kittay (2001; 2011; Kittay, Jennings & Wasunna, 2005), add that it must also be understood to be a value or moral principle. In my research project, I chose to align myself with those theorists who recognize the dual nature of care as a principle underlying the approach to a set of caring practices undertaken by those involved in caregiving relationships. While care models vary as previously discussed, among them is the poorly studied model of mutual care in which care is defined as a process of exchange involving give and take by both conventionally identified caregivers and care recipients (Horwitz et al., 1996). This model has been primarily studied as isolated instances of mutual care or in the private familial context, where familial ties influence the nature of mutual relationships, rather than in public or institutional contexts.

My interest in the mutual care model lies in the potential it appears to hold for alleviating the negative consequences associated with viewing care as a unidirectional undertaking (Illich, 2003; Taussig, 1980); understanding dependency on others as unique to some such as the elderly and problematic for caregivers (Kittay, 2001; 2011; Kittay, Jennings & Wasunna, 2005); and engaging in caregiving practices over extended periods of time (Essex & Hong, 2005; Forster, 2007; Hoyert & Seltzer, 1992; Jeglic et al., 2005; Lin et al., 2012; Vitaliano et al., 2004). My stated interest demonstrates that I value care founded on interdependence and cooperation (Sumarah, 1988; Cushing, 2003a; 2003b; Cushing & Lewis, 2002; Taussig, 1980), in contrast to medical anthropologist Kleinman's (1988) approach to good care as the outcome of understanding the patient's perception of the problem. Kleinman's (1988) approach is particularly problematic in the case of persons with intellectual disabilities who are frequently misunderstood because of their reliance on nonverbal communicative strategies. Instead, I align myself with the principles underlying the mutual care model, in which care involves the common well-being of all persons involved. I assume an attempt to operationalize the mutual care model by community members with and without intellectual disabilities at L'Arche in my approach to their experiences of care.

3.1.4 Community

L'Arche communities are intentional groupings of people with and without intellectual disabilities who live together in collectively run homes. When engaging with the concept of community and the lived experiences of *Il Chicco* members, I make use of anthropologist Tsing's (1993) definition of the term. Unlike in many other ethnographic efforts, Tsing (1993) refrains from understanding and representing community as a self-generated homogeneous way of perceiving the world. Instead, she (1993) argues that there is much disagreement among people as to what constitutes community. Like culture, communities are unfixed and susceptible to external and internal forces that shape the direction change takes. I sustain that disagreement does not take away from the value inherent in discussing the contested ideas that form the basis of a group's collective identity; divergent ideas influence the nature and possibility of relationships at L'Arche.

In light of the lack of agreement among theorists as to the nature and qualities of community, I am positioning myself as favoring theories regarding what constitutes and defines individual and collective identity. In this dissertation, my interest in identity formation arises out of a renegotiation of previously prescribed roles of people with and without intellectual disabilities as powerful caregivers or powerless care recipients (Sökefeld, 2001). Deconstruction of previous identities and reconstruction of new ones at the individual and collective levels involve reframing of both internalized and situational identifications. Authors Timothy Owens, Dawn Robinson and Lynn Smith-Lovin (2010) review the large number of identity theories, noting that the sources of social-action guiding identity include "role relationships, affiliation with social groups, identification with social categories, [and] personal narratives" (p. 478). I align myself with these scholars who maintain that there is indeed "a parallel between processes at the individual and group levels, both in defining situations and in generating action" (p. 495). In other words, formation of identities through situation-framing and action-taking at the individual level mirrors the course of collective identity formation, and vice versa.

At the individual level, identities are either "internalization[s] of social positions within a self-structure" or "consensual, cultural identity meanings… implemented within situations that evoke them" (Owens, Robinson & Smith-Lovin, 2010, p. 478). These two descriptions of identity – as internalized or situational – represent the two most important schools of thought related to identity theorizing. At the group level, collective identification is bolstered by both internalized and situational identities at the individual level. Here, I agree with Joane Nagel, to whom Owens, Robinson and Smith-Lovin (2010) refer, who argues that collective identity variants are the result of negotiation between internal recognition and external ascription (p. 490).

3.2 The field site

My three months of field research began on July 2^{nd} 2012 in the L'Arche community of *Il Chicco*, situated on the outskirts of Rome, Italy (Spink, 2006, p. 291). This community is medium-sized with respect to others around the world. It is composed of homes where people with and without intellectual disabilities live together. The community is located near Ciampino International Airport and consists of core members, paid and unpaid assistants[3], a community leader and an administrative council, support personnel, and friends. There, I distributed my time between the *focolare* (homes), the *laboratori* (or workshops) where people with intellectual disabilities living at L'Arche are joined by others with intellectual disabilities who reside outside the community walls with family, and supplementary locations where members spent their time. My choice of *Il Chicco* was founded on my understanding of and involvement with L'Arche communities around the world; the "geographical location of the community" (Escrader, 2001); my familiarity with the cultural context; the location and cultural context of previously studied L'Arche communities; and the size of the community with respect to others. The community agreed to partner with me in my research (Appendices F).

3.3 Data collection

I engaged in the participant observation of daily happenings, conversations, interactions, and time management of all community members who were found on primary or related sites. These included core members, assistants, administrators, friends, and family members. These people were informally surveyed orally in order to understand the way all members define and interpret L'Arche's vision of mutuality in relationships across difference. I also formally interviewed fourteen members of the L'Arche community – one was a core member with intellectual disabilities, one was an administrator, two were relatives of core members, and the remaining ten were assistants. Most, though not all, of the people I interviewed were involved in direct caregiving relationships.

In order to gain a broad understanding of the experiences of care at L'Arche, I chose interviewees across categories of gender, age, citizenship, ethnicity, and tenure in L'Arche. Five of the interviewees were men while the others were women. This was representative of the greater number of female assistants, administrative staff and involved family members. Most of those interviewed were between the ages of thirty and sixty-five. Two of the fourteen interviewees were not of Italian origin while the Italian interviewees came from various parts of the country. The interviewees also differed in the amounts of time they had been involved with *Il Chicco*, involvement ranging from two to more than twenty years. Despite having set out to interview a greater number of people with intellectual disabilities, this proved to be a quite difficult task as most of the core members at *Il Chicco* are nonverbal. I hence chose to conduct a greater number of interviews overall and I chose to speak with family members and assistants whose shared experience with nonverbal members was quite extensive. These family members and assistants, by virtue of their special access to core members from their long-standing relationships and richer understanding of core member communicative strategies acted as interpreters of communicative moments for me, the recently arrive and relatively incapacitated participant-observer.

Employing methods used in other research projects conducted at L'Arche resulting in engaging willing and informed participants, community members were introducted to my research project in a presentation delivered on July 20th 2012, at a time when most community members were able to attend. In this presentation, I explained my project and asked for individuals who felt comfortable volunteering their time, thoughts and experiences to approach me individually afterwards. I also conversed with individuals on community grounds throughout the duration of my fieldwork and refrained from formally interviewing individuals until the end of my stay when I had become more familiar with the community and individual member's alternative modes of communicating: I initiated formal interviews on September 6th 2012. This voluntary form of recruitment was supplemented by asking additional persons to partake in order to reach a representational balance. When asked, additional participants demonstrated interest and eagerness to participate.

The interviews I conducted were voluntary, unpaid and confidential and took place in mostly private locations of the subject's choosing. I recorded interviews on an audiotape. The interview with a person with intellectual disabilities was conducted in the presence of an authorized L'Arche assistant. In accordance with the ethics guidelines provided by the American Anthropology Association (2009) and outlined in *The International Handbook of Applied Research in Intellectual Disabilities* (Emerson et al., 2004), I sought to honour the needs and choices of the people with intellectual disabilities with whom I worked. This involved respecting their dignity, privacy and confidentiality as well as practicing full disclosure permitting them to make informed decisions to the best of their abilities (AAA 2009; Angrosino 2004; Perry 2004). My research project was approved by the Concordia University Human Research Ethics Committee (Appendix I).

I wrote my interview questions, letter of information and consent form (Appendices A, B, C, D and E) in plain language in order to make my research project as accessible and comprehensible as possible for individuals involved (Perry, 2004). In my representation of individuals living at L'Arche throughout this dissertation, I made use of pseudonyms in order to protect the privacy of my informants. I did not, however, create composite identities of individuals because one of my primary goals was to humanize people with disabilities. I also refrained from including stories that required personal medical data to be relevant since it was unrelated to the purpose of the study, while being problematic and reductive as a way of speaking about people by referring to their medical file (Cushing, 2003b). Furthermore, certain persons could also be identified by medical information, in spite of my use of pseudonyms.

I concluded my time in community with individualized exchanges with members to whom I asked for feedback with regard to the relevance of my work and ability as a researcher. I also informed them of my timeline and gave them approximate dates for comments or revisions of my manuscript. Due to time constraints, I did not translate the entirety of my thesis into Italian for all community members to read. I hope to do so following the completion of my Masters degree. Finally, I took the opportunity to thank community members for their welcome, time and insight. In my report, I reflect on the various issues at play in my representation of individuals and L'Arche.

In terms of personal history, I am equipped with an Honours degree in Life Science from McMaster University and have always had an interest in health and care. Following the completion of my undergraduate degree in May 2010, I went to Italy where I decided to pursue a year-long experience in the L'Arche community in Bologna where I was responsible for the daily tasks involved in care for the six people with disabilities with whom I lived. Though I had been exposed to L'Arche through my family's involvement in the community in my hometown of London, Ontario, my experience as a live-in assistant in Bologna affected me deeply and exposed me to a new form of care. I was thus well prepared for this research project dealing with people with intellectual disabilities.

3.4 Data processing and analysis

I recorded my fieldnotes in a large notebook divided into sections including: general notes, questions and concerns (things to look into further or unclear linguistic or cultural references), stories, interview notes, and personal reflections (Cushing, 2003b). I also recorded formal interviews on my handheld Sony recorder ICD-P320. After each formal interview, I immediately transferred interviews onto my laptop computer where I cut the files into one-minute pieces for easy reference. I did this using the computer program Digital Voice Editor 3. I subsequently transcribed the interviews and saved both the digital files – the audio file and the transcribed document – onto an external hard drive purchased for this research project alone. Transcriptions of interviews were printed and copies of all digital files on the laptop computer and voice recorder were deleted. The external hard drive and all hardcopy fieldnotes and transcriptions were kept a locked room for safekeeping. My notebook and other related research files were not left in public areas unattended.

At the end of my fieldwork, I travelled from Italy to Canada with my laptop, external hard drive, notebook and transcriptions in my carry-on backpack that I brought with me on board the airplane. Upon my return, the aforementioned confidential items were stored in a locked filing cabinet with a single key, to which I alone have access. My fieldnotes and other information were available to my supervisor David Howes and the L'Arche president in case of concerns regarding misrepresentation of persons with intellectual disability. Both David Howes and the president did not refer to my notes. Fieldnotes and interviews are now stored in the locked filing cabinet and will be destroyed five years after the completion of my Masters degree.

3.5 Ethical considerations

I required written consent from formally interviewed people including the person with intellectual disabilities (Appendix E). The consent form that I drafted was translated into Italian prior to my field research. The person with intellectual disabilities gave consent directly and an assistant served as an intermediary throughout the entirety of the interview. L'Arche communities including *Il Chicco* have a blanket policy to which the legal guardians of most core members agree in advance that authorizes L'Arche assistants to make decisions for, and speak and write about core members for internal and external purposes. Assistants do so in accordance with the vision of L'Arche while respecting the dignity and privacy of its members. The legal guardians of the person with intellectual disabilities I interviewed also took part in the research project as an interviewee. I revisited each person's consent to participate in the study prior to formal interviews, formal conversations, and exchanges in order for it to remain clear throughout my field research that I was acting as a researcher rather than an assistant or other community member. Furthermore, I clarified the risks involved in consenting and I explained how I would make use of the experiences, stories, and anecdotes that people shared with me.

The process of obtaining written consent went as follows: During the introductory presentation on my research project, I emphasized the voluntary nature of participating in formal interviews and asked all of those who were interested in taking part in the project to approach me personally. Over the next three months, I acted as a participant observer at *Il Chicco* where I got to know community members, including those who demonstrated interest in being formally interviewed, and their various communication skills. In September of 2012, I scheduled formal interviews with interested individuals and assured that an assistant was available to act as intermediary in both the signing of the written consent form and the interview process in the case of the interview with a community core member. Prior to formal interviews, participants were asked to sign a written consent form. The assistant acting as an intermediate was asked to orally state her consent to participate as such. The oral consent, recorded on my handheld Sony Recorder was gathered from the assistant who was not formally interviewed at the time but who helped to facilitate communication between myself and the participant with intellectual disabilities. This assistant also assured the ease of the core member in question and clarified misunderstandings that arose throughout the course of the interview.

For informal interviews and exchanges, the implications of consenting to my research project were stated aloud. Individuals who chose to consent were informed of my research intentions and were asked to give their consent orally if they agree to participate. Some of these exchanges were recorded on my handheld Sony Recorder while others were simply recorded in my fieldnotes. My research project required consent from the president of the administrative council on behalf of L'Arche Italy (Appendix F), and from individuals with and without intellectual disabilities themselves.

Participants were free to withdraw consent and discontinue participation either verbally or in writing at any time without negative consequences. This was indicated on the consent form that individuals participating in formal interviews signed. It was also stated when oral consent was given for informal interviews and exchanges. A copy of written consent forms were given to all formally interviewed participants where mine and my supervisor's contact information were available should they have any additional questions concerning their rights as participants. No withdrawals by community members were declared during and in the months following my field research by either people with or people without intellectual disabilities.

Interviews and statements, stories or actions remained confidential; I did not disclose the identity of those with whom I worked. Unlike other studies on L’Arche by previous assistants and friends, I refrained from referring to individuals by name as my research investigated the positive and negative aspects of the organizational approach to care. I included general information about all participants in my study in order not to restrict persons to their medical diagnosis or a one-dimensional interpretation of who they are as is done in stereotyping (Cushing, 2003b). I also utilized pseudonyms and incorporated some of the character traits and complexities of all individuals involved without referring to specific details of their medical conditions or personal histories.

3.6 Benefits and limitations

Psychological welfare: I did not ask individuals about painful aspects of their past. Some of these aspects did emerge as a result of voluntary engagement by participants. However, I did not push individuals to respond to questions if they felt uncomfortable doing so or if they showed signs of distress or unease. Participants were free to discontinue participation or skip question(s) that made them uncomfortable at any time. Most respondents did not demonstrate discomfort or distress in response to my questions.

Reputation: The respondent with intellectual disabilities was interviewed in the presence of an assistant, rendering his story public in the sense that another, other than me, had access to it. Additionally, community members were mostly aware of the identity of the fourteen individuals who were formally interviewed and it was therefore important for me to protect their identities in this final version of my report. Also, interviewees shared potentially compromising stories about others; I avoided including these in my dissertation. Most stories that were shared with me were generally known by others at L'Arche and hence a part of public discourse. This study did not intend to uncover hidden truths; rather, I was interested in recording people's lived experiences of care in the context of a facility which operationalizes mutual care – or care as partnership. Identities and confidentiality were nonetheless protected in my final report. During the course of my fieldwork, I did not witness nor was I told about instances of intentional mistreatment or abuse by caretakers or others at *Il Chicco*. I also did not note criminal activity during my time in community.

4.0 RENEGOTIATING DISABILITY IN AN ITALIAN CONTEXT

4.1 Introduction

Disability is and has been represented in numerous ways in Italy since the beginning of the twentieth century. Today, disabled persons are primarily represented in one of three ways: as machines, as *bambinoni*, or big babies, and as a menace. A historical commitment to defense of society from individuals housed in institutions with the 1904 *pericolosità* Law has had an impact on shaping the current landscape of conceptions of disability in the Italian context (Dumont & Dumont, 2008). Though first person disability authors such as Italy's Claudio Imprudente (2011) agree that disabilities are less handicapping today than ever before, the notion of having to defend oneself from persons with disabilities remains prevalent among Italian citizens (Dumont & Dumont, 2008, p. 64).

These three principal conceptions can be manifested in the characteristically physical incarnation of greetings and affection in Italy. I spend the first half of this chapter describing these conceptions and exploring their bearings on care of persons with intellectual disabilities, beginning with the example of interaction between L'Arche members Sophia and Rebecca and church-goers recounted in the following scene.

Catholic mass is an integral part of the week for Il Chicco *community members. Normally, a Eucharistic service takes place every Wednesday in the community chapel, while Sundays are reserved for outings to parishes in the area. Unlike the worship spaces of other religious groups, Catholic churches are everywhere in Italy. The Ciampino parish nearest to* Il Chicco *is situated a mere three minute car ride away. By foot and in the company of non-motorized wheelchairs, the 'walk' to church takes a half hour.*

On this hot July evening following a two hour siesta, members from my household get ready for church. For some, preparation involves a run to the bathroom, a change of diaper, or a shower. For others, it necessitates the adornment of church-appropriate clothing including shoulder-covering tops and below-the-knee bottoms. At the agonizing thought of having to change my grey tank top for an unfortunately warmer black short-sleeved blouse – the heat is unbearable at this time of year – I am reminded of a sign at the entrance of a church in Sicily:

> RISPETTATE:
> -LA CHIESA, DIMORA SACRA DI DIO – <u>SILENZIO</u>!
> -IL CORPO, TEMPIO DI DELLO SPIRITO SANTO – <u>DECORO</u>!
> *RESPECT:*
> *-THE CHURCH, SACRED HOUSE OF GOD – <u>SILENCE</u>!*
> *-THE BODY, TEMPLE OF THE HOLY SPIRIT – <u>DECORUM</u>!*

When another assistant enters the living room where I am waiting with some of the core members, I ask to make a quick run up to my room on the third floor. In my house, most – though not all – core members are not left alone for extended periods of time. In this way, it is possible for assistants to curtail the risk of harm due to sudden epileptic seizures or unanticipated violent outbreaks that characterize the lives of some people. Though not entirely untrained on how to deal with these types of crisis situations, I am always happy to find myself in the company of assistants. Today, an assistant from one of the homes invites a small group of people to join her in attending a church service in downtown Rome. The other community members and I attend mass at the local parish instead.

*

Upon our arrival in the local parish, I note that the church is two-thirds full and smells of old incense. As is customary, community members select a spot in one of the first three rows of wooden pews on the right side of the church. There is some shuffling around *prior to mass as some of the community's social butterflies greet friends seated near them. Sophia, one of the two founding core members of* Il Chicco*, does not stop to socialize. Instead, she makes her way to the very front of the church where she assumes her place on an empty bench to the right of the altar. Conventionally, this bench is reserved for choir members, readers, or important religious figures. No one questions Sophia's seating choice. She has evidently done this before.*

Before the commencement of the church service, an assistant by the name of Rebecca makes her way toward Sophia whose attention is focused on twirling a blue Lego block between her thumb and middle finger. I am fascinated by Sophia's ability to remain focused on this task even up to hours at a time. Rebecca's advance draws Sophia's attention away from her block. The two women make eye contact and Rebecca gently reminds Sophia that she is in church. She does so by placing the palms of her hands together. It is time for prayer, she signs. Sophia nods, handing the block to Rebecca who places it in the pocket of her dark summer overalls.

The church service begins with a hymn that some community members join in singing. The unspoken rules surrounding sitting, standing, and kneeling do not appear to apply to L'Arche members, some of whom remain seated throughout the entirety of the service. At various points, Sophia appears to get distracted by other events or items of interest. In one instance, she begins to walk toward the sacristy (or Catholic holy place behind the altar where the Eucharist – or 'Body of Christ' – is kept) into which she disappears from sight. Something I have learned about Sophia since my arrival in community is that shiny objects and strings fascinate her; she deems these objects worthy of collection the same way I do *pottery pieces. Sophia's disappearance into the sacristy is worrisome in light of the slew of collectible items found in such a forbidden place.*

To my surprise, with Sophia's first step comes an immediate and almost perfectly synchronized reaction by Rebecca who follows her into the sacristy. Based on other encounters with Sophia, I expect to hear something shatter, rip, or break and, if nothing else, the scream of a woman whose mission has been interrupted. Though otherwise nonverbal, Sophia is able to communicate much through the use of sounds and body language. Instead, a silent moment passes and before long, Sophia and Rebecca exit the sacristy one after the other.

Toward the end of mass, a similar occurrence takes place in which Sophia's attention is drawn to yet another item of interest. This time, however, the stakes have been raised; Sophia is attracted to a woman's shiny necklace and hair piece. In her characteristic way, Sophia quickly and silently approaches the woman who becomes visibly rigid with every step Sophia takes in her direction. Sophia continues to advance into the woman's forbidden social space. Soon, she is very close. The woman, who had only moments ago been speaking with a small group of people, takes full consciousness of Sophia's attention on her.

I am near the group when the scene begins to unravel. Despite having come to know Sophia better over the course of my month in community, I do not know her well and cannot yet ask her to acknowledge my requests without provoking a scream, scratch, or hair pull. Sophia is very intelligent, I am told by several community members. She is also incredibly furba*, or cunning, they say. I quickly search the room for other assistants; everyone appears occupied with something or someone else. Like the woman with the shiny necklace, I too become anxious.*

I decide that I have no choice but to ask Sophia not to touch the woman's jewellery. Sophia knows that I am at times afraid of her. My fear and consequent abrupt manner is my defence against the unknown. So too are Sophia's at times violent reactions to me. Instead, Rebecca appears behind Sophia before I take my first step. Without asking her to cease observing the light show taking place in the woman's diamond-like necklace, Rebecca places a hand on Sophia's shoulder. They remain there a few moments until Sophia decides that she has seen enough. I observe the scene and expect Rebecca to address the woman with the necklace. Instead, when Sophia has had her fill, she and Rebecca quietly leave the church arm in arm.

The shiny necklace-wearing woman's reaction to and my own musings about previous or potential interactions with Sophia point to our shared position within dominant frameworks of representation with regard to persons with intellectual disabilities. On the other hand, Rebecca's reaction to Sophia indicates that these women have done away with dominant representations through repeated interactions over a prolonged period of time. Concretely, Rebecca does not force Sophia to move away from the woman nor does she treat her as an object of care or control. Rebecca also refrains from interpreting Sophia's behaviour as a disturbance and from reproaching or punishing her for disobeying social norms as one might with a child. Rebecca finally refuses to view Sophia as a menace to the woman's well-being. Instead, she later praises Sophia for her patience and restraint in the face of tempting collectible objects.

Alternative conceptions of disability surface in the writings of Jean Vanier, the mission and philosophy of L'Arche, and the shared lives of assistants and core members such as Rebecca and Sophia. These include viewing the disabled as human first, as agents or normal, and as teachers. Rebecca’s praise of Sophia’s behaviour is an example of the latter conception in which Rebecca views Sophia as a teacher. Rebecca perceives Sophia’s behaviour as exemplary of restraint in the face of temptation while stressing her patience and commendable self-control. In the second half of this chapter, I explore the significance of alternative conceptions such as these at L’Arche. I also point to the importance of interaction in overcoming misrepresentational views of people with intellectual disabilities. A vital step in achieving a move away from representation toward engagement involves reframing dependency and cooperation as necessary and normal for people with and without disabilities alike (Kittay, 2001; 2011). Though I highlight the positive outcomes of interaction, I also identify some of the more difficult elements involved in this undertaking, the most important of which is risk-taking.

4.2 Conceptions of disability in the Italian context

The handicapping aspects of disability take on concrete characteristics in the Italian context due to various "cultural and situational views of cause and cure and of fate and fault" (Kasnitz & Shuttleworth, 2001, p. 3). Though the social movement that engendered a reform in Italy's legislation surrounding the care of mentally ill persons and those with intellectual disabilities was successful in changing the public's perception of these people, certain negative or discriminatory cultural and situational views still prevail. These conceptions range from the view of disabled persons as objects of care labour lacking dignity and personhood, to an understanding of disabled people as voiceless children with no sexuality (Cushing, 2003b). Most prominent, however, is the outdated view of disability upon which the 1904 Law was founded; disabled persons are seen as a menace from which society must be defended (Dumont & Dumont, 2008, p. 64). The later conception is further reinforced by complimentary health-related ideas of contagions, disturbance, and abnormality or sickness, the outcomes of which manifest themselves in instances of marginalization, harm, violence and or defensive behaviour. In a country where affection and physical contact hold an important place in upholding social relationships (Chillot, 2013; Field, 2001; Gallace & Spence, 2010; Remland, Jones & Brinkman, 1995), such conceptions of disability become handicapping.

A part of the Italian National Health Services, the community-based mental health care network that operates facilities for the mentally ill and persons with intellectual disabilities is run by the Department of Mental Health (DMH) (Lora, 2009, p. 7). The community-based network encompasses a range of facilities including Community Mental Health Care Centers, Day Care Facilities, General Hospital Psychiatric Units and Residential

Facilities (Lora, 2009). Of these services, residential facilities such as L'Arche often represent the only form of long-term care accessible to chronic and disabled patients becoming "a home for life" for the majority of them (Lora, 2009, p. 12). This is largely due to the lack of formal limitations on the length of stay and low admission, discharge and turnover rates in residential facilities.

Persons with intellectual disabilities living in or making use of community-based services accountable to the DMH are theoretically treated according to legislation founded on principles established at the time of the social reform movement of the 1960s. Though the legislation itself has since changed, the principles of the original psychiatric reform remain goals of current care programs across the country. Due to the relative newness of the reform movement, some mental health care professionals and authors including Monica Bettoni and Bruno Benigni (2009) – who were present and active at the time of reform in the province of Arezzo, the first off-shoot location influenced by Basaglia's ideas – continue to influence the field of mental health. In one of their recent works, Bettoni and Benigni (2009) outline the 'enduring principles' that served as the foundation of the social movement's beginnings thirty-five years ago and continue to remain important today. The enduring principles include:

1) It is right and possible to give everyone hope and to build a mental health care system involving treatment and social inclusion for all.
2) In order for someone to overcome illness and embark on a path toward recovery, the energies of the person in question, the institutions, and the community must be made available.
3) Overcoming the limitations caused by psychic suffering as a means of attaining full social inclusion necessitates collaboration between professionals from the various sciences and sectors of intervention on a single project located both in time and space.
4) Social inclusion and the eradication of prejudices surrounding mental illness are the result of action rather than ideological musings.
5) Social inclusion requires an alliance between all party members: subjects themselves, healthcare professionals, institutions, civil society, and families. This agreement must

> involve all members in an ethical, cultural, and material set of socially contextualized changes. (Bettoni & Benigni, 2009, p. 19-21)

4.2.1 The disabled as machines

Despite the idyllic goals laid out in the beginnings of Italian mental health care reform, it becomes clear upon closer inspection that several negative and discriminatory conceptions of disability pervade community-based services and the psyches of the Italian populace. In interviews with *Il Chicco* assistants who had previously worked in other centers providing care for people with intellectual disabilities, one of the primary approaches assistants observed involved treating these people as machines. Roberto and Marika, who have now been assistants at L'Arche for nine and three years respectively, describe their encounters with this approach to disability in two other centers. They explain:

> Roberto – The person in another center is a machine. He/she is washed. Breakfast. Lunch...
>
> Marika – In that place the relationship between people with and without handicap was annulled. Therefore, first off the... uniform: gloves, masks. People did not eat seated at table together. People were fed. Antonio [one of the core members now living at L'Arche] was fed from behind by an assistant on his/her feet. Washing was not a washing of intimacy, privacy, relationship or accompaniment. It was a little bit like a car at the automatic carwash... There weren't single rooms either. On the contrary, there were even quadruple rooms... The *ragazzi*[4] were undressed and placed... taken to the bathroom, washed with a tube, and brought back to their rooms.

Here, Roberto and Marika depict the approaches to care in other centers as harsh and mechanical. They also note that because regulations are based on the conception of people with disabilities as machines in these centers, employees are obligated to make use of distancing methods and tools that separate them from the people they care for.

In the above passages, both Roberto and Marika portray a process by which people with intellectual disabilities become 'machines' or the mere objects of care labour. People such as Antonio are stripped of personhood in these contexts in which they are not treated with dignity. They are also understood to be incapable of relationships with even the few people with whom they interact. Contrary to the claims made by Bettoni and Benigni (2009), Antonio and others have not reached "full social citizenship" (p. 19). In Marika's description, the daily proceedings of eating and washing are voided of intimacy and respect for the other. In both of these activities, employees in these other centers avert coming into contact with people like Antonio through distancing methods such as standing behind him, disallowing eye contact and thereby denying humanizing mutual recognition. Employees also distance themselves from people with intellectual disabilities thanks to intermediary objects such as gloves, masks and water tubes – objects that seem to acquire particular significance in this context as mediators in social interaction. Furthermore, the objects limit the assistant's ability to sense the other's body and odours.

4.2.2 The disabled as bambinoni*, or big babies*

In addition to the conception of persons with intellectual disabilities as the objects – in the literal sense – of care labour, the particularly problematic view of persons with intellectual disabilities as voiceless *bambinoni*, or big babies who are void of sexuality, is evident in Italy. This conception is reinforced by the notion of degrees of intellectual disability and the medicalized categorization of such persons as having equivalent intelligence quotients to those of young children (Cushing, 2003b). Though this view is problematic when applied in the institutional context and familial home, it is often difficult to distinguish the tendency to infantilize from closely related behaviours used to demonstrate fondness toward these same people. For this reason, some behaviours such as referring to core members at L'Arche as *ragazzi* – or youngsters – can be interpreted as either belittling or caring by community members and visitors.

Nevertheless, not all behaviour ambiguously connotes infantilizing or fondness. In some case, discouraging the expression of or not recognizing expressive touch or overtly sexual activities as expressions of sexuality is infantilizing. In these instances, engagement in sexual activities with people with intellectual disabilities is reframed as asexual. This trend is unfortunately similar to suppression and avoidance mechanisms employed by adults when interacting with children who demonstrate an interest in understanding sexuality. The degree of infantilizing, hence, varies greatly, ranging from relatively harmless addressing core members as *ragazzi* to more problematic behaviours such as engagement in sexual activities with them without recognizing the sexual nature of these activities.

L'Arche assistant Rosetta notes that babying of core members also takes other forms. She describes infantilizing that she notices among some colleagues in the following way:

> ... at times in sum, the *ragazzi* tend to be seen as children, no? And therefore... "Ah well... what's the issue? I'm only cuddling with them." No? As though it is something to be revered. But cuddling is nonetheless a sexual act no?... In the morning, I greet them [the *ragazzi*] but I don't feel the need to throw myself at them. It seems to me a real invasion... you know a bit... disrespectful.

Here, Rosetta elaborates on the physical aspect of the babying behaviour. Unlike in the interactions portrayed by Roberto and Marika at other centers, this conception engenders an elevated or exaggerated quantity of physical contact between persons with and without intellectual disabilities. Rosetta and others question the implications of such types of contact with adult core members whose sexuality is ignored or assumed absent in these moments of physicality. In addition to labelling and partaking in elevated physical contact, babying behaviour is also noticeable in the way persons with intellectual disabilities are dressed, in the way their actions are interpreted as ‘naughty’ or ‘mischievous,’ and in the way choices with regard to food and daytime activities are made on their behalf.

4.2.3 The disabled as a menace

Lastly and perhaps most importantly, people with intellectual disabilities are perceived as a menace toward Italian society. This perception dates back to the early twentieth century *pericolosità* law (Dumont & Dumont, 2008) and is hence deeply rooted in the way Italian citizens approach the mentally ill and people with intellectual disabilities. Enactment of beliefs surrounding the threatening nature of these people is seen in both social interactions and in institutional contexts such as the centers described by Roberto and Marika.

Sophia’s social interaction with the woman at church exemplifies the discomfort felt by many when interacting in public spaces with people with intellectual disabilities. Sophia’s approach causes the woman to become tense and interrupt her on-going conversation with a small group of people. Though the woman does not, at any moment, express her distress verbally, she quite readily communicates through body language that Sophia’s presence and closeness disturb her. Whether or not she in fact considers Sophia a threat to her well-being, the woman prepares to react to Sophia’s departure from social norm that dictate appropriate distance between two strangers.

Institutional approaches to care of persons with intellectual disabilities such as the distancing tools and methods described by Marika also attest to this dominant misrepresentation. Another assistant, David, who has also previously worked in other centers prior to his arrival at L’Arche, elaborates on the detached attitude he assumed when caring for persons with intellectual disabilities as a result of circumstances at his previous workplace. He describes:

> Assistants were not allowed to eat with the *ragazzi* even if there were leftovers. First, the *ragazzi* had to eat. There was a bit of a detached rapport with them. There [at the center], things were done *for* them. [emphasis added]

When the 1904 Law was first put into place, it served as the basis for segregation of mentally ill persons and those with intellectual disabilities in asylums across the country. Today, the conception of people with intellectual disabilities as a menace to others justifies their privation from otherwise healthy human interactions such as eating together with those whom they interact with on a daily basis. David accurately describes the attitude taken toward people in these centers as reflective of a more discrete form of segregation.

Importantly, the conception of the disabled as a menace is today justified by other prominent ideas including disability as contagious, disability as disturbance of social 'peace,' and disability as sickness. The aforementioned supporting theories are equally ingrained, though where they come from per se is not entirely clear. Medical anthropologist Whitacker (2003) provides a valuable point of departure in her work on conceptions of health in the Emilia-Romagna region. She observes that one of the widely held beliefs related to conceptions of health involves the permeability of the human body (Whitacker, 2003, p. 348). According to Whitacker (2003), Italians conceive of the body as permeable and hence engage in "moderation in personal conduct to prevent debilitation" (p. 348). Though Whitacker (2003) here makes reference to "microbial infection, [and] modern-day miasmas such as pollution or additives in food," among others, this notion can also be seen applied to persons with disabilities who tend to be regarded as sick or unhealthy (p. 348). In other words, avoidance of contact with persons with disabilities adheres to a generalized cautious approach to harmful environmental agents. However, unlike in the case of atmospheric insults and microbial infections, it is based on the faulty notion of disability as sickness and contagious.

My interview with L'Arche assistant Marika confirms these observations. Marika draws attention to the prevalence of the ideas of sickness and contagion in the center where they worked prior to coming to L'Arche.

> ...there [at the center], it was very strong not on my part naturally but in the sense of nurturing a conception of handicap as 'sickness': contagious sickness. More than once if there was someone with nieces/nephews... the nieces/nephews came and... "Don't let them touch the children eh!?" It was as if, I'm not sure, they [the *ragazzi*] could give them something contagious no? Something that the child could catch.

Here, Marika describes explicit and unfounded references to sickness and contagion in the approaches of family members of persons with intellectual disabilities at the center where she formerly worked. Such attitudes toward the disabled deprive them of interaction including physical contact with young family members. Avoidance of such contact is reinforced by the idea that people with intellectual disabilities are menacing to those who interact with them particularly through means involving bodily contact.

4.2.4 Bearings of dominant perceptions on persons with intellectual disabilities

The dominant conceptions of disability in Italy are manifest in important consequences for people with intellectual disabilities. For example, someone may experience moments of exaggerated physical contact with individuals who perceive them as *bambinoni* while, on the other hand, experiencing isolation and rejection by others who view them as threatening. In what follows, I describe the handicapping outcomes of the three primary conceptions of disability listed above. These include instances of marginalization, harm, violence and/or defensive behaviour. Though I do not delve into each of these as fully as I would otherwise like to, given the constraints of this thesis, I present an example of each outcome in order to demonstrate the overwhelmingly negative impact of dominant misrepresentations. The handicapping outcomes, when contrasted to possible positive ones, point to the relevance of social and cultural theories of disability construction.

First, social marginalization is an important handicapping outcome of dominant perceptions of disability. For instance, the common cultural practice of greeting with hugging or kissing tends to be extended to people with intellectual disabilities more infrequently and with a greater sense of unease or discomfort by Italians. This results in highly evident social marginalization that is less manifest in 'non-contact' countries such as Canada and England. This difference can be attributed to the lack of socio-cultural expectations regarding affection in public in these countries (Remland, Jones & Brinkman, 1995). Furthermore, given that social integration in Italy relies heavily on presentability, or recognizable performances of 'normalcy' and 'beauty,' persons with intellectual disabilities are disadvantaged by the visibility of their disabilities. Various impairments tend to necessitate the need for mechanical or other assistance, and/or result in physiological deformations, speech impediments, and erratic, unpredictable behaviour.

A second handicapping outcome associated with dominant misrepresentations involves harm done unto persons with intellectual disabilities. In the first half of the century in Italy, abuses including physical violence, restraint, segregation, sterilization, and over prescription of pharmaceutical drugs were permitted in asylums under the guise of defence against the 'dangerous' mentally ill and intellectually disabled (Dumont & Dumont, 2008). Today, harm takes other forms including sexual abuse, enforced sexual abstinence, mass sterilization, and physical, verbal, emotional or psychological violence (Cushing, 2003; Buckingham-Rivard, 2010). Some studies such as one conducted by Boyd et al. (2008)

shows, for example, that 90-95% of fetuses affected by Down syndrome and indentified using prenatal genetic diagnosis in Italy are subsequently aborted (p. 693). Buckingham-Rivard (2010) and Cushing (2003b) identify similar trends in other countries including Canada. A growing body of literature also points to a much more elevated frequency and severity of abuse among person with disabilities who are at greater risk of abuse than their non-disabled counterparts (Buckingham-Rivard, 2010).

Violence and harm subsequently result in the adoption of a range of defensive or aggressive behaviours by people with intellectual disabilities (Buckingham-Rivard, 2010). This is yet another outcome of dominant misconceptions. Roberto, a long time assistant at L'Arche, speaks to the defence mechanisms employed by some core members at L'Arche at the beginning of their time in community. He makes specific reference to Federico, a young man now living at L'Arche for three years, who initially refused to be touched by others upon his arrival in community. Instead, Federico defended himself by pushing others away, and distanced himself from or refused to cooperate with assistants while being shaved in the morning, for example. Roberto states:

> Look the thing that was also a bit strange for me took place when they [new core members] were welcomed at L'Arche, the *ragazzi* that came from other institutions... seeing some of their responses. That is, you came close to them. It was a question of defence. Take Federico who was afraid when you tried to get close to him. Or an Antonio who arrived having been scalded [with boiling water].

Roberto testifies to the harm suffered by some of the current L'Arche core members, people whose primary means of telling their stories – nonverbal communication – is not always easy to decipher. Though the negative outcomes of normalized and normalizing conceptions of disability are multiple and specific to each individual, it is clear that instances of repeated marginalization, harm, and violence deeply affect the lives of persons with intellectual disabilities including some of the core members now living at L'Arche.

4.3 (Alternative) conceptions of disability at L'Arche

Various conceptions of disability can be seen at play at L'Arche, notably, the conceptions of disability proposed in the writings of Vanier (1989; 2007) and echoed in the works of other scholars and non academics alike form the theoretical basis for the L'Arche Charter (Appendix G) and the L'Arche Mission and Identity (Appendix H). Cushing (2003b) notes that those who enter L'Arche, particularly assistants, are enculturated into L'Arche's alternative approach to both disability and care in order to subsequently reproduce this environment for others (p. 7). In practice, it is possible to identify the L'Arche approach to disability in various encounters between persons with and without disabilities both in and outside of the community walls, as exemplified by Sophia and Rebecca's interaction at church. As stated by Cushing (2003b), "Although the ideas and ideology are powerful, knowing them intellectually is only a first step" (p. 294). In the following section, I will first outline the alternative conception of disability proposed by Vanier and others at L'Arche. Then, I will illustrate instances of the application of these conceptions in the 'practice' of daily living for members of *Il Chicco*. In this segment, I argue that misrepresentations such as those enumerated above are overcome through interaction and engagement by assistants and core members alike. Overcoming dominant conceptions of disability also involves reframing dependency as normal for everyone (Kittay, 2001; 2011).

4.3.1 The disabled as human first

The founder of the first L'Arche home in Trosly-Breuil in 1964 and an enduring important figure for the international organisation, Vanier has written numerous books, articles and letters in which he defines the place of persons with disabilities in society. In his book *Our life together: A memoir in letters*, Vanier (2007) describes what he calls the five stages of changing attitudes toward people with intellectual disabilities. They are:

1) React to them with fear of their 'abnormal' behaviour or disfiguration. Label disability as a disorder and consequently reject the disabled while ultimately seeking to do away with them.
2) View them as human. Approach them with pity and confide their care to big institutions.
3) Get to know them as human beings worthy of respect and compassion. Attend to their needs while attempting to respond with competence.
4) Discover through a wonder-filled and thankful approach that becoming close to them and entering into authentic relationships with them, one is transformed.
5) See the face of God in them. The weak or marginalized are the most worthy and powerful for they bring others closer to God. This step is close to the fourth. (Vanier, 2007, p. 12-13)

These stages outline the process of focusing on the humanity of people with disabilities at L'Arche (Appendix G). For many assistants, these stages accurately portray the transformation they undergo during their first deep encounter with people with disabilities.

Marika who is able to compare and contrast the L'Arche approach to that of other centers describes one of the stages of transition she underwent in her relationships with Pietro, a core member from her L'Arche home. Pietro is a nonverbal man with limited psychomotor activity who requires assistance with all daily activities including bathing, eating, and changing. Marika's initial approach to Pietro resembles Vanier's description of the second stage of changing attitudes toward people with intellectual disabilities. She explains her transition this way:

> With Pietro in particular, I had to make a transition because my beginning with Pietro made it impossible for me to enter into a relationship with him. Therefore Pietro for me was a sick body I had to move, and to which I could cause harm if I wasn't careful. Therefore I moved him, I think, as though he was a time bomb. My way was very rigid, very hard, very careful. I actually hurt myself this way. There was absolutely no relationship with him. He was completely uncoordinated. Until there came the moment of transition. The transition was, as I always recount, I finally said: "Gosh Pietro, help me!" And Pietro put his arm around my neck. There, something was born. Now, Pietro understands how... because I talk to him, because I tell him, because I

> warn him when I am turning him. At first, he had to be completely passive and hence could not help me in any way. But I had no type of relationship with him and with his body. Now, I feel when he is more rigid, when he is more relaxed, when something is wrong. I feel that he collaborates. I don't feel tired anymore when I accompany Pietro whereas I had really hurt myself in the beginning.

Here, Marika emphasizes Vanier's point about the importance of a personal relationship with Pietro. Further along in the interview, she also describes having almost abandoned hope of accompanying Pietro in his morning and evening routines because of how badly she had injured her back while moving him. Her moment of true encounter with Pietro occurs when she reaches out to him as to another person, a call to which he responds in an unprecedented way. Vanier (2007) also highlights the importance of the humanity of people with intellectual disabilities, stating that "It is the person who is important" (p. 14). In Elkin's (2008) words, "disability is secondary to humanness" (p. 28). For this reason, a shared life with persons with intellectual disabilities is at the basis of the L'Arche experience.

Vanier's ideas about disability are also seen reflected in the L'Arche International official documents. In the L'Arche Identity Statement and Mission, disability is conceived in the following way: "We celebrate the unique value of every person and recognise our need of one another. Our mission is to... Make known the gifts of people with intellectual disabilities, revealed through mutually transforming relationships" (Appendix H). Here, in addition to a focus on humanity, the unique value and gifts of people with intellectual disabilities are central to who they are. Furthermore, all community members are seen as of equal value (L'Arche, n.d.). At *Il Chicco*, these L'Arche ideas are outlined in the booklet they give all newly-arrived assistants. On the L'Arche website and in this booklet, it is also possible to find what Escrader (2001) calls the pedagogy of L'Arche that involves living with, eating with, and working with people with disabilities rather than for them. This is distinctly different from the approach David describes above as characteristic of the other center he worked in.

L'Arche recognizes, however, its inability to welcome all intellectually disabled persons into the home-like settings they propose. In the L'Arche Charter, this limitation is described: "L'Arche knows that it cannot welcome everyone... 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" (Appendix G). This is the case at *Il Chicco* where some core members – and assistants as well, of course – have spent time in community only to leave it subsequently for a variety of reasons including an elevated need for time alone because of the collective nature of everyday life and the intimacy of contact with other community members.

Also evidenced in the stages outlined by Vanier is what Cushing (2003b) refers to as L'Arche's "compelling moral and spiritual perspective on disability and caregiving" (p. 294). Additionally, the final stages and the ideas expressed in L'Arche's official documents align themselves, as argued by Elkin (2008), "with social theories of disabilities that understand disablement to be an ever-changing concept whose definition depends on the political, economic, social and cultural contexts within which individuals live" (p. 28; Grönvik, 2007; Kasnitz & Shuttleworth, 2001). L'Arche's role is to enable individuals with intellectual disabilities to find a place in society which does not yet accommodate their needs.

Many of L'Arche's theoretical orientations toward disability are visible in the lives of *Il Chicco* community members. In some cases, however, L'Arche's theoretical orientation meets conflicting dominant conceptions of disability with the arrival of new assistants or in particular moments of encounter. For the most part, attitudes such as those held by extra-

L’Arche members eventually evolve toward L’Arche’s core orientation. Nevertheless, this transformation does not happen uniformly. For example, Arturo, one of the core members in the home where I lived frequently set the table for evening meals in the house. In order to determine the number of places to set, he circulated around the house counting the number of assistants and outside guests. He then often entered the kitchen addressing himself to me, stating: “We are seven, and you are five and therefore we are twelve for dinner.” In this statement, Arturo distinguished between ‘us’ core members or persons with disabilities and ‘you’ assistants and guests. When core members from other homes came as invited guest for dinner in his home, he did not include them in his ‘us’ but did distinguish them from the ‘you’ in which assistants were counted. The invited core members were often named in addition to the unchanging seven ‘us’ and the variable ‘you’.

4.3.2 Practically applied conceptions

Despite instances such as these, alternative conceptions of disability at L’Arche nonetheless prevail over their normalizing counterparts. Recurrent conceptions include persons with intellectual disabilities as agents, as normal, as people worthy of respect, care and a valid place in community and society, as highly perceptive and communicative individuals, and as teachers. The result of alternative conceptions can be seen in interactions such as Sophia and Rebecca’s in which the negative outcomes suffered as a consequence of misrepresentation are avoided. Though the result does not highlight the risks faced by both Sophia and Rebecca in the initial stages of their relationship, it does demonstrate that they have overcome misrepresentation through interaction. In the case of these two women, a shared life over the course of three years and repeated interactions including difficult moments has allowed them to build the relationship they are involved in today.

The conception of persons with intellectual disabilities as agents is evident in the intentional choice of language heard from various assistants. At *Il Chicco*, there is talk of the difference between *stare* and *fare*, or between 'being' and 'doing'. Initially, many new assistants tend to want to 'do' a lot upon their arrival in community; they are also inclined to do things *for* core members. At L'Arche, assistants are instead encouraged to 'be' and to 'be with' core members, a task with which many express having difficulty. Furthermore, daily tasks and community activities are undertaken together with core members. An assistant Niccolò describes his transition to 'working with' from 'working for' in the following way:

> The fact of 'doing' is because I am the type of person who has difficulty 'being'. At first, I was afraid of, of silences. I mean, we are both silent. Oh god! We have to have something to do. We can't stay here in complete silence! Therefore my peculiarity is that I do, do, do, do, do... And it isn't all bad, at the end, but it has to be counterbalanced by knowing how to 'be'.

He goes on to discuss the way decisions are made surrounding how many vegetables to plant in the community garden. He explains:

> Therefore, the fact that instead of planting fifteen zucchini plants, I plant seven, it's because that possibility, instead of taking it to care of the other zucchinis, I take it to 'be' more. Therefore it becomes a search for balance. I mean, you realize that maybe if you hadn't planted fifteen, things were good all the same. Better yet, maybe I would have, I could have gotten Stefano to plant more of them. And get him... given that you see that he has fun when he is there planting, he is entertained! Maybe he doesn't place them properly. And in that case I place them better. But, I shouldn't be interested in the correct placement of the zucchini plant. I should be interested in the relationship.

In this passage, Niccolò speaks of the importance of undertaking the task of planting zucchinis with Stefano rather than for him. Here, he describes questioning his tendency to 'do for' rather 'do with,' acknowledging that it is at times difficult to prioritize valuing his relationship with Stefano and others over getting tasks done.

The conception of core members as normal is expressed particularly with regards to their tastes in food, their dress, their daily activities, and their sexuality. For example, the mother of one of the core members, Antonio, describes her son's tastes as normal and typically Mediterranean. Other assistants suggest that masturbation or sexual desires expressed by core members toward other core members or assistants are also normal behaviours. The forms these expressions take and the moments and places in which they are expressed are discussed in great detail by groups of assistants at weekly meetings.

The more problematic outcomes of viewing people with disabilities as normal – rather than sick – take place when community is seen as a therapy or remedy for the societal problems that render disabilities handicapping. Though this view is not prevalent among community members today, some previous persons in community have encouraged the families of certain core members to slowly decrease, in the hopes of eliminating, the pharmaceutical drugs taken by these individuals. When taken too far, these 'experiments' have lead to some core members suffering a great deal both physically and socially as a consequence. For this reason, Kittay's (2001; 2011) notion of dependency is instructive as it recognizes the social and cultural construction of aspects of disability while framing the need of persons such as Pietro for constant assistance as realistic and normal, because needs characterize the lives of all individuals at various points in time.

In addition to the conceptions of persons with intellectual disabilities as agents and as normal, two other approaches frequently resurface in the lives of L'Arche community members. These are viewing persons as people worthy of respect, care and a valid place in community and society, and as highly perceptive and communicative individuals. These qualities are described by Maurizio, an assistant in the daytime workshop, and Benilda, an administrator who has worked at *Il Chicco* for over ten years. They describe people with intellectual disabilities in the following ways:

> Maurizio – To me they are equal. I mean, disabled or not disabled, it's people you have in front of you, people who ask, and people who offer.
>
> Benilda – When I came [to *Il Chicco*] the first time, I cried. I cried because I was moved. I saw the way the assistants took care of, and how they considered the *ragazzi*.

The mother of a core member also emphasized the immense respect for persons with intellectual disabilities she encountered at L'Arche for the first time after having visited other care centres throughout Rome. The perceptiveness and communicative ability of persons with disabilities will be further discussed in Chapter Five.

4.3.3 The disabled as teachers

Lastly, persons with intellectual disabilities at L'Arche are often described as teachers by other community members (Escrader, 2001). An assistant, Roberto, recounts having learned about life from the community core members. He states:

> As I always say, I think that there isn't a university faculty that is capable of helping you know and touch in the truest sense what life is and what a gift life is [in the way core members do].

He goes on to say that it is thanks to core members that he has been able to rethink what is valuable in life. Another assistant, Camila, describes some of the lessons she learned a bit differently. She describes:

> But I can tell you that I can't stand putting gloves on when I wash the *ragazzi*. It was Sophia who taught me this, however. Because when for the first time, that famous first time that I was telling you about, that she asked me to wash her in the shower. I was putting gloves on, having seen other assistants do the same, and she took them off my hands. And therefore she said to me: 'look, when it comes to me, you can wash me without gloves.' And I don't wash the *ragazzi* with gloves now, even in conditions... With this, I don't mean that I don't note the smell, or that they don't stink. But I can tell you that I no longer feel nauseous. I am not bothered but I feel that in front of me, there is a friend. There is a person that I like, that I like accompanying.

Here, Camila, emphasizes what it is that she heard Sophia express in her nonverbal gesture of removing the gloves she had placed on her hands. Ever since then, Camila describes having changed her way of accompanying not only Sophia but other core members as well. Interaction with Sophia allowed her to overcome the framework she had been working in prior to their encounter.

Another assistant, Ilenia, also recounts the lesson she has learned from Emilio, a core member whom she has known for years. She says:

> It really is what Emilio has taught me in all of this time... that he is Emilio much more than I am Ilenia despite the fact that he is, in good and bad, motionless if no one moves him. And he can do absolutely nothing without someone else. He can't even decide whether or not to eat or not to eat something because he has a feeding tube. And absurdly, when, I think of what I would want in life, I mean the thing that would make my life full and make me feel at peace and serene with the universe, for me... that's always it.

In the lessons described by these three assistants, core members take on the role of teachers or wise persons. In all cases described above, essential to the teaching of core members is receptiveness on the part of assistants who 'read into' their behaviours, gestures or words in particular ways. Assistants also have to be willing to risk misinterpreting or being hurt by the violence or defensiveness of some core members. Engagement of core members and assistants alike is fundamental in these communications.

Rebecca, the assistant who accompanies Sophia at church, demonstrates receptiveness and engagement in that she fully considers Sophia and her expressed desire to admire the woman's shiny necklace. Rebecca does not anticipate or attempt to prevent a violent or defensive gesture by Sophia nor does Sophia respond defensively or violently to Rebecca the way she might to someone by whom she felt threatened. In fact, when Rebecca speaks of core members such as Sophia, she says "You know I learned from the *ragazzi*. It's them. They teach me everyday, everyday. They help me discover my weaknesses, my strengths in unexpected moments, unexpected occasions." Rebecca's openness to learning provides a possibility – the possibility for relationship and learning. Like Roberto, Camila, and Ilenia, Rebecca embodies the final stages of changing attitudes toward people with intellectual disabilities described by Vanier. The means by which the aforementioned lessons are communicated and understood will be discussed in Chapter Five.

5.0 COMMUNICATION AND THE PROLONGED UNCERTAINTY OF COMPREHENSION

5.1 Introduction

Communication is an important means by which relationships develop and are maintained through time. Because relationships are at the core of the care model that is operationalized at L'Arche, I take this chapter to explore the nature and significance of communication in relationships among *Il Chicco* members. First, I elaborate on the forms that messages take. Though language – including Standard Italian, regional dialects, and *comunicazione aumentativa e alternativa*[5] – is indeed employed as a means of relating to others, I take particular interest in nonverbal messages that involve the engagement of multiple senses. Among these nonverbal expressions are several means specific to the Italian social and cultural context where, as previously mentioned, the sense of touch is relied upon heavily in everyday life. In response to message transmission by communicators with and without intellectual disabilities, a number of methods of interpretation are encouraged at L'Arche where each person's unique form of communication must be learned in order for mutually caring relationships to take shape (Brown, 2003). In the following scene, Pietro and Zeta make use of some of these unique forms of nonverbal communication, the meaning of which are interpreted differently by several assistants.

I am fascinated by Pietro and Zeta's relationship. Zeta, a vivacious young woman in her early twenties who is regularly teased for her dense and curly short hair, tends to initiate most of their interactions due to Pietro's need for assisted mobility. On long summer afternoons, Pietro – a middle aged man with stunning blue-green eyes and a phenomenal *smile – frequently rests in his old, faithful wheelchair by the books and prayer candles of the house living room. Zeta, on the other hand, habitually flips through magazines, taking breaks to wander the common spaces of the house in search of entertainment.*

This summer, Pietro suffers enormously from the suffocating summer heat. In recent days, he demonstrates his discomfort lamenting and sleeping through entire afternoons. A lover of good food – especially pastas, pizzas, meats, and beer – Pietro expresses his unhappiness most clearly when he refuses to eat or drink. Unlike Pietro, Zeta expresses herself with the use of hand gestures and a handful of verbal expressions including her oft repeated and multi-meaning nonsensical articulation 'callacalla.' Pietro has been living in community over ten years while Zeta is still considered a 'new' core member, having lived in the same house as Pietro less than five years.

*

Over the past few months, I have noticed Zeta approach Pietro inquisitively on numerous occasions. Normally, when she comes close to him, Zeta begins by pointing to the black seat belt that rests just below Pietro's stomach. At times, I have also seen her grab it tentatively while awaiting Pietro's reaction to her contact. Pietro has a characteristic tendency of shaking his head rhythmically from left to right as though keeping time to the community's song. If he is doing so when Zeta approaches, Pietro stops. He observes. And he begins to rock his head back and forth again moments later. On some occasions, Zeta looks around to see whether someone is watching them.

Some assistants have noted that Zeta loves wheelchairs, strollers and vehicle rides. She also enjoys wearing a belt and in many instances, Zeta's interactions with Pietro are interpreted by assistants as being related to her love of his wheelchair rather than a *fascination with Pietro himself. In fact, even when Pietro is not in his chair, Zeta approaches the chair with much interest. Once in a while, an assistant helps Zeta make her way onto the chair where she remains happily for some time. Zeta expresses her joy in these moments with hand flapping, the extension of her lean legs, and ballerina-like toe pointing.*

*Zeta and Pietro also interact in other instances, however, rendering interpretation of their behaviour too complex for the aforementioned line of reasoning. Sometimes, Pietro's wheelchair cushion slides forward and assistants are obligated to lift Pietro while pushing the worn cushion back into place. In these moments, Zeta loyally makes her way to the scene of the action. When assistants help Pietro in repositioning himself, Zeta often laughs or giggles while placing her hand in front of her mouth. I have heard several assistants respond to Zeta's behaviour with “*Che c’e da ridere?,*” or “What is there to laugh at?,” subsequently sending her away. Other assistants interpret Zeta's behaviour to be an expression of concern; hence, they respond to her laugher with tender words of consolation.*

For his part, Pietro reacts to the manoeuvre by resuming or ceasing his lament, a deep-throated groan that Pietro often produces with a tormented expression on his face. Many assistants assure me that the forward position of the pillow obligates Pietro to slouch considerably, an arrangement that is uncomfortable for him over long periods of time. In the event that Pietro continues to moan post repositioning, assistants assume that the source of Pietro's discomfort is not the pillow's misplacement but the heat, fatigue, boredom... Regardless of the outcome, Pietro is indubitably aware of Zeta's presence and reaction in these moments.

Despite an inability to express themselves through language use, Zeta and Pietro clearly communicate complex messages with means such as relentless groaning, head-shaking, touching and pointing, giggling, and toe-pointing. It is thanks to these interactions that Zeta and Pietro relate to one another and to those around them. Communication, though often unproblematized (Backer, 2007), does not come without moments of frustration and doubt surrounding comprehension of the communicated message. Core members and assistants alike often recount or express frustration when misunderstood. Several assistants in fact describe these instances of misunderstanding and uncertainty as characteristic of their experiences in community. Following my discussion of means of interpretation at L'Arche, I will spend a significant portion of the chapter discussing instances of core member and assistant frustration. I will also elaborate on the significance of the prolonged uncertainty of comprehension as a product *of* communication as well as an approach community members subsequently take *toward* relationships in this context. Lastly, I will describe some successful instances of nonverbal communication in order to contrast them with miscommunications between verbal community members including assistants, administrators, and families or the greater community.

5.2 Communication and relationships

Communication is defined by cultural anthropologists as one of three things: first, as the transmission of information, second, as negotiations at the core of subjectivity and sociality, and third, as the intersubjective foundation for claims to both psychological and social reality (Jackson, 2008, p. 665). Anthropologist Eric Wolf (1996), who focuses on the first of these definitions, argues that communication is a process of "generating, sending, and receiving messages" (p. 6) including verbal and nonverbal messages such as gestures, bodily comportments, icons, displays of objects and representations of various types. Wolf (1996) goes on to argue that shared messages must "first be cast into appropriate cultural and linguistic codes;" communication involves the use of codes and participation in coding and decoding (p. 6). Wolf (1999) also notes that codes are not fixed as they vary greatly with the social and cultural contexts in which they are used.

Theoretically and when applied to languages, Wolf's (1999) depiction of communication as a system of codes is indeed elegant. However, codes become problematic when one attempts to tackle nonverbal forms of communication that are variable in ways that words or determinate signs are not. Brown (2003) demonstrates the variability in meaning of nonverbal messages with a case, namely gestures. She asserts: "one gesture may have different meanings, depending on the region, person using the gesture, and the one interpreting it" (Brown, 2003, p. 16). Variability, therefore, lies in the form of communication employed by the socially and culturally mediated communicator, the intention of the communicator, and in the receiver's methods of deciphering the meaning of the message.

An example of such a gesture is Zeta's open hand placement over her mouth as she appears to laugh or giggle when Pietro is repositioned. According to Brown (2003), the meaning of Zeta's hand position and laughter are dependent on Zeta herself as much as they are on their interpretation by Pietro or the assistants. Zeta's raised hand and laughter could mean anything from teasing and mocking, to a request for attention or a demonstration of concern, as described by assistants. It could also mean none of the above. In interactions with people with intellectual disabilities such as Zeta, the 'true' meaning of her laughter is not confirmed by Zeta for her interpreting receiver. This is at once because of Zeta's inability to speak and her use of few gestures to communicate multiple messages. An invariable outcome of communication with Zeta is a constant – though at times more in the foreground than at others – sense of uncertainty surrounding understanding. The second and third definitions of communication proposed by cultural anthropologists equally involve a sense of uncertainty as a result of interaction.

Together, the definitions of communication proposed by cultural anthropologists highlight the nature of communication as a means of interacting with and relating to others. Taken this way, communication – or lack thereof – can hence be understood to be the groundwork upon which people construct relationships with one another (Brown, 2003). Like Brown (2003) and Buckingham-Rivard (2010) before me, I understand communication to be foundational for relationships and hence the basis of the approach to caregiving that is promoted and encouraged at L'Arche (Vanier, 2007; Cushing 2003b). In other words, communication among community members is crucial to their personal well-being and that of the community as a whole.

An interesting paradox presents itself when the causal association between communication and relationships is flipped on its head. One could easily and convincingly argue that relationships are the means by which channels of communication are solidified. Though this is evident in numerous human interactions, it is particularly representative of those among verbal and nonverbal community members at *Il Chicco*. The paradox of communication and relationship – a chicken-and-egg debate – is pronounced in interactions between verbal and nonverbal community members due to the uncertainty surrounding interpretation of nonverbal messages. Despite the communication-relationship conundrum, what remains certain is the crucial role communication plays in caregiving relationships.

At *Il Chicco*, several people in fact point to the importance of communication for relationships and for care. When asked to define care, several assistants and community members including Alice, the mother of a core member Antonio, indeed equate communication and attentive listening with care itself. They state:

> Marika – 'Taking care of,' for me is listening – listening while always searching to, to mediate.
>
> David – Taking care of another especially when it comes to core members primarily means being attentive. Attentive to what they say verbally or nonverbally. Attentive to their needs in that moment. Attentive to what they want and what they may desire. And from there, attentiveness makes it so that we have to always be present during important moments in their lives in the house or outside of the community in all activities.
>
> Alice – So the ideal care [for Antonio] involves searching to understand him the best possible inasmuch as, inasmuch as it is possible. And searching to do the things that he likes doing.

Communication is hence seen as both the gateway to caregiving relationships, a product of relationships, and as care itself. This is evident in interactions between community members with and without intellectual disabilities.

5.3 Forms of communication

In what follows, I will now explore the primary means of communication put into practice at *Il Chicco*. A first and rather noticeable form of expression is oral communication between verbal core members, assistants, and administrative staff. Given that *Il Chicco* is situated near Rome, its members communicate primarily in Italian while at times referring to dialectal phrases from the area when conversing with fellow Romans. A large majority of core members and assistants are Italian citizens while a small minority of foreign assistants spend varying periods of time in community, rarely surpassing two years. Many of these foreign assistants arrive in community with limited or no Italian language capacity. In the months immediately following the arrival of a foreign assistant, numerous exchanges take place in English or French – second languages to some, though not all, Italian assistants and administrative members.

In addition to spoken Italian and dialects, *Il Chicco* community members make use of nonverbal language to communicate with one another. Brown (2003) defines this form of expression as follows "Nonverbal communication refers to 'messages other than words that are either sent with intent or typically interpreted by a receiver as meaningful'" (p. 15). Brown (2003), whose work focuses on relationships between verbal and nonverbal members at L'Arche, outlines several forms of nonverbal communication including facial expression, gaze, body movement, gestures, posture, physical contact, and interpersonal distance. Many of these are used by community members with and without intellectual disabilities alike. Brown (2003) notes, however, that a lack of verbal communicative ability is more common in people with intellectual disabilities, and nonverbal means are thus employed by these people out of necessity (p. 14). Brown (2003) goes on to explain that the lack of verbal skills among persons with intellectual disabilities can be “attributed to psychological deficiencies, hearing and speech disorders, or the simple fact of having grown up in a language deprived environment such as a large institution” (p. 14). This in fact is the case for most *Il Chicco* core members who lack verbal communicative ability. They represent more than sixty five percent of the people welcomed in this community and include both Zeta and Pietro.

Among the various means of nonverbal communication at L’Arche, some are worthy of note as they demonstrate the highly sensual nature of exchange between community members. Though messages may take on numerous forms, they are often transmitted more successfully when they make use of multiple sensory channels (Howes, 2003; Howes & Classen, 1991). Key nonverbal modes fall under two fluid categories: the positive and negative health statuses of members, and bodily contact manifested in caring and violent gestures. In what follows, I will describe these modes at greater length and take some time to discuss the significance of touch at L’Arche and in general.

5.3.1 Health statuses as nonverbal communication

Health problems or related issues range widely among core members of *Il Chicco*. Some, such as Emilio, have been near death on various occasions throughout the course of their lives. Several experienced assistants and long time friends recount difficult moments in community when the state of health of certain core members was at a critical point. One of the most ‘famous’ of these is the story of Emilio’s declaration of death. As a young boy, Emilio was proclaimed unlikely to live past the age of 6 by numerous doctors. Instead, Emilio is today 32 years of age and a man in the fullest of senses. Despite an inability to communicate verbally, Emilio's life testifies to a larger message; Emilio lives every day against all odds.

The message Emilio communicates with his recoveries in unlikely circumstances is a hopeful one. However, assistants and core members alike at times also communicate bleak messages through somatisation – or the physical manifestation of distressed mental states ('Somatisation,' 2013). Giulia, an assistant who has been working in community for more than twenty years, notes the following:

> Well I don't know if it's madness but I have observed concurrently let's say... in synchrony with 'big tensions' in community, the *ragazzi* got sick more often. In my opinion, they express a lot at the corporeal level. I mean, there is a correspondence. Now, it hasn't been proven scientifically, (laughs) obviously! But I have observed it on several occasions. I don't know if it's me that has, that with my head I want to see it this way somehow – this correspondence. But I am not the only one that has noted it, in sum.

She goes on to demonstrate her observation by explaining the way she and Antonio, one of the nonverbal men she frequently works with in the workshop, both express their *malessere*, or malaise, corporeally. Here, Giulia highlights the primacy of touch in her interactions with Antonio. She explains:

> A lot is communicated via touch. If I am upset with my daughter, I bring from home all of the stress that I live there, and with my hands and my tense body, I go do a manoeuvre with Antonio – a mobilization, a massage. It's inevitable that I transmit it [to him] because a lot is passed on through bodily contact. And they [the *ragazzi*], they are extremely sensitive to this. And when they arrive [from home], they [also] express it [*malessere*] very well – nervousness, muscle tension, rigidity – whether it be because of pain, or because of having been yelled at by someone.

Later on in my interview with her, Giulia also comments on Antonio's tendency to throw up frequently for extended periods of time at various points throughout the year – for example, during the hottest summer months. She describes this behaviour as another bodily means that Antonio employs to communicate with those around him.

Other health related modes of expression include a wide range of emergencies and physical demonstrations of need. In some cases and for some people, emergencies such as mild or grave injuries and bleeding are brought about by instances of intentional or unintentional self mutilation such as Zeta's biting of a hand when unsatisfied; assistant or core member loss or gain of weight in response to external factors; and/or inattention or haste when undertaking dangerous activities such as running or moving wood, among others. Haste, tension, and a rough manner are also noticeable among assistants who express discontent through nonverbal means during their work shifts. Communication with the use of physical demonstrations of need, on the other hand, range from screaming, pulling, defecating, and dirtying, to frequent hugging or touching, pointing at objects or depictions, and alertness or tiredness at unusual moments of the day. Each of these demonstrations could warrant its own discussion.

5.3.2 Caring and violent gestures as nonverbal communication

Another prevalent nonverbal means of communication at L'Arche involves bodily contact manifested in caring and violent gestures. Caring gestures involving bodily contact include hugging, kissing, holding hands, dancing, changing places on the couch or at table in order to be next to another person, eating, washing, and several others. For example, Beppe, one of the core members in community, demonstrates care toward some of the wheelchair bound core members who are largely nonverbal by gently placing his hand on the side of their faces and kissing their foreheads. This simple motion involves bodily contact outside of the necessary physical exchanges with assistants involved in morning and evening routines as well as bathroom runs for these people.

Change in nonverbal communication – from violent to caring gestures or vice versa – is also indicative of the state of relationships between community members. Camila, one of the live-in assistants, describes the transformation in her physical relationship with Federico, a core member with whom she initially had difficulty expressing herself. She recounts:

> Federico is the person who when I arrived [in community] he moved his face away from you when you got close. And then they told me that he had come from an institution where he had been hit [abused] and therefore he... when someone gets close – someone unknown to him – for him, that someone could try to hit him rather than caress him. Rico doesn't let just anyone shave him, when it is someone he doesn't know. Now, seeing a Federico that allows others to caress him... he even offers me his cheek to get a kiss! He lets others shave him or wash his mouth. Once, when I was washing his mouth, another assistant passed by us and told me: "*O mamma mia!* Now that's trust!," seeing this gesture.

Camila's description of Federico's initial hesitancies regarding being touched and subsequent transformation demonstrate the significance of contact as a means of communicating trust and affection in relationships. Similarly, accompanied swimming – especially for individuals who require assistance in the water – is for many core members another form of gratuitous bodily contact requiring trust on the part of both people involved. For many, the possibility and frequency of caring bodily contact is an important sign of successful communication.

Violence is also employed by both verbal and nonverbal members as a means of communication; aggression ranges from slapping, hitting, swearing, and screaming, to hair pulling, pushing, and kicking. Frequently, though not in all cases, violence expresses frustration felt by an individual. These, in turn, tend to be associated with the inability to communicate or to be understood. At other moments, frustrations are the result of tough situations, nervousness, environmental factors, or interpersonal disagreements.

Violent gestures are employed by assistants and core members alike. Though he may or may not intend to hurt others, Matteo – the bongo playing core member – sometimes reverts to aggression when communicating with others. One of Matteo's problematic performances involves throwing objects around or at fellow community members as a means of requesting attention, demonstrating frustration or other. He also, less frequently, pushes them in order to communicate messages including nastiness, boredom, or playfulness. In my interview with core member Lorenzo, he confirms having been hit by Matteo. He says, "Yes, like this" while demonstrating with a closed fist the way Matteo hits him on the head. Conflicts and intense or difficult relationships such as Lorenzo and Matteo's are demonstrated and expressed through nonverbal messages when other forms of expression do not sufficiently reflect what is felt by those involved.

Pietro, mentioned above, also makes use of bodily contact to indicate rejection of another person or an activity proposed to him. Rosetta, an assistant from Pietro's workshop who has known him since his arrival in community explains:

> Look, what I can tell you with certainty is that out of all of the *ragazzi*, [Pietro] is the one who is most able to make you understand whether or not he wants to do them [activities]. I mean, if Pietro doesn't want to do the activity, you actually hear him lament or he moves you with his hand. I don't know if you've ever experienced him send you away? And there you understand that maybe you've done enough, in sum. You do something else. You get him to do something else or you leave him in peace.

Despite being nonverbal and having a limited ability to move quickly, Pietro is nonetheless able to communicate a refusal to partake in a given activity by pushing Rosetta away with his arm.

5.3.3 The significance of touch

In the aforementioned examples of nonverbal communication at L'Arche, an assortment of senses is used to communicate messages of different kinds including respect for another, need for attention, and misunderstanding, among others. For example, the sense of smell is called upon in nonverbal physical demonstrations of need such as dirtying, the expulsion of gas, or defecation by certain core members. Some of these people resort to measures that require the immediate and one-on-one support of an assistant because actions are undertaken in unacceptable spaces or at unexpected times. These measures include intentionally getting dirty in various ways, hence producing smells that other community members find upsetting.

Generally, messages are communicated most effectively using multiple sensory channels (Howes, 2003). However, it became evident over the course of my fieldwork in community that nonverbal messages at L'Arche tend to involve touch alone or in combination with another or other senses. In most encounters, touch is involved in transferring a message from the communicator to the listener. This is in part due to the contact nature of the Italian context in which *Il Chicco* is located. Here, physical contact is central to social interactions between strangers and friends alike. It is also in part due to the necessity of numerous core members such as Pietro for assistance with moving, eating, and bathing.

Anthropologist Ruth Barcan (2011), in her sensorial ethnography of complementary and alternative medical practices, describes the significance of touch in relational encounters. She begins by observing that touch is the closest of senses; it is "available only in proximity and dispersed throughout the body" (Barcan, 2011, p. 141). Touch, she explains, is also understood to be the most reciprocal of senses in that touching always already involves being touched. Barcan (2011) notes that scholars have long interpreted touch to be the least deceiving – and hence most authentic – of senses because of its primacy in development and proximity (p. 142). Importantly, touch transmits pleasure and pain while "simultaneously affirm[ing] both our separateness from, and our ability to connect with, others; it is at once contact and difference" (Barcan, 2011, p. 143). These conceptions of touch are evident in Italian physically incarnated greetings such as hugging and kissing. They also come to the fore in verbal expressions including "*Senti*," or 'feel', used in the way Anglophones use 'look' or 'listen' to attract their auditor's attention. The verb *sentire* has several meanings when translate including 'feel,' 'sense,' 'hear,' and 'taste.' Here, the primary senses in Italian culture – namely touch, hearing and taste – are clearly identified (Howes & Classen, 1991).

As previously stated, the importance of touch is also highlighted in perceptions of the corporeal communicative ability of nonverbal core members at L'Arche. In her thesis on the nature of touch at L'Arche, Lindsay Paige Buckingham-Rivard (2010) outlines six different types of touch in caregiving relationships. These include instrumental touch, procedural touch, functional touch, expressive touch, accidental touch, and therapeutic touch[6] (Buckingham-Rivard, 2010, p. 14). Throughout her observation period in a L'Arche community in Ontario, Canada, Buckingham-Rivard (2010) traces the way each of the six types of touch is utilized by community members. One of Buckingham-Rivard's (2010) most important observations involves the use of what she terms 'community touch' at L'Arche. She notes: "various forms of expressive touch during community time contribute to a feeling of unity and mutuality" (Buckingham-Rivard, 2010, p. 143). Forms of community touch include hand-holding for prayer prior to meals and dancing during moments of celebration. My observations confirm the occurrence of each of these forms of touch at *Il Chicco*.

5.4 Methods of interpretation

As discussed, verbal and nonverbal expressions are communicated by people with and without intellectual disabilities alike and form the basis of relationship building between community members. At L'Arche and in a particular way at *Il Chicco*, expression involves the use of bodily contact by those communicating messages. These messages are subsequently received and meaning is deduced from a variety of signals. In addition to a list of nonverbal expressions employed by nonverbal core members mentioned above, Brown (2003) also establishes a list of some of the primary methods employed at L'Arche by people learning to 'read' and interpret the expressions of nonverbal community members. Once again, these readings make use of the senses. First, however, Brown (2003) stresses that a desire to know and understand nonverbal individuals must be at the base of interactions with them (p. 65). A lack of such desire quickly leads to frustration and misunderstanding, and hinders the possibility of entering into a relationship with nonverbal individuals.

Nevertheless, desire to communicate is not enough. Brown (2003) outlines six techniques used and promoted at L'Arche for interpreting messages communicated by nonverbal core members. These techniques include: 1) watching and learning from experienced assistants who are familiar with daily routine, medical conditions, and preferred activities, among others; 2) undergoing training – for example, participating in internal or external classes on *comunicazione alternativa aumentativa* or sign language basics; 3) observing and paying close attention to core members and to one's own reactions to various circumstances; 4) intentionally spending time with people one knows less even if this is initially uncomfortable; 5) slowing down one's pace in order to match that of the person with whom one is trying to communicate; and 6) dedicating an extended period of time to the entire process as getting to know others and vice versa increases with time spent on the task (Brown, 2003, p. 65-74). Brown (2003) notes that these techniques often prove effective in relationship-building among assistants and core members at L'Arche.

5.5 Frustration and uncertainty

The methods outlined by Brown (2003) do not preclude the possibility of difficult outcomes associated with the laborious task of learning to communicate with others. Brown (2003) affirms that core members tend to experience frustration because of inexperienced or inattentive assistants who do not understand their nonverbal expressions (p. 95). On the other hand, she observes that assistants become frustrated when core members ignore their attempts at communicating and lack a desire to partake in exchanges. They subsequently become violent thus frightening others, or express reluctance in getting to know and trust new assistants time after time (Brown, 2003, p. 96-98). The frustrations elaborated above are evident in the lives of *Il Chicco* members. Yet another outcome of learning to engage in alternative forms of communication became evident throughout the course of my fieldwork. This outcome involved a feeling of uncertainty surrounding comprehension of verbal and nonverbal messages. In addition to being seen as the outcome of communication, it is also framed as a desirable disposition toward interactions with verbal and nonverbal members. Uncertainty, assistants almost unanimously claim, is part and parcel of the L'Arche experience.

5.5.1 Core member frustration

Core members may experience frustration in response to being misunderstood by assistants. Take, for example, the interactions between Zeta and Pietro that are interpreted in a variety of ways by assistants. As previously mentioned, some interpret Zeta's laugher throughout Pietro's manoeuvre to denote mocking while others think Zeta is concerned in these moments. If Zeta is indeed concerned and assistants send her away when she laughs, this may cause her to feel rejected and, if nothing else, misunderstood.

Sophia, who is mentioned in the introduction of the previous chapter, also demonstrates her frustration in response to inexperienced and inattentive assistants in various ways including screaming, hair pulling, and scratching. For this reason, in the church scene, I am reluctant to approach her, knowing that we have not yet found a way of communicating. Over the course of the summer, our ability to correspond in fact greatly increases as misunderstandings decrease; we begin to get to know one another. Evidently, Rebecca – the assistant who is present in the church scene with Sophia – has surpassed the stage of total misunderstanding. She is hence able to communicate respect, presence, and concern with Sophia through the use of bodily contact such as a hand on Sophia's shoulder. Frustration is avoided thanks to the relationship that Rebecca and Sophia have developed over three years of living together.

5.5.2 Assistant frustration

Assistants also experience frustration at various points and with particular nonverbal individuals with whom they struggle to develop a relationship. Numerous assistants express having lived difficult moments with core members. Roberto, Giulia, and Maurizio describe these instances and the outcome of living through them in the following ways:

> Roberto – You have to take numerous slaps before you can enter into relationship with a *ragazzo*. You have to sweat to acquire a relationship, a friendship.
>
> Giulia – There is a lot of work that we assistants have to do when someone like Antonio arrives [in community]. And you really have to get your head going, you have to imagine many things. And yet to be very welcoming because the easiest thing to do... that really makes me feel bad [is] hearing expressions that I hear in community. It's the easiest way to get rid of Antonio. "He is acting up and I won't look at him anymore now until he stops." For me, the person is important. Their expression.

> Antonio has only this means [his cry] of self-determination. He is saying: "Hey! I am here too! Listen to me! Something is wrong, you have to listen to me!" Even though his cry really, really moves me. I mean, it make me nervous to be honest. It isn't something... now it's better because I have come to know him. At first, it was terrible. I mean it causes anxiety because it is heard so, so strongly.
>
> Maurizio – I lived relationships that were also very physical. I mean, with Arturo, the number of times we have gotten into a fist fight. Now it's no longer the case because a balanced relationship has been established. I mean, some of the things were quite crude. And that was my apprenticeship.

These assistants frame incidents as a part of a greater learning experience. In fact, 'contact' and eventual ability to communicate – with nonverbal core members especially – becomes crucial in subsequent moments of *crisi*, or crisis, such as the summer months in the absence of a community leader. Here, the importance and the rewards involved in risk-taking and undergoing moments of frustration are described by these assistants.

5.5.3 Uncertainty in understanding

In addition to moments of frustration, several assistants describe a feeling of uncertainty surrounding the interpretation or nonverbal methods employed by core members to express themselves. Uncertainty, in many cases, is portrayed as the product of interaction with community members such as Zeta and Pietro. An assistant, Camila, is in fact critical of those who claim that they know with confidence what core members communicate through nonverbal messages. In my interview with her, she distinguishes between moments of certain comprehension within the context of a relationship with others in which neither a relational foundation nor time spent together guarantee understanding as an outcome. She explains:

> But it really irritates me when someone says with absolute certainty that they have understood what they [core members] think. That really irritates me. I don't exclude that in the context of a relationship, I don't exclude it at all, that Beatrice communicates in the context of a relationship. But it has to be a nice and serious important

> relationship. A relationship that is built over several years, over much time spent together. Because it's difficult, I mean, after such little time to say: "Yeah, I know." I mean, but you have to ask yourself: "How much time have I really spent with Beatrice?" And someone can respond: "No but it depends on the intensity." Of course, I don't doubt it but... a relationship over several years is... it's that I can guarantee you Sarah that... (laughs) I once talked with Rosetta and Giulia who have known the *ragazzi* since they were children and who have seen them grow. There, one can talk about a relationship. But many times, Rosetta has told me: "But I don't know! I don't know what Beatrice wants in the moment. I don't know. I can tell you 'maybe' because I have seen her react this way rather than in another. But I don't know for sure."

Camila here speaks of uncertainty as an outcome of communication with core members such as Beatrice. She also appears to propose that uncertainty is also an approach to communication with them. In this passage, Camila refers to long time assistants Rosetta and Giulia in order to demonstrate her point. She maintains that if they who have been at *Il Chicco* for decades cannot claim to know what Beatrice communicates with certainty, someone who has recently arrived in community could not possibly be able to either.

The two experienced assistants – Rosetta and Giulia – that Camila makes reference to reiterate a similar approach to the one taken by Camila toward comprehension. In an informal conversation in their workshop, Rosetta and Giulia affirm that they cannot speak with absolute conviction about the needs and meaning of nonverbal messages transmitted by core members. Instead, both of these women told me that they did not feel comfortable speaking on behalf of core members and that they were suspicious of anyone who said they could. This response demonstrates that uncertainty becomes a part and parcel of the desired outlook on communication and relationships taken on by assistants.

In fact, most assistants I interviewed and spoke with in community expressed hesitation regarding their ability to accurately understand and care for core members. Camila explains that she prefers to maintain such an approach because it allows nonverbal core members such as Zeta the possibility of growing and changing. She says:

> It seems that Zeta likes certain things but Zeta is growing. Zeta is more feminine now compared to last year. She likes getting dressed a certain way a lot more now. And therefore being... I mean knowing... seeking to get to know her without thinking that you have to get anywhere specific in the process or feeling that you have to fit them [core members] in a box. Absolutely not! Because I would not want anyone to do it with me either. If someone says: "I know Camila. And she is like this, this, this, this, and this" (laughs). Therefore I would feel blocked, without the ability to surprise. On the contrary!

Camila, here, explains that she always tentatively names Zeta's preferences because she views Zeta as a person in constant state of growth. Unlike other approaches to care, such as Kleinman's (1988) that focus on defining problems with certainty, Camila's approach involves attributing to Zeta and other core members the same human qualities she wants others to recognize in her. The most important of these characteristics for Camila is the freedom to change.

Camila is not the only assistant who justifies her approach to communicating with nonverbal members this way. Another assistant, Rebecca, also describes uncertainty surrounding her ability to communicate with and care for others. She says that she feels that she is only seventy percent good at caring. She also expresses contentment with her incomplete care status. She exclaims with joy: "I still have room to grow! And you know, the truth is, I don't want to get to one hundred percent." When I asked why, she responded saying that, for her, reaching perfection in care and in communication is comparable to dying. It represents an end and a perception that involves no longer having anything to learn or to improve on. According to Rebecca, and in synchrony with the views of many other assistants, such a perception is fundamentally problematic in a place such as L'Arche where care is not about definitions and certainty but about relationships. This runs counter to dominant care models in which the central focus is appropriately defining and addressing the source of the manifested problem.

5.6 Nonverbal communication and verbal miscommunications

Despite various instances of frustration experienced by both assistants and core members, several nonverbal exchanges between community members are indeed successful. Many people describe these moments as triumphs and turning points in their relationships. These successful nonverbal communications contrast greatly with the verbal miscommunications that take place at L'Arche primarily in relationships among assistants, between assistants and administrative staff, and between assistants or administrative staff and the families of L'Arche core members. Unlike the triumphs in nonverbal exchanges, a lack of communication between verbal members hinders the possibility of relationship for them and hence weakens the global sense of community. As is the case for wellbeing of community member dyads, the wellbeing of *Il Chicco* as a whole is greatly affected by the frequency, effectiveness, and content of communication.

5.6.1 Successful nonverbal communication

Moments of successful nonverbal communication are described by assistants as successes of the greatest kind and as necessary when living through eventual difficult moments. Rebecca, for example, describes initially experiencing less difficulty communicating with nonverbal core members in community. Having been born in an Eastern European country and having arrived in community with no knowledge of the Italian language, she describes quickly learning to communicate nonverbally with all community members. During her interview, she jokes about not having had to surpass a language barrier with nonverbal core members such as Emilio. Another foreign assistant, David, describes a powerful instance of nonverbal communication with Stefano, a deaf core member:

> I have always asked myself about a day when I was in [country of origin]. Before leaving, I had left the picture of Stefano and me at the sea. When I came home, they told me that in the evening Stefano would kiss the picture before going to sleep. And one day, it was the day of his birthday, I was in [country of origin] and I wasn't even aware of it but I called that day because it had been a while since I had talked to everyone. I called accidentally. It was the day of his birthday. They passed the phone to him and later asked him who was on the phone. He indicated the picture where we were the two of us. And so we asked ourselves: Stefano hears? If I spoke with him, there is no way he heard me. But how did he know to indicate me as the one with whom he had spoken? Therefore, he [Stefano] doesn't say it verbally but he makes it known [that he cares for you] even when he prays for you. Chooses between various photos and then tells you (shows a picture with his finger). I am praying for you. He takes care of you. In his prayers, he offers you to God. Yes. He doesn't say it verbally but he makes it known to you. He takes care of you in that, in that way also. Yes.

The episode recounted by David is mysterious. Nevertheless, David also highlights Stefano's tangible nonverbal communicative abilities when he elaborates on Stefano's gestures and actions including prayer, thanks to which he feels cared for by him. David later ads: "it isn't per chance that out of all of the *ragazzi* from the community to whom I am nonetheless tied, with Stefano I have a sort of special relationship."

Yet another assistant, Niccolò, describes his relationship with a nonverbal core member, Italo, as one of communion. When I asked him how he had come to be in communion with Italo, Niccolò describes the following:

> Being together. You don't need many words. Because with Italo, I arrive and Italo hugs me. And I often don't even know why! But at the bottom, Italo and I don't have big conversations because he doesn't speak. Therefore it comes from spending time together and sharing life. Sharing individual moments. And it's not only work because in the morning, many things happen. And hence I cannot say that it's only work [that we share] in the good and bad. Because at times, we should be working but Tom, Dick and Harry, and... show up and we become very distracted. But many times, the simple fact of going for a walk together or look out at scenery together without having to talk... you enter into communion. You share. You are together.

Relationships such as Niccolò and Italo's are understood to be the result of spending time together and communicating presence, trust, and companionship through nonverbal language such as hugging. Camila also expresses triumph when she succeeds in understanding yet another of Zeta's nonverbal gestures. Upon picking up on Zeta's nonverbal cue, Camila communicates great joy and celebrates with Zeta for whom the success is of no lesser value. Understanding and being understood are equally important in relationship-building.

My own experience interviewing Lorenzo, a core member with limited verbal ability, confirmed this feeling of triumph for me. At numerous points throughout his interview, Lorenzo makes use of gestures in order to describe activities, events, or feelings. In one instant, Lorenzo explains the tasks he helps with in his community home. Having forgotten the word 'plate,' Lorenzo rotates his right hand in circles to indicate the act of washing dishes while encouraging me to engage in a guessing game saying: "*Aiutami*," or help me. In these instances, Lorenzo expected me to guess what he might be referring to; I uttered my guesses verbally and Lorenzo confirmed the correct answer if and when I got to it.

5.6.2 Verbal miscommunications

Instances of verbal misunderstandings contrast greatly with the success stories outlined above. Miscommunications, particularly during the difficult summer months in the absence of a community leader and at this moment in Italian history, are detrimental to the wellbeing of community members and the sense of community itself. These misunderstandings occur between assistants, assistants and administrative staff, and L'Arche assistants and administrative staff and the families of L'Arche core members. Though they are not limited to inter-community relationships, I will focus on these specifically as they comprise the greatest roadblocks in the L'Arche goals outlined in the community Charter (Appendix G).

In interviews with numerous assistants, significant misunderstandings were communicated to me including differing understandings of core member behaviour and appropriate response; interpretations of the necessity and means of adhering to established community regulations, traditions, and schedules; views on the decision-making process; perspectives on the role of community members in various positions; outlooks on a contested L'Arche past and an equally debated desirable future direction, including the importance of spirituality and religion; and positions regarding the appropriate place of family members in the lives of core members, to name a few. Though each of these is certainly an area that requires much work by community members, I am more concerned with the way these various misunderstanding have an impact on relationships themselves and on the sense of community that is fostered (or not) as a consequence.

The impact of miscommunications on relationships often involves frustration and uncertainty described above. Marika describes the verbal miscommunications that frustrate and discourage her this way:

> According to me, we aren't even used to talking. And then we haven't yet reached a common understanding. Therefore something as simple as, I don't know, Zeta can stay in the kitchen while we cook, or can't she? With you yes, with me no, with him yes, with him no, with him no... Arturo can use his computer or can't he? With him yes, with him now, with him yes, with him no... This isn't a decision-making process. We have said things who knows how many times. I have even written things down in order to create a kind of rule for the house, for example. No? It could even be accompanied by images. It's just that lately it's always becoming a bit redundant. There is a lot of talk and very little action. But then if I attempt to do it alone, ah well it's because I did it alone.

She goes on to note that the result of a lack of common rules or agreement on basic daily tasks and activities leads to the creation of a very gloomy environment, particularly for the core members. This atmosphere is often described by community members as *pesante*, or heavy, instead of the otherwise joyous and *leggero*, or light, air felt in community when things are going well. She says:

> You see Fiorella goes to her room to do things on her own. Arturo and Lorenzo sometimes begin to play the goose game in the living room. Pietro remains in his spot. Maybe someone remembers to give them something to drink once in a while. This is depressing! But I can't say that it isn't realistic.

Marika claims that the miscommunications between verbal assistants and administrative staff accompanied by a more generalized lack of organisation lead to poor uses of time and disheartening scenes such as the one described above. As is confirmed by my daily observations, these scenarios cause tension between community members to accumulate, and harm their sense of identity. I will discuss these outcomes further in Chapter Seven.

6.0 MUTUAL CARE

6.1 Introduction

The two previous chapters introduce the socio-cultural contexts in which *Il Chicco* community members live their lives. In Chapter Four, I explore normalizing perceptions of disability in Italy in order to contrast them with alternative conceptions of disability notable in Vanier's works, the L'Arche Mission and Charter, as well as the daily lives of individual community members. In Chapter Five, communication through verbal and nonverbal messages is presented as the primary means by which people with and without intellectual disabilities enter into relationship with one another. At L'Arche, as I will demonstrate in this chapter, relationships serve as the foundation for care in its various forms. I take the following relationship snapshots as a starting point.

Snapshot 1: Piera and Rocco

If there is one thing that keeps Piera motivated to get through her morning activities, it is the thought of making her way to the kitchen for the preparation of 11 a.m. tea. Though tea may or may not be of actual interest to Piera, Rocco, the community cook, is. In fact, Piera is often heard loudly calling Rocco's name across the courtyard when he takes a leave from the kitchen to pick fresh herbs, spices or vegetables from the community garden to add to the lunch-hour meal. Piera regularly works outside with the others from her workshop on maintaining the gardens, including raised grounds built a few years ago and accessible to everyone including wheelchair-bound core members. She is also involved in making recycled paper and teas from the cultivated plants. This summer, Piera is the only person *with intellectual disabilities still living with her family to attend a workshop on a daily basis. Rocco’s position is also unique. Unlike other assistants, he is, simply put, simply the cook.*

*Having both lived the majority of their lives near Rome, Rocco and Piera speak similar Italian dialects. I have noted that some assistants do not always understand Piera when she speaks despite her relative articulateness. Rocco, on the other hand, appears to comprehend Piera well. Many find it amusing that Piera is quite possessive of Rocco and jealous of those who spend extended amounts of time with him or close to him. She demonstrates her jealousy or frustration in certain moments by screaming “*E mio!,*” or “He’s mine!,” to which Rocco tends to respond with an acknowledgement of Piera’s outbreak. Fortunately, assistants say, Rocco is only the cook. Unlike a meagre cook, however, Rocco’s presence is affirmed and confirmed by Piera’s recognition of his value and importance in community and in her life.*

Snapshot 2: Fiorella and Camila

Her choice: dark blue almost black. Fiorella, a verbal core member with a penchant for the 1985 motion picture classic Ladyhawke*’s handsome hero Captain Navarre – or Navarro as she likes to call him – has wanted to dye her hair for some time. Normally, she undertakes such activities in her workshop in the company of Noemi, an ex* maestra *of art and highly creative person. This time, however, Noemi is too busy for such an endeavour. Instead, Camila, an assistant from southern Italy who has been living with Fiorella for just over a year, becomes the hairdresser this afternoon. While other house members relax in the living room, Camila and Fiorella set up a makeshift hair parlour in the larger of the main floor bathrooms. There, Camila massages the black gooey hair dye into Fiorella’s sensitive scalp with gloved hands. Despite the low assistant to core member ratio, I am also* *encouraged to participate in Fiorella's hair dying adventure. Naturally, I run up to the third floor where my camera awaits me. Over the next hour, I snap beautiful smiles on both Fiorella and Camila's faces as these two women who otherwise have a tendency of preferring to spend time with others share this intimate moment together. Though color is a matter of taste, care is a matter of time. Today, Fiorella and Camila have won the jackpot.*

Snapshot 3: Valeria, Pietro and Matteo

There are two nurse practitioners, a head nurse and various rotating doctors present in community at several points throughout the week. At Il Chicco*, recent changes in legislation have resulted in hiring additional personnel in order to fill the requirements laid out by the Lazio region. This summer,* Il Chicco *awaits accreditation in order to become a recognized* struttura sanitaria*, or health center. In addition to the new hires, two experienced and long-term personnel live these changes as well.*

Valeria is one of the experienced personnel; she is a nurse practitioner who has been working at L'Arche just under a decade. Often circulating in heals – a feat I greatly admire given the nature of her job – and a phenomenal dessert-maker, Valeria is familiar with the community core members and their health conditions. Despite her familiarity with each of the core members, entry into her office reveals a side of Valeria otherwise invisible to the untrained eye. On the wall up against which her desk rests are several pictures of Valeria and her family with core members Pietro and Matteo. Though some of these photos are recent, the majority date back to a time when Matteo was significantly heavier and when Pietro held a fuller head of hair. When I ask her about these pictures, Valeria tells me that she has a close relationship with Pietro and Matteo, one she cannot nurture in the way she would like given her familial obligations and recent changes in community life. As the *summer months pass, I do note Valeria's affinity for both of these men – an affinity she expresses in frequent visits to them in their respective homes, caring gestures and playful teasing. Pietro and Matteo are both responsive to Valeria in these moments of encounter and turn to her – Matteo more easily than Pietro – in moments of need.*

Relationships at L'Arche evolve from moments of encounter such as the ones recounted above. Relationships in this context involve exchange in a way that those between caregivers and care recipients in other contexts do not (Sumarah, 1987a; 1987b; Forster, 2007). Unlike other models established on a unidirectional notion of care, care at L'Arche involves cooperation and interdependence (Sumarah, 1987a). In this chapter, I will begin with a discussion of the significance of caregiving relationships between persons with and without intellectual disabilities at L'Arche. I will then name the primary outcomes allowed for by relationships between community members including overcoming dominant conceptions of disability, communicating and adopting an attitude of uncertainty toward caring for others at L'Arche, and mutual well-being as a result of caring *about* (the value) and caring *for* (the practice) others and vice versa. Furthermore, I will refer to the works of Vanier (1989; 1997; 1998; 2008) and others (Cushing, 2003a; 2003b; Cushing & Lewis, 2002; Escrader, 2001) in an attempt to sketch a portrait of ideal relationships at L'Arche – mutual caregiving interactions or, in Vanier's (1998) words, relationships of communion between people with and without intellectual disabilities.

Finally, I will spend the remainder of the chapter delving into the six principles of mutual care at L'Arche and the factors that have an impact on the possibility and success of mutually caring relationships across difference at *Il Chicco*. These will include factors such as the human aspects of relationships including jealousy evident in Piera and Rocco's relationship; time constraints, staff availability as a consequence of government funding, and personal affinities as in the case of Fiorella and Camila's relationship; and legal changes and a caregiving burden associated with fulfilling community responsibilities and statutory services at play in Valeria's relationship with Pietro and Matteo. Furthermore, I will look at two other limiting factors highlighted in the fourth snapshot that follows. The first limiting factor of note is the desire and ability to recognize and value 'other' forms of care such as Italo's gesture toward Benilda. The second involves the delicate power negotiation involved in all relationships and particularly pertinent to the possibility for empowerment of persons with intellectual disabilities. These limits on mutual care and others will be discussed.

Snapshot 4: Benilda, Italo and Niccolò

Today, Italo and Niccolò are showing me some of the activities they undertake in their workshop. As we leave the workshop space situated under one of the homes, Italo and Niccolò note that the sunflowers require trimming as they have already begun to wilt and dry. Several small bees buzz around the plants collecting what is left of these bright yellow flower heads. Upon hearing Niccolò point out an undone job, Italo – a keen collaborator and strong manual core member – disappears into the community greenhouse. He soon returns with garden scissors in hand. Niccolò and Italo subsequently cut the dead and half-dead flowers near the base. Upon stumbling across an intact flower, Niccolò cuts the stem slightly shorter and prunes the dead leaves that render it uninviting. Handing it to Italo, Niccolò encourages him to run up to the office. There, Italo offers the flower to Benilda, one of the two secretaries working in the office of Il Chicco*, who thanks him with a "*Ma grazie!,*" or "Why thank you!" Her thankfulness is audible from where Niccolò and I are busy working. Italo returns with a determined stride while mumbling one of his* *characteristic expressions "*Mammaggia mammaggia,*" which roughly refers to the polite vulgarity* mannaggia*, or dammit.*

Later on, Italo and Niccolò's show me the literal fruits of their labour, one of which is a meter-long zucchini Italo proudly poses for a photo with. Two external members including a physician and long time community friend ask to purchase vegetables upon seeing Italo's morning harvest. Italo collects the dividends from the regular customer, both of whom willingly pay two times the requested price for their zucchinis and cucumbers.

Before leaving on an outing to the nearby hardware store for glue, Niccolò encourages Italo to deposit their earnings in their workshop register. While awaiting Italo in the car, Niccolò turns to me saying "I trust Italo with money. This is something I cannot yet do with everyone." He goes on to explain that some other core members tend to pocket the merits while Italo demonstrates a great sense of responsibility toward these small earnings. Along with other members of their workshop, Niccolò and Italo agree that the best way to spend their collective income is to treat themselves – quite exceptionally – to an extravagant seafood dinner.

6.2 Relationships as the foundation for care and well-being at L'Arche

Relationships are at the heart of what community members experience and take part in at L'Arche (Cushing 2003a; 2003b; Cushing & Lewis, 2002; Escrader, 2001; L'Arche n.d.; Pottie, 2001; Pottie & Sumarah, 2004; Sumarah, 1987b; Vanier, 1989; 1997; 1998; 2008). Although most relationships are caregiving in nature – particularly those between assistants and core members – other relationship configurations include varying degrees of friendship or work interactions primarily between core members, between assistants, and/or between administrative staff. Despite the variability in relationships found and fostered at L'Arche, the writings of Vanier (1989; 1997; 1998; 2008), the Mission and Identity Statement of L'Arche (Appendix H), and the work of scholars including Sumarah (1987b), Cushing (2003a; 2003b), Cushing and Lewis (2002), and Forster (2007) focus their attention on relationships between persons with and without intellectual disabilities. Cushing (2003b) justifies her choice by stating that these relationships embody the spiritual, moral, and political aims of L'Arche and remain insufficiently documented in academic literature (p. 241). Because of my interests in mutual care as a model, I too will focus on caregiving relationships such as those featured in snapshots two, three and four in what follows. Nevertheless, I recognize that the other types of relationship configurations are equally deserving of academic attention.

Caregiving relationships between persons with and without intellectual disabilities are also significant in that they "form an illuminating case of working with diversity" and across difference (Cushing, 2003, p. 241). In the previous two chapters, I highlight two of the important sources of difference that characterize the relationships between assistants and core members at L'Arche. The first source of diversity is the range of (dis)abilities of community members and a resulting wide range of care needs. A second important source of difference between many assistants and core members is the form of expression as well as the degree of communicative ability that is frequently mediated by a variety of biological, social or cultural factors. Though other sources of difference arise, variable (dis)ability and communication represent fundamental gaps in all relationships among persons with and without intellectual disabilities. Encounters across these differences become significant because they provide assistants and core members a set of three possibilities which I will explore in what follows: namely the possibility of overcoming dominant conceptions of disability; the possibility of communicating and adopting an attitude of uncertainty toward caring for others; and the possibility of well-being for assistants and core members alike.

6.2.1 Overcoming dominant conceptions of disability

As elucidated in the previous chapters, interactions between persons with and without intellectual disabilities enable community members to overcome the misrepresentational conceptions of persons with intellectual disabilities (Cushing & Lewis, 2002). Though not all of those who spend time at *Il Chicco* succeed in moving from dominant representations to interaction, L'Arche fosters an environment in which relationships are *possible* and *desirable* in a way that other care centers do not (Escrader, 2001; Forster, 2007). When assistants Marika, Roberto and David describe the other centers they were exposed to prior to their arrival at L'Arche, they elaborate on the way relationships with people with intellectual disabilities in these other centers are discouraged or avoided through professionally-sanctioned distancing and othering methods (Cushing, 2003b).

On the other hand, L'Arche encourages relationships in various ways such as planned week-long vacations in the summer months with an elevated assistant to core member ratio. All core members participate in a vacation group and assistants who are able to take time away from other obligations do the same. Vacations normally involve special activities such as afternoons on the beach, visiting important religious sites, and touring or shopping. Other L'Arche events meant to promote relationships include weekly and monthly gatherings such as mass in the community chapel, birthday celebrations, and community get-togethers like the *incontrò di comunita* mentioned in the introductory chapter. Also, moments of one-on-one time with others including Camila and Fiorella's hair dying adventure or Italo and Niccolò's outing to the hardware store are essential to nurturing budding relationships between community members.

6.2.2 Communication and adopting an attitude of uncertainty

Relationships across differing means of communication also challenge assistants and core members to find new ways of exchanging messages with one another. For both assistants and verbal as well as nonverbal core members there is often an uncertain understanding of the content of what is indeed being communicated. As I note in Matteo's interaction with Elisa, communication does occur above and beyond transmission of content and includes such messages as tone and tension. Assistants and core members alike are hence encouraged to be attentive toward one another in the context of their relationships. Attentiveness and respect do not, however, guarantee comprehension of the other's communicated message. Uncertainty is an outcome of relationships across difference.

Uncertainty is also, as I have argued in the Chapter Five, an attitude toward the other that allows both assistants and core members alike to view themselves as perpetual learners. The stance of a learner, unlike that of a teacher or master, promotes humility and respectful listening; it contributes to levelling – particularly in the initial stages – the power dynamics at play in such delicate relationships.

Some community members describe moving beyond uncertainty in comprehension toward a sense of conviction in theirs and the other's ability to grasp the essence of a transmitted message, even when parts are misunderstood or lost entirely by either party. Long-term assistant, Giulia, attributes her ability to overcome uncertainty to a learning process she undertook upon exposure to strategies employed by other assistants present in the initial stages of her time at *Il Chicco.*

> I was trained by the people I found here [in community] before me to not worry about what [core members] understand, what they don't understand, or how much they understand of what I say. I address them as though they understand everything. I trained myself and learned to adopt this kind of attitude that then reflects a bit the respect toward the other person that you want to transmit, no? I can imagine that they don't get everything. But what they do understand goes far beyond words. They understand the tone of my voice. They understand my nervousness or my serenity.

Giulia here does not focus on specific messages transmitted through verbal or nonverbal means, though she does note that some of these are indeed grasped by core members. Instead, she refers to the meaning she aims to convey through her daily interactions with people with intellectual disabilities, namely respect and recognition of the humanness of her fellow community members. Though the attitude of a learner in relationships can engender a situation of mutual caregiving, it can also be frightening and hurtful if the other person involved does not adopt a similar approach. For this reason, L'Arche has tended to create support networks for new assistants for whom accompaniment in the initial stages of entering into relationships across difference can be quite difficult.

6.2.3 Mutual Well-being

Another significant possibility available to assistants and core members as a result of relationships across difference is well-being. This takes place when someone cares *for* and *about* another (Kittay, 2001; 2011; Held 2006). Such an understanding of care is in fact prevalent among *Il Chicco* community members. Valeria's relationship with Pietro and Matteo described in the introduction to this chapter illustrates the dual nature of care. On the one hand, Valeria engages in a variety of practices that allow Pietro and Matteo's biological needs to be met. She is a nurse practitioner who manages and administers pharmaceutical drugs Pietro requires at various moments of the day. Valeria also accompanies these men to appointments with medical professionals and assists them in their morning routines. For Pietro, this involves changing his diaper, cleaning his body and ensuring hygienic living conditions for him, dressing him appropriately for the day's activities, moving him from his bed to his wheelchair, helping him eat by placing food on his utensil that he is then able to manipulate on his own and ensuring that he ingests his prescribed medications.

In addition to the practices that Valeria engages in while caring *for* Pietro and Matteo, she also cares *about* these two men in that she performs the practices mentioned above with care – with a sense of concern toward and in solidarity with them. Valeria is responsive to these men, as they too are toward her, and demonstrates concern for them with her frequent visits to their homes and playful teasing. What I have described is only half of the story, however. Pietro and Matteo similarly engage in caring *for* and caring *about* Valeria in their own ways. For example, when Valeria is seated close to Pietro, he runs his fingers through her hair, a gesture she much appreciates. Pietro also emotionally supports Valeria who comes to spend time with him when she needs to take a break during a hectic day. Other assistants have also pointed to Pietro's incredible patience in initial stages of their time at L'Arche. This patience involves undergoing rough or uncomfortable manoeuvres by untrained assistants while waiting for them to learn to take on a gentler approach to his body. As a result of these and other gestures carried out with great care, Valeria feels valued by these men.

Though Valeria does not herself describe it this way because I do not ask her directly, another assistant, Ilenia, attempts to put the reciprocal nature of her relationship with a core member Emilio into words. She describes the care she receives and feels as a result of her interactions with Emilio, a man with no verbal capacity and limited motor activity similar to Pietro, as follows: "When I've gone haywire, Emilio is personally close to me. He doesn't say anything... I mean... it's the fact of being there that, that speaks more volume than anything else. He transmits much more than others." Here, Ilenia describes feeling cared for and about by Emilio who is attentive and present in a way others are not when she is emotionally or mentally upset.

For Vanier (1989, 2008) and others such as Henry Nowen who have firsthand experience in living at L'Arche, well-being as a result of being cared for and cared about in the context of relationships across difference are not seen as a theoretical concept but as lived experience in its truest sense. Attaining a state of well-being initially entails a slow process and subsequently requires maintenance by those involved. Kittay (2011) in fact speaks of care as a form of investment in the other persons' well-being. She argues that because people are always 'selves-in-relation,' one's "own sense of well-being is tied to the adequate care and well-being of another" (Kittay, 2011, p. 54). Achieving a state of well-being hence involves a process in which both the conventional caregiver and the recipient of care are involved in giving and receiving. As a consequence, individuals who enter into mutually caregiving relationships often undergo moments of transition prior to attaining a relative state of balance such as is the case for Valeria's relationship with Pietro and Matteo. This relationship, unlike many between newer L'Arche members, is the result of a process that has had the benefit of years of shared experience. Below, I demonstrate the role of relationships in the healing process that leads to a mutual state of well-being for core members and assistants alike.

For several existing core members in community, a clear and poignant transformation occurs when they arrive in community where they begin to enter into relationship with others. Authors such as of Cushing (2003b) have noted that transformation narratives circulate among community members and serve as motivational examples for those living difficult or intense relations with others. In Chapter Five, Camila describes the change in Federico's reactions to interaction and contact with others as having moved from fear and rejection to trust and contact. Camila's testimony is supported by Rosetta's lived experience with Federico upon his arrival in community. She describes the first activities she undertook with him:

> Federico [eventually] let others hold his hand and agreed to lie down on a mattress. For days he agreed to do only that. I would say: "C'mon Federico, lie down." And I would show him some materials but he didn't want to [partake]. Then slowly, it required patience on my part, and listening too, I mean somehow he felt that I respected him. I mean, I didn't go there telling him: "C'mon Federico! Let's do this thing," no? But I showed him the material first. "Look at this. Look, I will do it first on myself," no? And he would watch me. For a long time, many days, he only watched me as I undertook various activities. Then, probably, he began to trust me. He understood that it wasn't something violent or something that would cause him harm and so he started to allow me to do activities with him. And this was the beautiful moment of transition. Something was unlocked.

Above, Rosetta describes a significant change in her relationship with Federico. In this case, Federico was afraid of Rosetta because he had learned from previous experiences in another center, that it was best not to trust others immediately. Federico suspected that Rosetta may abuse of his trust as others had done before. Rosetta here portrays being unable to engage in rehabilitative sensorial activities with Federico prior to what she identifies as the moment of transition toward a relationship founded on trust rather than fear. Like other L'Arche examples, Rosetta and Federico's relationship is at the basis of Rosetta's ability to care for Federico.

Examples demonstrating initial distrust by assistants rather than core members also circulate at *Il Chicco*. For instance, the uncertainties I express regarding my interactions with Sophia in the church scene are distinctive of the fear and uncertainty several new assistants describe when initially getting to know Sophia. Despite overcoming these fears in time and thanks to frequent positive interactions with Sophia over the summer months, I am aware that this is not the case for all of the people who come to L'Arche. As in the case of Rosetta and Federico, Sophia can care for me through gestures such as kissing and hand-holding when I cease to fear contact with her and when I begin to trust her.

The central role of relationships in the healing process has been demonstrated at L'Arche, as described above, and in caregiving relationships generally. Numerous scholars including Taussig (1980), Kinsley (1996), Cushing (2003b) and countless illness narratives (Frank 1991) have convincingly argued that a relationship of trust between caregivers and the recipients of care are in fact *necessary* for care and crucial to the healing process rather than merely secondary to biological and physical aspects of care.

Here, it is important to note that by health, I intend to refer to "complete physical, mental, and social well-being" (World Health Organization, 1946, Preamble). In his book *Health, Healing, and Religion*, David Kinsley (1996) stresses the potency of ritualistic and symbolic aspects of medicine in the healing process. He utilizes the placebo effect[7] in order to demonstrate that healing involves more than instrumental care resulting in biological changes. In addition to representing patients' symbolic ability and intention to heal themselves, Kinsley (1996) argues that the placebo effect also represents the healer's influence on and concern for the patient. These symbolic qualities of the relationship between caregivers and the recipients of care are always at play, Kingsley (1996) argues, in healing situations and frequently result in positive healing results. Kinsley (1996) concludes with: "Indeed, the placebo effect might be thought of as the tangible expression of the patient's faith and trust in the healer" (p. 166).

6.3 Mutual care

Though Kingsley (1996) demonstrates with the placebo effect the importance of relationships founded on trust, he fails to unpack some of the more problematic aspects of viewing caregiving relationships as practitioner-patient relationships in the first place. As discussed previously, understanding care as partnership is productive in that it proposes breaking down power relations between caregiving partners while understanding care as a mutual endeavour. Such an approach to care is still relatively new with respect to the biomedical, independent living, community-based and client-centered models discussed earlier and is implemented in few publicly funded caregiving contexts to date (Forster, 2007). Some scholars including Horwitz et al. (1996), Oeseburg and Abma (2006), Williams and Robinson (2001), Komter and Schans (2008), Lewinter (2003), and Graham and Bassett (2005) have begun to shed light on the use of the mutual care model in familial or private contexts but very few studies exist wherein mutual care is systematically implemented in public or private institutions.

Sumarah's (1987b) work on L'Arche is in fact one of the first of its kind to describe care as partnership outside of the familial home. In years following Sumarah's (1987a' 1987b) publications, numerous theses by master and doctoral students including Pottie (2001), Escrader (2001; 2008), Cushing (2003b), Brown (2003), Bowling (2006), Forster (2007), Buckingham-Rivard (2010) make reference to the mutual care model in research on L'Arche communities in Canada and the United States. None, however, is focused on the application of this model at L'Arche outside of North America. Despite the considerable contextual differences between my research and theirs, it becomes evident through an analysis of *Il Chicco* community member voices that a similar project of mutual care is promoted and undertaken in the Roman branch of this international organization. In the next section, I will discuss the L'Arche orientation toward mutual care and outline Vanier's conception of ideal assistant-core member relations at L'Arche. Subsequently, I will demonstrate the veracity of the principles outlined by Cushing (2002) in their attempt to theorize mutual care at L'Arche while highlighting the practical application of these principles by *Il Chicco* core members and assistants.

6.3.1 Ideal assistant-core member relationships at L'Arche

As previously mentioned, L'Arche promotes the idea of mutual relationships across difference between people with and without intellectual disabilities (L'Arche, n.d.). This concept originates in the ideas and work of Vanier, the founder of this international organization. Though Vanier does not make use of the term mutuality in caregiving relationships – which is later coined by the international organization and used by scholars such as Sumarah (1987b) and Cushing (2003a; 2003b), he does extensively describe assistant-core member relationships at L'Arche. He identifies friendship between community members as a form of communion. The following passages in two of Vanier's books describe the type of relationships that are encouraged between assistants and core members.

> L'Arche is rooted in love. We assistants live in communion with those with intellectual disabilities because as human beings we seek... to love and be loved. (2007, p.1)
>
> Communion is mutual trust, mutual belonging; it is the to-and-fro movement of love between two people where each one gives and each one receives. Communion is not a fixed state, it is an ever-growing and deepening reality that can turn sour if one person tries to possess the other, thus preventing growth. Community is mutual vulnerability and openness one to the other. It is liberation for both, indeed, where both are allowed to be themselves, where both are called to grow in greater freedom and openness to others and to the universe. (1998, p. 28)

Relationships of communion between assistants and core members at L'Arche are the purpose toward which interactions are directed. Importantly, Vanier refers to trust and belonging as defining characteristics of relationships between assistants and core members. For Vanier (2007), relationships must be authentic and unique to those involved. Assistants and core members are described as equal participants in a to-and-fro process of giving and receiving. Vanier here describes the object of exchange as love that promotes growth in both assistant and core member while avoiding possession of and control over the other. He also portrays communion as liberating in that it allows people to be themselves while discovering the other.

Vanier (1998) also notes that successful negotiations of power are fundamental to communion between assistants and core members. Like anthropologist Wolfe (1999), Vanier (1998) views power as an aspect of human relationships involving a balancing act that is never permanently achieved. Relationships of communion, Vanier (1998) emphasizes, are not fixed in time and space. Assistants and core members are hence encouraged to engage in relationships that do not guarantee a predictable or secure outcome while being willing to give up much of what society deems valuable including power over others. Cushing (2003) argues that "Being engaged in these relations involves power-sharing, openness and vulnerability and hence entails risking certain loss for uncertain gains" (p. 251). Unlike forms of relationships such as competitive rapports that society encourages, Vanier (1998) and L'Arche propose a riskier type of relationship that requires both caregivers and the recipients of care to recognize their weakness and their mutual dependency. The risk involved in power-sharing, openness and vulnerability is one of the primary costs of mutuality in caregiving relationships, especially when attempts at which end in a failure to successfully achieve a state of communion at all or for extended periods of time.

6.3.2 The principles of mutual care in practice

Cushing (2003a), an anthropologist and disability theorist, outlines six characteristics that she deems fundamental to mutually caring relationships at L'Arche. These principles reflect Vanier's desire for relationships of communion between assistants and core members and take into account their practical application in the Canadian communities in which Cushing conducted her fieldwork. The social and cultural context in which *Il Chicco* is situated is distinctly different from that of the communities studied by Cushing in her doctoral work. However, the similarities of lived experiences of L'Arche members across the Atlantic Ocean are far greater than the differences that separate them. For this reason, I take Cushing's principles as my basis for describing the nature of mutually caregiving relationships at *Il Chicco*.

Il Chicco community members engage in mutually caring relationships with others on a daily basis. The first principle of mutuality in caregiving relationships outlined by Cushing (2003a) is its generalness; in other words, mutualilty is first "a general way to approach all relationships (including but not limited to, caregiving)" (p. 88). Some assistant-core member relationships such as Fiorella and Camila's involve sharing all aspects of daily life together. These women live together in the same home where they cook, eat, sleep, watch movies, go on outings, attend church services, and listen to music together. Other relationships of friendship, such as Piera and Rocco's involve days punctuated with brief moments of interaction to prepare tea, share a meal or socialize by the swimming pool. Both Piera and

Rocco do not live in community nor do they interact very frequently with respect to Fiorella and Camila. Yet other assistant-core member relationships such as Italo and Niccolò's involve sharing occupational activities that include working the land and tending to the community garden, eating together, and prayer. Relationships between assistant-core member dyads or any two community members generally differ one from the other and are lived more or less easily for various reasons. However, mutual care is a general attribute of all relationships between community members who are encouraged to approach others with openness and respect.

Cushing (2003a) argues that mutuality at L'Arche is also "particular" in addition to its general nature in that it is an attribute of relationships that involve "caring for and about a specific, unique person rather than a category of client" (p. 88). Marika is an assistant who played a large role in welcoming Damiano, a middle aged man who had previously lived a primarily solitary life, into community. She describes entering into a relationship of mutual care with Damiano in the following way:

> I felt a great responsibility not for Damiano the case but for Damiano as a person – a man of fifty seven years that was moving from solitude to community. I spent the first three months day and night with him and it was very intense. It was intense because Damiano spoke to something very deep in me. That is, a life of deep solitude. When you encounter that level of solitude with a person who does not speak, with a person whose rhythms are very slow, with a person who caries you into another dimension... for me it was very, very, very, very powerful. I was very touched the first year when I finally went home for ten days. He spent the first night [upon my return] in the room where I was sleeping sitting in a chair watching me. I was touched when he started doing things only with me that were not already a part of the repertory of activities he was known to engage in at night. They were things he did only for me. [For example] Normally, he throws his pyjama and bed sheets [out of his window]. With me, he would bring them into my room. Therefore he had... he knew it was me because... There! Maybe the thing they [core members] make you feel each in their own way is that they are looking at *you*. Whereas maybe what I live, that we live outside [of community] is that no one sees you for who you are but for what you do. For what you have done. For what you possess. How you dress. How much money you have. What

> job you do. What car you own. Instead, here [at *Il Chicco*] it really is... I am Marika. And that's enough. There isn't a need to demonstrate anything more.

Marika and Damiano's relationship is here described as both intense and unique. Marika does not refer to Damiano as a client but as a friend who was in need of accompaniment upon his arrival in community. Marika also addresses the process involved in entering into a relationship with Damiano and what it is that she found valuable in this process. Importantly, she notes that she was touched by a change she observed in Damiano when he began to recognize her and relate to her differently. Marika and Damiano's interactions are unique to them and arise over time in the particulars of their relationship. As concluded by Cushing (2003a), mutuality is hence both an attitude toward relationships generally while remaining pronounced and intensified "in the particulars of particular relationships" such as Marika and Damiano's (p. 88).

A second principle of mutual care at L'Arche is the undeniable instrumental nature of assistant-core member relationships. By instrumental, I mean that persons with intellectual disabilities, by virtue of their significant limitations both in intellectual functioning and adaptive behaviour, are in need of support from L'Arche assistants. According to Cushing (2003a), it is imperative to attend to this difference and the imbalance it generates as a result; "this is always initially and fundamentally an instrumental relationship" which "is never free from the inherent imbalance of the instrumental motive" (p. 88). Cushing (2003a) also highlights the philosophical and ethical debate surrounding the possibility and desirability of relationships of this nature as it is said that clients may be inclined to feel that they may jeopardize the quality of care they receive if they do not partake in non-instrumental relationships with their caretakers. On the other hand, Cushing (2003a) notes that since people with intellectual disabilities often already "experience a paucity of informal social contact," it is "illogical and even iatrogenic to prohibit relationships with caregivers" (p. 88). The inherent imbalance in relationships between people with and without intellectual disabilities at L'Arche caused by their instrumental nature in fact influences the possibility of entering into and sustaining mutually caring relationships among assistants and volunteers.

Vanier also recognizes the instrumental nature of assistant-core member relationships in his work. For Vanier (2007), the first element of caregiving relationships at L'Arche is the body because it represents what is common among people with and without intellectual disabilities. The instrumental nature of relationships is also described by *Il Chicco* community members for whom activities such as eating meals together, bathing, dressing, and preparing for work are a central part of their daily lives. Lorenzo, a core member in his fifties who has been living in community more than ten years, describes the tasks assistants help him with.

> Lorenzo – Shower.
>
> Sarah – Your shower.
>
> Lorenzo – Good right? Then...
>
> Sarah – Then?
>
> Lorenzo – The beard. The beard. I've been good right? And then ferfume [perfume]. Ferfume right? Good right? Then pants. Pants. Good right? Then washes these [points to his pants] are dirty.

The tasks including shaving, dressing, preparing for work or an outing, and caring for cleaning his laundry are simple yet important in Lorenzo's life. Later on in his interview, he also describes an appreciation for assistants such as Marika and Maurizio who remain by his side when he is sick with a fever. Lorenzo recognizes the day-to-day instrumental care assistants provide him that allows him to function in daily life. Lorenzo also adds that he is also involved in caring for those with whom he lives. The activities he engages in include helping with setting the table, cleaning up after a meal, painting, playing, praying for others, and being sensitive about the choice of music to play in common areas in order to appeal to all listeners.

A third principle of mutuality at L'Arche is the *process* involved in entering into mutually caring relationships rather than the outcome of such an endeavour. Cushing (2003a), whose work is supported by Pottie's (2001) previous analysis of reciprocal friendship relationships at L'Arche, states: "The notion of mutuality in relationships at L'Arche is concerned mainly with the daily process or ongoing, subjective shift of learning to be open to the value of difference" (p. 88). At L'Arche, a focus is placed on the process of encountering diversity and entering into relationships with radically different others through repeated moments of encounter over time. For many assistants, the beginning of this process is often scary and can become quite overwhelming. Ilenia, an assistant who has been involved in community or more than a decade, describes the beginning of her relationship with Emilio for whom L'Arche has been a home since the age of six. She recounts:

> At the beginning, I was ok with everything except Emilio. The beginning lasted up until I actually lived with him. I mean, the beginning for me was from the moment I first met him in 94. I would take him in my arms when he was already bathed and when his [feeding] tube was in place and hidden in his pants. I didn't even want to see it. In those moments, I would spend two minutes with him cuddling but I always did it with great caution because I was afraid of hurting him. I was afraid of making a false movement. There. Or when he was in bed, I would come close to him only for a brief moment but only so that others wouldn't think I was afraid of being in touch with him. I didn't do it in search of a real relationship with him. It was simply because I couldn't allow others to understand that, that I couldn't.... no. When I [then] lived with him, it was no longer possible to [avoid contact]. In fact when they told me I was being sent to [Emilio's home]... I was happy for Beatrice, happy for Alice but I said to myself... shit... Emilio is there too. I can't escape anymore.

Ilenia here recounts her initial fear of contact with Emilio. She explicitly describes her repulsion toward him that she attributes to his feeding tube – a tube Emilio still has eighteen years later. As long as the tube was out of sight, Ilenia recounts feeling comfortable being around him. In this passage, Ilenia also elaborates on being afraid to hurt Emilio as a result of falsely engaging in a manoeuvre during his morning routine, for example.

Because being an assistant at L'Arche requires all assistants to become involved in the instrumental care of the core members in their home, Ilenia reacts initially negatively to the thought of having to care for Emilio. When Ilenia is assigned to his house, she laments no longer being able to 'escape' the risks involved in engaging in a caregiving relationships with him. Some individuals who come into community are in fact tempted to leave it, while others follow through with leaving, as a result of the feelings Ilenia describes. It is for this reason that several assistants, including Marika mentioned above, note the importance of accompaniment through this process. Ilenia and Emilio's relationship has changed significantly since their first encounter in the early nineties. In fact, at the end of Chapter Four, Ilenia describes Emilio as her teacher and as a person whose ability to be fully himself is what she admires most in him. The process that has taken her from repulsion to admiration has been slow and very enriching, she explains.

Ilenia, who now considers herself to be in a very intimate relationship with Emilio, is adamant about yet another crucial element in the risky process involved in mutual care. For her, *basta che ti ci metti*, roughly translated to 'you just have to put yourself out there.' Relationships require risk and a considerable investment on behalf of both community members involved. However, unless the process of encountering difference is truly initiated, mutual care cannot take place. For this reason, one-on-one interactions such as Italo and Niccolò's outing to the hardware store and Camila and Fiorella's hair dying adventure are crucial moments for these assistant-core member dyads in that they allow for intimacy and encounter in a way that larger community activities do not.

Cushing (2003a) notes a fourth principle of mutual – or reciprocal – care at L'Arche in the creation of what she calls an "alternative currency" for exchanges that take place between assistants and core members. Cushing (2003a) argues that an ability and desire to value various forms of care is crucial to recognizing mutuality in relationships. Like the feminist push toward rethinking care labour – unpaid and unvalued labour that is often performed by women and accounts for a large percentage of care – L'Arche encourages assistants and core members alike to enter into the "L'Arche paradigm" (Cushing, 2003a, p. 88) and to rethink care value and human value. In other words, L'Arche proposes rethinking *who* the 'givers' of care are and *what* is indeed being given or exchanged by those involved. Without such rethinking, mutuality in caregiving relationships at L'Arche would be almost entirely impossible.

Cushing (2003a), whose work primarily focuses on L'Arche assistants, argues that the creation of an alternative currency involves assistants recognizing "the gifts inherent in their clients' [the core members'] lives" (p. 89). As I note in previous chapters, the lives of core members become valuable for assistants through reading into the actions of core members in particular ways, for example. Their lives are also seen as valuable when interpreted as examples of patience or kindness. This brings us back to a previous discussion on conceptions of the disabled as teachers prevalent among several community assistants. Though Valeria performs multiple caring practices for Matteo and Pietro, it is evident that she values their presence and friendship highly. Valeria's care labour is compensated for by a salary while caring practices undertaken with care that are exchanged by these relationship partners are seen as of equal value given the gift inherent in the lives of core members such as Matteo and Pietro.

At *Il Chicco,* several community members acknowledge the gifts intrinsic in the lives of core members. Among these is Lorenzo's sister, Ada, who has been an important figure in his life. She talks about core members at L'Arche with much affection.

> I adore, I love each one of the *ragazzi*. I mean, they give me a... on the one hand an incredible energy just like, just like... that is a non-indifferent energy. But they transmit so many things, so many values, that then when I leave here... every time I leave this place, every Saturday I feel like another person. I feel full, full of so much. Of everything. I don't even know how to explain it. It's a sensation that is a bit... that can't be described.

When value is attributed to or recognized in the presence of core members like in the case of Ada, Cushing (2003a) maintains that balance is restored as assistants and guests who engage in mutually caring relationships while in community receive in return for what they give. Furthermore, instrumental care is compensated for as paid labour for most assistants. Some assistants are unpaid, however, and their compensation is considered to come in other forms including the fulfillment of a vocational calling. This will be further discussed in Chapter Seven.

The fifth principle of mutual care at L'Arche according to Cushing (2003a) is participation by assistants in a solidarity project with people with intellectual disabilities living at L'Arche. She notes that this project of solidarity often involves aspects that are moral, spiritual, and political in nature (Cushing, 2003a). Cushing (2003a) states that "This kind of solidarity seeks to reverse the reproduction of structural inequality that is typical of normative relations like caregiving" (p. 89). She also argues that many assistants frame their behaviour of cultivating relationships with people with intellectual disabilities "as a way of recognizing and alleviating their disenfranchisement" (Cushing, 2003a, p. 89). Reversing structural inequalities in caregiving relationships is by no means an easy task; it requires participation by all community members in moving beyond dominant conceptions of disability, redefining concepts such as what counts as care, and power sharing, among others.

This fifth principle is evident in the aims that L'Arche sets out for itself in its' Charter. There, L'Arche outlines its' principle goal to serve as a symbol of hope in a world that is fraught with divisions (Appendix G). The Charter states: "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" (Appendix G). L'Arche makes a point of distinguishing the desire to serve as a "*sign* that a society, to be truly human, must be founded on welcome and respect for the weak and the downtrodden" from the oft confused goal that many attribute to organizations like L'Arche to serve as a *solution* to the difficulties surrounding the integration of persons with intellectual disabilities in greater community life (Appendix G). L'Arche also recognises that is not a place for everyone.

The project of solidarity with people with intellectual disabilities is seen in multiple aspects of the lives of assistants at *Il Chicco*. From eating meals together, to utilizing the same washrooms, assistants at *Il Chicco* share most aspects of life with the core members. Ilenia, for example, expresses the beauty and challenge of shared life as follows: "Here, on the one hand unfortunately, but [on the other] thankfully, you aren't alone. And yet this involves a little bit of give and take," something that she describes as difficult at times. Despite a desire by most assistants to engage in a common life with core members, debates surround the bounds of the solidarity project they engage in. By this, I intend to mean that assistants do not always agree on the aspects of life that are or should be invested in this solidarity project. For example, at *Il Chicco*, there is disagreement surrounding what activities are acceptable for assistants to engage in after core members have gone to bed. Differing views on what L'Arche is and what it can and should demand of assistants will be further discussed in Chapter Seven. However, the fifth principle involves assistant participation to some degree in actions of solidarity with core members in an attempt to reverse some of the structural inequalities people with intellectual disabilities suffer in conventional caregiving relationships.

The sixth and final principle of mutual care outlined by Cushing (2003a) involves the recognition of caregiving as labour even in the L'Arche context. According to Cushing (2003a), relational mutuality in caregiving interactions "should not overshadow the fact that what the caregivers [assistants] are doing is labour, and needs to be credited as such" (p. 89). Here, Cushing (2003a) warns against falling into viewing care labour as symmetrical when this is not in fact the case at L'Arche, in the familial home, in other institutional contexts or elsewhere. Along with feminist care theorists such as Eva Kittay (2001; 2011), Cushing (2003a) argues that "the practice or labour is inherently asymmetrical, and that must be recognized to avoid further undermining the value of the labour of care" (p. 89). The labour of care is in fact often undermined and unaccounted for. L'Arche does not propose disregarding the labour of care. Instead, L'Arche encourages the recognition of mutually caring relationships that modify the conventional experiences and outcomes associated with caregiving relationships.

Some assistants such as Rosetta are clear about the importance of maintaining a balance both in relationship and in their work lives. She notes that relationships with core members who do not speak and have many physical needs can at times be *pesante*, or heavy.

According to Rosetta, core members also have similar needs for separation and time apart from the other community members with whom they are in relationships.

> I mean, I think that if Emilio [a core member] is a normal person like he should respectfully be regarded as, I have to think that he has his problems and I have mine. I think that he too, once in a while, must think: 'Enough. I can't do it anymore! Let me see someone else!' No?

Rosetta also argues that a 'saving grace' for her has been the work of setting boundaries and recognizing her relational limits as well as her limits in terms of the carework she performs at *Il Chicco* on a daily basis. Rosetta promotes pacing oneself both in relationships and in carework, a task many new assistants struggle with achieving. Rosetta attributes this to the initial state of *inamoramento*, or falling in love, that numerous assistants experience upon entry in community.

Despite the distinction between mutual care in relationships and the labour of care, the two forms of care are intricately interconnected in that relationships are indeed what change the weight and success of carework. Without mutual caring as the model of relationships best suited for caregiving, conventional negative outcomes associated with caregiving and receiving care remain widespread. These outcomes include maintenance of power relations promoting domination rather than care (Kittay, 2001), caregiver dissatisfaction, burnout and health risks (Essex & Hong, 2005; Forster, 2007; Hoyert & Seltzer, 1992; Jeglic et al., 2005; Lin et al., 2012; Vitaliano et al., 2004) and care recipient disempowerment (Illich, 2003; Taussig, 1980).

6.3.3 Factors that impact the possibility and success of mutually caring relationships

There are numerous factors that impact the possibility and success of mutually caring relationships at L'Arche. These are mediated by:

1. The socio-cultural context in which the L'Arche community finds itself:

The experiences of L'Arche *Il Chicco* community members are largely influenced by factors such as the contact nature of Italian social exchanges (Remland et al., 2005). They are also mediated by characteristic features of the Italian populace. A notable characteristic that plays a large role in shaping the types of relationships individuals are able to engage in is the cynic or depressed state of Italian citizens (Mammone & Veltri, 2008). The results associated with a negative outlook on others, social groups and social institutions are multiple while some of them are particularly relevant to intimate interpersonal relationships such as those between community members at L'Arche. According to Li and Leung (2011), socially cynical people tend to avoid interactions with others while preferring competition over alternate forms of conflict resolution, interact infrequently with others, and receive little social support as a consequence. These behaviours are subsequently correlated with decreased self-esteem and life satisfaction as well as a wide range of negative outcomes such as loneliness, low levels of interpersonal trust, suicidal ideation and low life and job satisfaction (Li & Leung, 2011).

Some of these negative attitudes and behaviours are evident among community members. The precise impact of socially cynical attitudes toward others, social groups and institutions is difficult to pinpoint especially given the brief nature of my fieldwork. However, certain examples do present themselves during my time at *Il Chicco*. A poignant case involves a generalized skepticism surrounding the institutionalization of L'Arche itself through changes required for accreditation by the Italian government. Throughout the summer months, implemented regulations or enforcement of existing orientations or rules was often seen as problematic or threatening by numerous community members. Ilenia, a head of house at *Il Chicco* describes the Italian approach to procedures as follows: “there isn’t a procedure. There aren’t rules. There aren’t things written down. There aren’t consequences when something does not go well.” Her observation indicates a lack of parameters with which to evaluate the appropriateness of certain behaviours in a workplace such as L’Arche. However, it is evident that even when rules and regulations are in fact put in place, the necessity of respecting them is equally ambiguous. Another example of the result of socially cynical attitudes is mistrust of people in almost any and all positions of authority. This, coupled with skepticism surrounding rules and regulations, often resulted in tension among disagreeing members and difficulty in implementing community projects.

2. <u>The legal context in which the L’Arche community finds itself including policy and regulations surrounding the care of persons with intellectual disabilities:</u>

At *Il Chicco*, the recent push toward accreditation involves the employment of staff members including assistants who possess determinate qualifications. The necessity of hiring qualified staff, such as trained nurse practitioners and personal care assistants, implies that a different demographic of people are permitted to engage in mutually caregiving relationships at L’Arche. Also, a decrease in funding attributed to organizations such as L’Arche translates into a decreasing assistant to core member ratio. Assistants find themselves in fewer numbers and the quality of care as well as the possibility of entering into authentic relationships with core members due to time constraints becomes challenging. One-on-one interactions, such as Niccolò and Italo’s outing to the hardware store and Fiorella and Camila’s hair dying experience, are rare and precious occasions.

David, an assistant, describes the impact of changing assistant to core member ratios on mutual relationships this way:

> Already, the way L'Arche presents itself favors this type of relationship [with people with intellectual disabilities]. It is obvious that in a period when there are more assistants, volunteers, the rapport becomes even more solidified than when for example there are crises, or difficult moments when there is less personnel and the attention just isn't the same. To find yourself alone with four core members isn't... you can't give [core members] the same kind of attention that is possible when you are, let's say, two or three assistants with four [core members]. I mean, there too, everything changes.

David is clear in this passage that the possibility of mutual relationship is largely mediated by the assistant to core member ratio. He notes that relationships built during intimate exchanges become particularly important during difficult moments or crises.

Other changes, including health related regulations surrounding core member participation in activities such as cooking, have an impact on the familiar nature of care experiences at L'Arche. An assistant, Ilenia, notes that L'Arche's transition into a healthcare center is "castrating" for community life. She demonstrates her point by referring to a sign that hung for some time next to pictures of three core members on the kitchen door in one of the homes. The sign read: "Denied access to unauthorized operators." According to the regulative body in the Lazio region of Italy, the 'unauthorized operators' refer to core members for whom it is prohibited to be in the kitchen. Ilenia, on the other hand, argues that 'unauthorized operators' should in fact refer to those for whom L'Arche is not a home. Rules such as these impact core member and assistant participation in domestic tasks that are central to their shared lives.

3. <u>A desire and capacity to overcome dominant conceptions of disability, communication, care and dependency:</u>

Overcoming dominant conceptions of disability influences the possibility and success of mutually caring relationships. It is a task both people with and without disabilities at L'Arche must undertake. First, the ability of core members to engage in mutually caring relationships at L'Arche depends on their own internalized conceptions of disability and their sense of self worth. Like those whose oppression is internalized, people with disabilities themselves often take on the dominant perceptions of disability that are projected onto them. Arturo, a core member who is mentioned in previous chapters, distinguishes an ‘us’ people with intellectual disabilities from a ‘them’ assistants and guests. Such dichotomizing is counterproductive to L’Arche’s attempt to promote relationships where people with intellectual disabilities are viewed as people first, rather than as machines, *bambinoni*, or menaces. Such a change in perception is also encouraged for assistants at L’Arche. As previously mentioned, change is at times rendered difficult by the violent or defensive behaviour of certain core members.

Communicating and adopting an attitude of uncertainty toward others are also central to entering into relationships of mutual well-being with other community members. As discussed in Chapter Five, verbal and nonverbal communication is central to relationship building and must be viewed as an undertaking, the product of which does not guarantee certainty of comprehension. A desire to adopt an attitude of uncertainty regarding comprehension is also indispensable to overcome presumptuous approaches to care as a unidirectional endeavour. Also, L’Arche requires that care relationships be redefined as reciprocal. For this to be possible, L’Arche encourages the establishment of an alternative exchange currency that values the lives and gifts of core members. Lastly, L’Arche proposes that the goals of care relationships be redefined. A previous focus on independence and autonomy in care models that are unsatisfactory for care of persons with intellectual disabilities must shift toward refraining from viewing assistance as a limitation (Kittay 2011). Instead, theorists such as Kittay (2001; 2011) argue that adequate approaches to care begin by embracing needed dependencies.

4. The human aspect of relationships involving affinities toward some and not others, jealousy, intercultural differences, personalities, etc.:

Like all human interactions, relationships at L'Arche are also highly mediated by the human aspects of relationships. For example, Piera feels threatened by Rocco's interactions with other community members. She often has outbreaks when he spends extended amounts of time in close contact with other people. Piera's outbreaks mediate the possibility available for Rocco to interact with others without provoking an at times violent reaction in Piera. These and other complex dynamics between community members impact the possibility and success of their mutually caring relationships. Fiorella and Camila, for instance, do not dislike one another and yet they spend very little time together. This is in part because each of these women has affinities for other community members with whom they prefer to spend their time. Other dynamics including tensions between community members whose personalities clash also influence the general ambiance in L'Arche homes. This, in turn, impacts the way people relate to each of them and how they engage one another in various contexts.

A further important aspect of relationships at L'Arche is the elevated assistant turnover rate in community that causes instability because it involves constant training of new assistants and often translates into reluctance on the part of some core members to enter into relationships with newly-arrived assistants. This too affects the possibility and success of current and future mutually caregiving relationships at L'Arche.

5. The internal L'Arche culture:

The importance of a balanced internal L'Arche culture and the people that play a role in creating it will be discussed in detail in Chapter Seven.

7.0 IDENTITY CRISES

7.1 Introduction

Experiences at L'Arche are highly mediated by the socio-cultural context – external context – in which communities find themselves and the internal environment that is created as a result of interpretations and practical applications of L'Arche's vision. The external factors nominated in previous chapters such as the characteristic cynicism of Italian citizens and the contact nature of Italian social interactions play a significant part in the way disability, communication, and care are experienced and engaged in by community members. Experiences of care at L'Arche are also highly mediated by internal dynamics.

Though L'Arche began as a Christian community where lay people lived with people with intellectual disabilities, it has since undergone significant changes – and continues to do so – from the time of its beginnings almost fifty years ago (Egan, 1987; Cushing, 2003b). Notable changes have ranged from ceasing to allow for the inclusion of entire families in L'Arche homes. Joe Egan (1987) argues that such changes involved recognizing the family as community within community, and identifying these smaller units undesirable. Other changes such as Vanier's resignation as International Coordinator of the Federation of L'Arche communities in 1981, seventeen years after opening the first L'Arche home in Trosly-Breuil, have been significant (L'Arche, n.d.). The thirty year old story of the L'Arche community of *Il Chicco* is similarly punctuated with moments of transitions as a result of changing interpretations and applications of the organization's vision. These variations are a primary source of tension among community members.

I often hear assistants discuss ways of addressing and expressing spirituality at L'Arche. I have noticed that it is generally accepted by all community members that spirituality has an important place in the past of L'Arche and in the lives of many community core members. One such person is Stefano, a short-statured man with a determined stride and a charming love of socks and threads. Though Stefano is deaf and silent, his days are full of much expression and movement. Some of my favorite expressions include his dexterous ability to bounce small objects in the palm of his hand with little effort, his interest in the smell and texture of food as well as his expressions of great joy upon discovering that pasta is being served for lunch or dinner.

Toward the end of my stay at Il Chicco*, I witness Stefano express his spirituality in a way that is new for me. Normally, a time of prayer at the beginning and the end of the day is held in all L'Arche households where assistants and core members alike express their prayer intentions – including thanksgiving and concern. At times, community members sing the L'Arche prayer. This is a song that has been translated and modified to suit the two communities of L'Arche in Italy including* Il Chicco*. It begins with a request to Mary, the mother of Jesus: "*O Maria, ti chiediamo di benedire la nostra casa*," or "Oh Maria, we ask you to bless our home." In the company of assistants and core members, Stefano gestures the words of a melody he cannot hear. Stefano does, however, understand its' meaning.*

Signore benedici noi con la mano dei tuoi poveri
Lord bless us with the hand of your poor
Raise hands/ bring hands down to form a cradle/ point to others/ show the open palm of both hands/ point at the sky again/ lower a hand to indicate a person of small size

Signore soridi a noi nello sguardo dei tuoi poveri
Lord smile at us with the eyes of your poor
Raise hands/ indicate a smile with your hands and mouth/ point to others/ indicate the face by drawing a circle in the air around it/ point at the sky again/ lower a hand to indicate a person of small size

Signore ricevi noi un giorno nella beata compagnia dei tuoi poveri

Lord receive us one day in the blessed company of your poor
Raise hands/ bring hands down to form a cradle/ point to others/ point at the sky again/ open arms wide with palms facing upward while looking toward the sky

Here, Stefano's participation is voluntary and moving. At times, however, Stefano does not want to partake in spiritual or religious activities. One Sunday afternoon, he expresses a desire to stay home rather than attend mass at the local parish with a group from the community. Assistants often disagree on the appropriate way to respond to Stefano in these situations. Though he is a spiritual man who expresses his faith clearly, varying interpretations and applications of L'Arche's spiritual vision and mission at times create conflict in how to respond to Stefano's refusal to participate in these events. Some assistants view community events and religious celebrations as compulsory. Others feel obliged to persuade core members to partake in community events because of a low assistant to core member ratio and an inability to allow core members to choose otherwise. Yet other assistants defend the choice of core members in as many situations as possible. Assistants themselves also have differing views of the importance of attending religious or other events and interpretations of the nature and appropriate form of such events at L'Arche.

In the following chapter, I will focus on the contested stories that form the basis of the experience of *Il Chicco* community members. In my time at *Il Chicco*, I noted three important unclear or debated topics that have a significant impact on people's experiences of care, each surrounding L'Arche identity. Identity, in this case, is collective in that it involves "identification with shared features along with a recognition of shared opportunities and constraints afforded by those features" (Owers, Robinson & Smith-Lovin, 2010, p. 490). Collective identity allows for the mobilization of joint actions by a group of persons. I want to note that the uncertainties surrounding L'Arche's identity arose at a time when *Il Chicco* was going through a difficult moment in the absence of a community leader, head of assistants, and stable international coordinator. The four months of observation also came at a particular moment in Italian history at a time when retaining positive outlooks on life in the presence of governmental cuts to social programs, decreased donations to the Italian branch of the foundation, elevated rates of unemployment and elevated instances of depression. These factors in turn mediate the internal environment of *Il Chicco*. This environment is also arguably mediated by a community's contact with other L'Arche communities.

Varying internal interpretations and applications of the L'Arche vision by communities members influence the ways in which they define and understand L'Arche generally, the community of *Il Chicco* specifically, and their individuals places within each of these. These varying experiences modify identification *with* L'Arche and *as* community members. Disagreements surround what L'Arche is, who and what counts as community, and how the values of L'Arche including spirituality are to be internalized or enacted by individual community members such as Stefano. I dub these disagreements the primary identity 'crises' of *Il Chicco* in that they consist of the primary reasons behind the lack of confidence and certainty in what is shared and common to the group. This lack of confidence and certainty subsequently provokes temporary or prolonged cessation of action by members of that group, a state I noted as characteristic of *Il Chicco* throughout the summer months of 2012. The identity crises I will discuss in this chapter are meant to serve as points of reflection for L'Arche as they appear to characterize a period of time that some communities are unfortunately faced with at various points throughout their history. My observations also point to some of the short-comings of mutual care as it is applied and experienced at L'Arche.

7.2 L’Arche

The shifting internal interpretations and applications of the L’Arche vision by community members influence the ways they conceive of and identify with L’Arche generally. L’Arche is founded on a set of tenets regarding community life that are outlined in the Charter and in the Mission and Identity statements (Appendices G and H). Though quite clearly stated, these tenets are not experienced by all community members as unproblematic nor do they generate a homogeneous way of perceiving care or community (Tsing, 1993). Instead, differing readings of the L’Arche tenets often result in tensions among community members. In this first section, I will summarize the four elements of L’Arche communities that are outlined in the L’Arche Charter (Appendix G). Following a description of each of these elements, I will present some of the agreeing or disagreeing interpretations and applications of these tenets by community members. This will serve to demonstrate the range of experiences in this context. These are also meant to serve as a point of departure from which to begin to resolve some of the underlying tensions between community members.

The first element of L’Arche communities is faith. As outlined in the Charter, “L’Arche are communities of faith, rooted in prayer and trust in God” (Appendix G). Communities “seek to be guided by God and by their weakest members, through whom God's presence is revealed” (Appendix G). This element is reminiscent of Vanier’s (2007) fifth stage of changing attitudes toward the disabled in which Vanier defines the ultimate state as closeness with God through relationships with people with intellectual disabilities. In the Charter, L’Arche communities are classified as either following a single faith tradition or as inter-religious. As a consequence, communities are encouraged to sustain ties with religious authorities and members, to partake in local churches or other places of worship (Appendix G). Many assistants who choose to live in community homes for extended periods of time are motivated to do so upon learning about the characteristic spirituality of L'Arche.

As evidenced in the scene concerning Stefano's refusal to partake in mass at the local parish, varying interpretations and applications of L'Arche's faith or religious element at times simulate disagreement among community members. In the L'Arche Charter, a 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" (Appendix G). Though this is theoretically sound, the right of individual members to discover, deepen and live out their spiritual lives is threatened by the communal aspect of life that often requires core members such as Stefano to be accompanied in their daily activities. Furthermore, practical problems present themselves when there are few assistants or when there is uncertainty surrounding the appropriate way of interpreting the desires of core members who do not appears to demonstrate a preference regarding participation in or exemption from religious celebrations and services.

For some assistants such as Niccolò, "the spiritual aspect [of L'Arche] is an added value," while for others, it is an aspect they struggle to apprehend. One of the greatest concerns I heard multiple assistants express regarding spirituality and faith was a necessity for them to take on leadership positions in moments of prayer, for example. Many assistants who were themselves uncomfortable with L'Arche Italy's ties to the Catholic tradition or with participation in religious rituals or celebrations often demonstrated difficulty partaking actively in these events. These included celebrations such as daily morning or evening prayer. Discomfort felt by assistants was rarely coupled with disrespect toward those who partook in these rituals freely. On the other hand, some assistants who were firm in their spiritual or religious beliefs at times imposed participation on other community members. When these moments of confrontation regarding the nature and performance of L'Arche's spiritual character did not lead to tension among community members, encounter across difference fostered a great sense of respect and appreciation of multiple and diverging spiritual expressions.

The second element of L'Arche is its' call to unity that "is founded on the covenant of love to which God calls all the community members" (Appendix G). This call to unity involves embracing differences. It also "presupposes that the person with a handicap is at the centre of community life" (Appendix G). L'Arche advocates a lifestyle similar to family life as community members are involved in living, working, praying and celebrating together. As previously noted, relationships are at the heart of what is lived at L'Arche and are prioritized above other endeavours. Communities are also engaged in accompanying their members throughout their lives, if they so choose. L'Arche communities all over the world are seen as united and "bound together by solidarity and mutual community" in the same way individual members are bound to one another by similar goals; collectively, communities "form a world-wide family" (Appendix G).

L'Arche's home lifestyle is expressed in multiple ways through shared undertaking of daily activities. Like in all homes, the intimacy and mutual quality of relationships such as those formed and maintained at L'Arche does not preclude the possibility of conflict among community members. However, as I witness throughout the summer months, the home lifestyle does allow each member to contribute in making it a home they too are a part of. At times, this means eating extravagant or exotic dishes prepared by adept or enthusiastic cooks from various corners of the world. At other times, it means suffering through tense or *pesante* afternoons because of unresolved conflicts between community members. Yet on other occasions, relationships prompt celebration and participation in life events such as witnessing and testifying to the engagement and marriage of intimate friends or mourning the loss of a close one. An assistant David describes this involvement:

> When we are all together, my suffering is also the other's suffering. The other's joy is also my joy. Therefore we participate. We feel close to one another in these moments, whether they are joyful or painful. Yes, this is also part of the actual trademark of L'Arche.

Here, David recognizes the value of shared life through times of joy and pain. He also identifies this quality of life with others as characteristic of L'Arche.

Similar to the first, L'Arche's second element is divergently understood by various community members. Some, such as assistant Camila, express views that are very much in accordance with the unity L'Arche encourages among individual members and L'Arche communities generally. Despite these feeling of concordance, Camila notes that the sense of community – or a sense of inter-connectedness with other community members – is not felt or shared by all members alike. She explains:

> Camila – I feel that I am not tied to the other assistants in believing in L'Arche and in feeling a part of L'Arche like...
>
> Sarah – L'Arche as in your community [*Il Chicco*]?
>
> Camila – No, L'Arche! As Arche, as a spirituality, as a way of life but this... I believe that this is because we don't want to or because probably there is a lack of knowledge [of L'Arche]. A sense of belonging is missing. I have heard that many, many of the assistants in community haven't had the possibility of, of going to France, of having very many exchanges [with other communities] and I can tell you that last year that was kind of my first taste of it when I went to Trosly for the first time with the *ragazzi* from our community (...) and with a big group from Bologna [the other Italian L'Arche community]. There, I came back really feeling like I was part of a big family. I said: 'Geez! But I'm not the only one, this isn't the only community. We aren't alone. No!

> I mean, we are so many! We are people who share something really important, who believe that we are enriched, that we are... that are happy to live together in this way. Closed up in our own community, we are simply paid employees, volunteers, administrative council members. We are many small islands that are tied together by [core members] Fiorella, Lorenzo, Arturo, Federico, when in fact [L'Arche] is something much greater, much greater.

Here, Camila attributes her sense of belonging to the greater L'Arche family to exposure and interaction with members of L'Arche in other places including Bologna and Trosly, France. She notes, however, that not all community members have had the opportunity to live such moments of exchange. A lack thereof, Camila suggests, promotes a sense of isolation felt by some community members. I would further argue that moments of crisis or difficult times in community such as extended periods in the absence of those in positions of leadership also contribute to this sense of isolation. This is because an important part of the mandate of community leaders and international coordinators is providing a sense of direction and connection to other L'Arche realities.

The third element of L'Arche is a call to growth. Essential to this element is a view of communities as "places of hope" (Appendix G). According to the Charter, "communities wish to secure for their members' education, work and therapeutic activities" that are meant to be "a source of dignity, growth and fulfilment for them" (Appendix G). This often involves undertaking work and activities that are in line with the interests of L'Arche members. Growth is a goal for all community members alike who "are invited to participate, as far as possible, in decisions concerning them" (Appendix G). Here, the importance of power sharing and shared decision-making is highlighted by the organization itself.

As previously stated, goals including decision-making that reflect the needs and desires of those involved and power-sharing are often difficult to attain as they require consistent work. They are also controversial in that there is no single understanding of what shared decision-making and power-sharing truly involve. For example, some people see it fit for those in positions of authority to decide on behalf of those represented without the necessity of consulting all community members individually. Others see all decisions as decisions concerning all members and hence propose that decisions be made as a group in as many situations as possible. Still others propose that decisions be justified to those who are not involved in the decision-making process. Once again, the scene describing Stefano's participation in Sunday mass is relevant here. Applications of what it actually means for Stefano to be involved in the decision-making process diverge from one assistant to another. Conflicts surrounding decision-making arise between community members in all roles and concern anything from what consists of appropriate work-wear, whether or not household doors should be locked in the day time, or how to spend community funds.

The fourth and final element of L'Arche communities involves integration into society. According to the L'Arche Charter, communities are called to "form an integral part of life in their localities" and should hence "seek to foster relationships with neighbours and friends" (Appendix H). Through various means including work, people with intellectual disabilities are able to integrate into society. L'Arche communities also seek to collaborate with the families of core members, professionals and government authorities as well as those who share a solidarity project similar to theirs involving justice and peace for people with intellectual disabilities (Appendix H). Lastly, L'Arche communities strive to be competent in the fields of work and multiple therapeutic activities they undertake.

Contestation regarding the fourth element of L'Arche communities primarily revolves around what integration truly entails and how far the solidarity project should go. Again here, much of what can be accomplished in terms of integration lies on the assistant to core member ratio at various moments throughout the day. As some community members additionally notice, get-togethers, school visits, community events and religious celebrations are highly energy-consuming activities. Niccolò, for example, wonders whether such activities are in fact always pleasurable or desirable for core members. He states:

> But sometimes, I have asked myself… poor [core members] don't have a choice! A group of fifty people from France come and they have to be present to welcome them. And that's ok. The next day, a group from Peru arrives and they have to be present. And again the next day, another group from America comes and they have to be present. This happens during the festive seasons particularly. It happens at Christmas, Easter. There is a back-and-forth of people that never ends. In those moments, I have asked myself and I have also brought it up in meetings, the community has to be a place where people come together. Great. It is important that community be able to open its doors to the local community. [But] it becomes an overload. This is my idea. Maybe if you go talk to Valentino [a core member], he will tell you that he is happy that there are new people every day.

In this passage, Niccolò affirms having difficulties himself with how much and how often *Il Chicco* is indeed open to the local community. Here, he exaggerates slightly with the amount of visitors. However, he portrays quite well the overwhelming sensation of having to consistently welcome and be open to the integration of various groups into brief moments of community life. He also recognizes that this is his personal stance and that others such as Valentino, the core member he makes reference to, may not share a similar opinion.

Later on in my interview with Niccolò, he also makes reference to another core member, Giorgia, who struggles with loud groups and chaos – whether organized or not. He states that it might be helpful, if nothing else, to have a way of differentiating between those who get tired of loud events or large gatherings such as Giorgia from others like Valentino who indeed appear to enjoy them.

7.3 *Il Chicco*

Varying interpretations and applications of L'Arche's vision also play a role in the way the community of *Il Chicco* specifically is understood and experienced by community members. Because the central members in community are the persons with intellectual disabilities who live a greater part of their lives at L'Arche, individual communities around the world are distinct because of the core members they welcome. The story of *Il Chicco* dates back to 1981 when the founding members welcomed two children with intellectual disabilities to live with them in a familial home (L'Arca Italia, n.d.). This soon grew into a larger home with the addition of four other children and years later, several adults. Today, the community is comprised of eighteen people with intellectual disabilities who live in homes on the initial property donated to the founding members by someone from the area. As a result of significant changes over more than thirty years of community life, there exist today varying experiences of L'Arche *Il Chicco* among community members. The ideas that are most polarizing include what counts as community through comparisons with *Il Chicco*'s past and with other institutions that welcome people with intellectual disabilities in Italy, and whom community includes.

An important way in which community members define and experience community is through recollections of and comparisons with the past. Unlike newer L'Arche communities, *Il Chicco* has a more than thirty year old story to recollect and with which to compare the current state of life. Ethnologist, Castellanos (2010) addresses the issue of recollection in his work on the symbolic construction of community in Italy. He notes: "Recollections of the past often take the form of nostalgia in which the past is made out to be simpler, emotionally fulfilling, when social relations were more direct and integrated, and there was more coherence in the community" (Castellanos, 2010, p. 64). Though not all of the recollections of *Il Chicco*'s past are recounted with the nostalgia Castellanos (2010) describes, many of them undeniably are. This is in part attributable to the state of emergency – as described by community members – in which *Il Chicco* found itself through the summer of 2012. The permanent absence of a community leader and responsible of assistants as well as the temporary absence of a regional director contribute to a directionless sense of shared life. Indeed, when contrasted with the simple and inspiring images of *Il Chicco*'s past, the present appeared precarious.

Castellanos (2010) further argues that upholding nostalgic images is the "manifestation of the longing for an idealized and romanticized past that has been lost" (p. 64). Yet again, this longing is exemplified by several community members who recall and recount stories from a past that is described as drastically different from the present. To counter this type of idealizing, some community members such as assistant Rebecca propose a more realistic outlook. She sustains: "The truth is there isn't a perfect community. It's also true that we shouldn't even search for a perfect community because [in] each community there is something to do. There isn't even room for you to grow otherwise eh?" Here, Rebecca proposes focusing on the third element of communities mentioned above, namely growth. Rebecca's statement counters many of the voices heard throughout the summer months that proclaim that "this," referring to the current state of *Il Chicco*, "is not community." These contested ideas point to ambiguity surrounding what community is when compared to what community has been.

Another means by which community members predominantly define and experience community is through comparisons with other centres that welcome people with intellectual disabilities and that do not identify as L'Arche. Throughout this thesis, several assistants including Roberto, Marika and David compare and contrast their previous experiences in other centres with their current knowledge and understanding of L'Arche. The comparisons provided by these assistants are overwhelmingly in favor of L'Arche's approach to care. Most families of core members with whom I spoke also praise *Il Chicco* community life. Some even go as far as equating *Il Chicco* with paradise when compared to other centers. Despite this abundantly positive view of *Il Chicco*, some assistants argue that it distinguishes itself from other institutions less so today than it has in the past. Whether this is because positive changes have taken place encouraging other centres to modify their approach or because *Il Chicco* is indeed less able to provide a unique approach to shared life for people with and without intellectual disabilities today is complex to discriminate. However, the positive outlook on L'Arche's approach through comparisons with other centers is problematized by voices such as these that indicate a range of experiences by community members.

Contestations surrounding what counts as community highlight yet another facet that contributes to the sense of collective identity, namely membership (Owens, Robinson & Smith-Lovin, 2010). As sense of collective identity requires individual members to identify with the collective body and have the collective body identify with them. L'Arche membership, though open to most people who share the vision and philosophy of L'Arche, is not available to everyone. In the L'Arche Charter, the following is explicitly stated: "L'Arche knows that it cannot welcome everyone who has a mental handicap. It seeks to offer not a solution but a sign" (Appendix H). L'Arche cannot and does not claim to offer a place where all people with intellectual disabilities can live. Today, for example, *Il Chicco* no longer welcomes children with intellectual disabilities as it did initially. Furthermore, some adults with intellectual disabilities have lived numerous years in community only to be transferred to other care centres when their needs and those of the larger community no longer concurred.

Despite this Charter statement's referral to core members specifically, it is also true that L'Arche cannot welcome all people who desire to become assistants and live an experience at L'Arche. Reasons for rejection or demission of assistants are multiple, though an important one involves a lack of a particular type of schooling or qualifications required for work with people with intellectual disabilities in Italy. Other reasons for leaving L'Arche do not tend to include a disagreement with L'Arche's vision and mission but with unprofessional behaviour or inter-relational tensions with others. Though I do not wish to presume the reasons for Elisa's – the previous community leader – demission, I am told by other assistants that they may be related to the aforementioned factors. The landscape of community members is hence at once shaped by external factors as much as it is by personal preferences and workplace politics.

For those who do remain involved in community life, contestation surrounding membership is slightly different. For these individuals, the quality and quantity of involvement are often deemed representative of the potency or validity of their membership. In addition to core members and assistants, those involved to various degrees in community life include administrators, council members, friends and families. Some people, such as Rebecca, describe membership as general and as inclusive. She explains: "L'Arche community is not only for *ragazzi*. [It was] created for everyone that in this very moment are inside, outside, *be*side it: all those who participate in community" (emphasis added). With 'beside,' Rebecca means to refer to the external members whom she deems equally important for community life. Membership, according to Rebecca, makes reference to the quality of a person's involvement. According to her, participatory involvement is sufficient grounds for belonging to community.

Another assistant, Marika, elaborates on the quantity of time involved in the validation of community membership. She also makes an interesting distinction in the following passage between community as an endeavour undertaken by willing subjects – or community as a way of life – and the labour involved in carework at L'Arche:

> I believe that the, that being involved in the project that is community does depend on the quantity of time that you physically spend in community. I don't feel, and I wouldn't want anyone to feel authorized to judge that what that person does is only work, is only 'community,' or a bit of both. I believe that each of us has the right to live what we live. I am convinced of the fact that the work-related part must be undertaken seriously. In the sense that if I am paid for four hours of work, in those four hours I have to do what I am paid to do. If I want to stay later, that's my free time.

First, Marika affirms that the quantity of time spent in community is not an appropriate measure of membership. In discarding this aspect, she implies that there are others who do attribute value to the amount of time spent on community activities. Normally, the validity or strength of membership is directly correlated with the quantity of time spent participating in community activities. Instead, Marika focuses on the quality of time spent while refusing to be a judge of whether 'community' or work-related tasks are undertaken by individual members. Though she contrasts 'community' with the labour of care, several community members refer to 'community' as a spirit with which they approach life at *Il Chicco*. Some activities are considered as undertaken with the spirit of community while others are only work-related activities. However, what counts as community or labour differs from one person to another.

In order to distinguish things undertaken in the spirit of ‘community’ or as a form of labour, it is useful to compare paid and unpaid assistants. For unpaid assistants, all of what they do is considered by most members as undertaken in the spirit of ‘community’. For these people, L’Arche is a way of life that they have chosen to engage in for a period of time. The validity of their membership is considered very strong and most in line with L’Arche’s vision and philosophy. Many community members in fact speak of unpaid assistants as the foundation upon which community rests and as characteristic of the original spirit with which founding members including Vanier began the L’Arche movement. Until recently, there were no paid assistants in the households of *Il Chicco.* Today, some – though not all – of these unpaid assistants do not possess the qualifications required by the Italian government to work with people with intellectual disabilities. It is primarily for this reason that they are unpaid. A small number of the now paid assistants previously worked as unpaid assistants for whom their occupation at L’Arche became a means of subsistence.

Other assistants are hired as paid employees who either work in the community workshops or as aids in L’Arche households. Most of these assistants possess qualifications required for work with people with intellectual disabilities. Unlike unpaid assistants whose membership is confirmed by their willingness to participate in community life for little monetary compensation, membership of paid assistants is complicated by the salary they receive for the care labour they perform. Furthermore, the membership value of paid assistants is also dependent on what they do with what Marika calls their ‘free time.’ Because ‘free time’ is not compensated for by a salary, it is seen in many ways as more valuable than paid work. Renunciation of an outside life is seen by some as admirable and at times even desirable. Again, value is attributed to membership according to the quantity of involvement by paid assistants. Finally, membership debates also surround the spirit with which paid employees approach care and community activities. Some community members argue that additional time spent in community above and beyond scheduled and paid work is unnecessary in that it does not bolster someone's status as a valuable community member. Instead, the spirit with which tasks are undertaken is indicative of the quality of participation and membership.

8.0 CONCLUSION

8.1 Research questions revised

Mutual care in the L'Arche community of *Il Chicco* in Rome is at once a rich example of working across differences between persons with and without disabilities toward a humanistic approach to the other, and a representation of the complex and often paradoxical nature of mutual relationships. Vanier advocates mutuality as an ideal for relationships generally and encourages as well as exemplifies the benefits of this model for conventional caregivers and recipients of care alike. Though challenging and attainable for brief instances, mutuality in relationships across difference is a meaningful endeavour that searches to empower and uplift all community members.

Throughout this thesis, I problematize the largely positive image of L'Arche with a snapshot of *Il Chicco* at a very difficult moment in community life. I attempt to provide a realistic and holistic image of community life in order to address three primary research questions. First, I set out to document the experiences of mutual care at L'Arche *Il Chicco*. Second, I search to define mutuality in caregiving relationships in one of the first L'Arche communities outside of France and North America while exploring the various interpretations and applications of this model by community members. Lastly, I address the primary factors that limit the possibility and success of the mutual care model as it is operationalized in a public context.

Despite the delicacy of conflicting experiences of care and understandings of community life, I present a sample of community member narratives from the plethora of lived experiences of care at *Il Chicco*. Throughout this thesis, I make use of ethnographic storytelling as a means with which to portray the sense I got from observing and taking part in simple and meaningful daily life with community members. My ethnographic vignettes get at some of the actions and interactions I witnessed among primarily nonverbal core members for whom narration, in the traditional sense of oral reciting, is impossible. I also refer to the divergent and often conflicting oral accounts of multiple verbal community members including assistants, administrative staff and external family members.

I am entirely aware that this thesis is a representation rather than a reproduction of community life. Everything from the research topic involving people with intellectual disabilities to the location of my fieldsite in Rome were choices I made based on their value as anthropological inquiry and the significance and importance they hold in my own life. This dissertation is, hence, as much a representation of community life as it is a reflection of who I am and the value I see inherent in striving for mutuality in caregiving relationship. As Unni Wikan (1992) puts it, inasmuch as the words of my research participants are ways of producing effects with intent rather than conveying intrinsic meaning, so too is my dissertation a reflection of my intention to join L'Arche's social project to humanize people with intellectual disability and care.

My presentation of varying experiences of care attempts to define and describe mutuality in caregiving relationships across difference. Though this is not a comparative study, I make use of previous work on L'Arche communities in Canada, France, and the United States in order to demonstrate the impact of the Italian socio-cultural context on mutual care. In doing so, I am able to demonstrate that Cushing's (2003a) six principles are in fact representative of mutuality in caregiving relationships among *Il Chicco* community members. However, the Italian socio-cultural context including notable characteristics such as the importance of touch in social relationships and cynicism among citizens as a result of chronic problems plays a significant role in shaping the nature of interactions generally and at L'Arche specifically.

The importance of touch in social interactions is striking in dominant conceptions of disability and in the counterpart alternative conceptions promoted and encouraged at L'Arche. Dominant conceptions including viewing the disabled as machines, as *bambinoni*, or as a menace all manifest themselves most clearly in physical moments of interaction between people with and without disability. Touch, in these instances, is overused, asexualized, or underused. The outcomes of these dominant conceptions on people with intellectual disabilities including those living at L'Arche include social marginalization, violence or harm, and the adoption of defensive or aggressive behaviour. On the contrary, *Il Chicco* members highlight the humanness of persons with intellectual disabilities while emphasizing the shared embodied nature of care. At L'Arche, core members are also described by several community members as teachers. These alternative conceptions, in turn, engender the possibility of mutual relationships and provide the possibility for positive body contact in a way that other conceptions do not. Here, it is evident that interaction between persons with and without intellectual disabilities at L'Arche provides them with the possibility of overcoming misrepresentations and of working toward actual integration.

The socio-cultural context is also significant in the nature and forms of communication between *Il Chicco* community members. At L'Arche, and at *ll Chicco* specifically where a large majority of core members are nonverbal, communication takes on distinctive forms including health statuses or caring and violent gestures. These subsequently require multiple methods of interpretation of nonverbal message transmission that at times result in moments of frustration. Another product of these alternative forms of communication is uncertainty surrounding comprehension. At L'Arche, uncertainty is a product of communication and often becomes an attitude toward comprehending others. Successful nonverbal interactions are, hence, experienced as victorious moments in which relational mutuality is possible between drastically different people whose communicated messages often go misunderstood by the other. On the other hand, miscommunication between verbal members also is hurtful and detrimental to community life that is highly susceptible to tensions between members.

As I demonstrate, tension is also the result of differing interpretations and applications of L'Arche's tenets and of community generally. At L'Arche, the internal culture created by community members is one of the primary factors that impacts the possibility and success of mutually caring relationships. The other important factors include the aforementioned socio-cultural context; the legal context in which the community finds itself including policy and regulations surrounding the care of persons with intellectual disabilities; a desire and capacity to overcome dominant conceptions of disability, communication, care and dependency; and the human aspect of relationships involving affinities toward some and not others, jealousy, intercultural differences, and personalities.

Though the situation at *Il Chicco* has changed drastically since my time there in the summer of 2012, this dissertation highlights the complexity of mutual relationships at L'Arche and the difficulties involved in applying ideals such as those advanced by Vanier to a publicly funded care center. Mutuality as an ideal is admirable in that it provokes the necessary rethinking of ideas that have come to dominate the field of care. Persons with and without disabilities in contexts such as L'Arche are encouraged to become empowered through power-sharing and mutual dependence on one another in decision-making and for care. For many, instrumental care only partially encompasses the assortment of caring gifts they receive from the other. Gifts also include moral lessons and self-realization.

However, as I have demonstrated in this dissertation, numerous factors interfere with mutual care. The most important of these is the social reality of living in community. The notable recruitment of a new community leader and the return of the international coordinator are both important factors to which some of the changes that have taken place since my departure can be attributed. Despite the limits of this model and the costs associated with it, I propose that mutual care as it is operationalized as L'Arche is indeed a viable counterpart to other care models.

8.2 Contributions to academia and anthropology

Though the scope of this research project is limited, it begins to fill some of the existing gaps in literature on the perceptions of care by persons with and without intellectual disabilities engaging in both providing and receiving care. My project attempts to understand and represent the experiences of care in the context of L'Arche from all vantage points while recognizing the limitations involved in the research tools I make use of. More specifically, the emphasis on words and language – or interviews and conversations – in the deduction of meaning is challenged by my work with people with intellectual disabilities. Instead, this project points to the importance of "going beyond the words" in a turn away from logocentric anthropology toward a focus on the intention of actors and an attention to silence (Wikan, 1992, p. 461).

My research project also aids in making a case for the value of L'Arche's unique approach to care while demonstrating the factors that limit the possibility and success of mutuality in the Italian context. I build on work by the few scholars who have written about L'Arche in North America in order to begin to fill the gap in academic literature on this growing international movement. Finally, my research addresses the mutual care model – a model which has the potential to inform the ways in which caregivers and cared-for alike frame and live their analogous experiences of care – in its practical application at L'Arche in Italy.

8.3 Directions for future research

Numerous directions for future research present themselves as a result of this research project. In fact, this dissertation touches on very little of what could be much more extensive research on mutuality in caregiving relationships generally and at L'Arche specifically. First, comparative work on conceptions of disability in Italy and in North America could engage more deeply with some of the differences I highlight throughout this dissertation. Second, a broad survey of the impact of social cynicism on the Italian populace as a result of recent changes in the social and political landscape could be further explored. Also, similarities and differences could be drawn between the nature and effects of Italian cynicism and those of social cynicism in other contexts; these could be useful for working across difference and toward a broader understanding of the impact of cynicism on relationships (Li & Leung, 2012). Third, research could also be conducted on the impact of uncertainty as an attitude toward communicating with nonverbal people in contexts such as L'Arche. The outcomes of such an approach could provide insights into alternative approaches to communication.

Fourth, L'Arche and those who operationalize the mutual care model could benefit from longitudinal work on the impacts of such a model on assistants and core members over time. For example, the effects of an elevated assistant turn-over rate on core members and their ability and desire to participate in mutual relationships could contribute to a greater understanding of the long-term effects of such a model on community members. Comparative work on L'Arche communities in different parts of the world could also elucidate further factors that impact the possibility and success of the mutual care model's application. Finally, other relationship dyads at L'Arche would be worth analyzing for the specificity of their interactions as a part of an organization that operationalizes the mutual care model.

ENDNOTES

[1] In her article 'Fieldwork that Failed,' Linda L. Kent (1992) discusses two of her unsuccessful fieldwork attempts at working with Gypsies during her graduate research. I make reference to her article title while remaining aware of the large body of unwritten or unpublished graduate and scholarly failed fieldwork experiences.

[2] Some assistants are paid while others are there on a voluntary basis. The assistant volunteers receive a monthly stipend that is meant to reimburse their living expenses and many of these volunteers are foreigners who spend medium to long periods of time in community. Some assistants live in the L'Arche homes while others do not. The assistant volunteers all live in community. I will refer to assistants generally when I speak of those who work or volunteer in community and take on the role of traditional caregivers.

[3] Someone who is nonverbal is "unable to produce an understandable spoken message" (Brown 2003:13).

[4] *Ragazzi* is a term employed by most of the L'Arche community members without intellectual disabilities in reference to the L'Arche core members and/or persons with intellectual disabilities at other centers. This common term can be translated to 'youngsters'. I do not translate the term in the cited passages in order to invoke the sense given by the interviewees.

[5] *Comunicazione aumentativa e alternativa*, or Alternative and augmentative communication (AAC) includes communication methods used by "people who are unable to use natural speech well or at all" to supplement or replace speech or writing and the informal alternative means of expression these individuals employ (Wickenden, 2011).

[6] Buckingham-Rivard (2010) defines her terms as follows: "First, instrumental touch is purposeful touching with the aid of an instrument or piece of equipment, for example taking someone's blood pressure. Procedural touch is defined as purposeful touching while completing a set of care tasks, such as a bed bath or wound dressing. Functional touch is purposeful touching in order to help with everyday tasks, for example, getting dressed or eating. Expressive touch is defined as a spontaneous touch with 'emotional intent to express feelings, e.g. holding a person's hand to convey empathy, [or] hugging a person.' Accidental touch is that which occurs unintentionally, such as bumping into a person. Sixth, therapeutic touch is purposeful touching with either a physiological or psychological benefit, such as a massage" (p.13-14).

[7] The placebo effect is "the resulting improvement in the patient" as a result of consumption or use of "anything prescribed by a doctor or healer that the doctor or healer believes has no medical effect on the condition from which the patient suffers (or complains)" (Kinsley 1996:159).

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APPENDIX A
Interview Question Template for Assistants and Administrators

- How long have you been living at L'Arche?
- What house do you live in and who live with you?
- What made you decide to come to/ live at L'Arche? Tell me about that.

Experiences of care

1. Who is cared for at L'Arche? Give me an example.
2. How do people care for one another?
    - i. How do you care for the people you live with? Give me an example.
    - ii. How do others care for you? Give me an example.
3. What does it look like, feel like, taste like, smell like or sound like when someone cares for you? Give me an example.
4. Are you good at caring for others?
    - i. How do you know? Give me an example.
    - ii. Are some people good at caring for you? Give me an example.
5. Where does your ability to or not to care for come from?
6. How do you think care provided at L'Arche differs from care provided elsewhere? Give me an example.
7. When do you know someone is in need of care? Give me an example.
8. When do you know someone is unwell or unhappy? Give me an example.
9. Have you ever been unwell or unhappy? Give me an example.

The limits of mutuality

2. What gets in the way of caring for other people? Give me an example.
3. Are some people easier to care for? Give me an example.
4. Are there times when others are not very good at caring for you? What happens?
5. Do you have to know people for a long time in order to be able to care for them?
    i. Care you care for new people also? Give me an example.
6. How do you get to know people here at L'Arche? Give me an example.
    i. Is there any difference between the way you get to know core members, assistants and/or administrators? Please explain.

Decision-making

7. How are decisions made at L'Arche (in your home, in the workshops, in the office, in the wider community)? Give me an example.
8. Do you get to make decisions?
    i. What do you get to decide? Give me an example?
    ii. What do other people get to decide? Give me an example?
    iii. How do community members receive decisions? Give me an example.

APPENDIX B
Interview Question Template for Persons with Intellectual Disabilities

I want to ask you a few questions about yourself and your community. If you have any queries, please ask me and I can try to explain myself. If you get tired or you do not want to answer a question, we can stop or move on to the next question at any point. Thanks again for agreeing to talk to me about your experience at L'Arche; this is valuable for my project.

- How long have you been living at L'Arche?
- What house do you live in and who lives with you?

Experiences of care

- Who is cared for at L'Arche?
    - How are you cared for? Give me an example.
    - What about ______ (names of other people with and without intellectual disabilities living at L'Arche?
- How do people care for one another here? Give me an example.
    - How do you care for the people you live with? Give me an example.
    - How do others care for you? Give me an example.
- What does it look like, feel like, taste like, smell like or sound life when someone cares for you? Give me an example.
- Are you good at caring for others?
    - How do you know? Give me an example.
    - Are some people good at caring for you? Give me an example.

- Is L’Arche different from other places you’ve lived? Give me an example.
- When do you know someone needs your help? Give me an example.
- How do you know someone is unwell or unhappy? Give me an example.
- Have you ever been unwell or unhappy? Give me an example?

The limits of mutuality

- What gets in the way of caring for other people? Give me an example.
- Are some people easier to care for? Give me an example.
- Are there times when others are not very good at caring for you? What happens?
- Do you have to know people for a long time in order to be able to care for them?
    - Can you care for new people also? Give me an example.
- How do you get to know people here at L’Arche? Give me an example.

Decision-making

- When you came to L’Arche, what did you get to choose (house, bedroom…)? Tell me about that.
- Do you get to make decisions at L’Arche?
    - What do you get to decide? Give me an example.
    - What do other people get to decide? Give me an example.

APPENDIX C
Interview Question Template for Legal Guardians and Family Members

Experiences of care

- What motivated you to have _______ (core member's name) come live at L'Arche?
    - According to you, how did ______ (core member's name) live this change?
    - How did you live this change?
- What does care of _____ (core member's name) at L'Arche consist of?
- According to you, what are the most important elements/aspects of ______'s (core member's name) care at L'Arche? Why? Give me an example.
- How does the care ______ (core member's name) receives at L'Arche differ from the care provided at home or in other centers/institutions/communities/? Please explain.
- Did you notice any significant changes in ______ (core member's name) following his/her move to L'Arche?
    - What did you notice in him/her? Give me an example.
    - What changes did you notice in those around him/her? Give me an example.

Decision-making

- In what ways do you see ______ (core member's name) included in or excluded from decisions made at L'Arche? Give me an example.

APPENDIX D
Sample Letter of Information for Assistants or Legal Guardians [English version]

Dear (name of assistant or legal guardian),

My name is Sarah Parisio. I am currently pursuing a Masters' degree in Social and Cultural Anthropology at Concordia University in Montréal Québec under the supervision of Dr. David Howes. Since my childhood, I have been involved in L'Arche through my parents' engagement in the communities near my hometown of London Ontario. Recently, I had the opportunity to live in a L'Arche home here in Italy where I was deeply marked by the practical application of L'Arche's vision. Over the years, I have read many book on L'Arche and heard countless testimonies by persons with and without disabilities who were transformed by their experiences of care in L'Arche. As a live-in volunteer, I discovered first hand the transformative value L'Arche's mission of engaging in mutual care relationships across difference.

I have long been interested in care and have found in L'Arche a model that is drastically different from the one operationalized in other care facilities. At L'Arche, mutuality in relationships is central to the wellbeing of all community members. Though this may seem self-evident for those of you who are now accustomed to the ways of L'Arche, I assure you that care is not often understood to work in this way. Elsewhere, care is understood to be provided by some and received by others. L'Arche's model is therefore radical in many ways and merits being explored further.

The research project that I hope to conduct will focus on understanding and communicating people's experiences of mutuality in caregiving relationships at L'Arche. In order to truly understand these experiences from various vantage points, I ask for your participation in this study. L'Arche consists of many members and it is important for me to document the experiences of all those involved.

Information for this research project will be collected primarily by means of observation and interview. I intend on living in community five days a week over a period of two and a half month. In doing so, I will be able to observe and take part in the daily activities of L'Arche members. The objective of observation is to discover how mutual care in relationships across difference is put into practice. Observation will begin in July 2012.

Interviews will be conducted toward the end of my time in community in order to allow for enough time for community members to get to know me and vice versa. An interview will be conducted with the following people: two core members (in the presence of an assistant), two assistants, and two administrators. The interview is intended to last anywhere from one to three hours and will consist of approximately twenty-five questions. During the interview, members will be asked to share their experiences of care within the context of L'Arche. The interviews will be taped and transcribed with your permission. It is possible to withdraw at any time during the interview and you may refuse to answer any of the questions you will be asked. You may also withdraw consent to participate in this study at any point until my departure from Italy. The information will be used for research purposes only and all names of persons and places will be omitted from the final report in order to protect the confidentiality and wellbeing of interviewees and related persons. Pseudonyms will be used in their place. Community members will be able to make revisions on the final report prior to submission of my thesis for verification and accuracy.

There are minimal risks involved in taking part in this research project. However, interviews will offer participants an opportunity to reflect on their experiences of care in the context of L'Arche while contributing to the small body of already existing research on this growing international organization. A copy of the final project will be given to L'Arche following the completion of my Masters thesis.

I am very interested in listening to what you may have to say about your experiences of care in the context of L'Arche and the way it differs from care provided elsewhere. Please consider participating in this research project.

If at any time you have questions about your rights and this research, or comments to make please contact me, Sarah Parisio, at 514.581.3507 or by email at sarah.parisio@gmail.com , or my supervisor Dr. David Howes in the Department of Sociology and Anthropology at 514.848.2424 ext. 2148 or by email at howesd@alcor.concordia.ca.

Sincerely,

Sarah Parisio

Sample Letter of Information for Assistants or Legal Guardians [Italian version]

Caro/a (nome del assistente o di un tutore legale),

Il mio nome è Sarah Parisio. In questo momento sto perseguendo un Master in Antropologia Sociale e Culturale presso l'università Concordia di Montréal Québec sotto la supervisione del Dr. David Howes. Fin dalla mia infanzia, sono stata coinvolta nell'Arca attraverso l'impegno dei miei genitori nelle comunità vicine alla mia città di London Ontario. Recentemente, ho avuto l'opportunità di vivere in un focolare qui in Italia, dove sono rimasto profondamente segnata dall'applicazione pratica della visione dell'Arca. Nel corso degli anni, ho letto molti libri su L'Arca e udito innumerevoli testimonianze da parte di persone con e senza disabilità che sono state trasformate dalle loro esperienze di cura. Come volontaria, ho scoperto in prima persona il valore trasformativo nel impegnarsi in relazioni di reciprocità.

Sono stata a lungo interessata nella cura degli altri e ho trovato all'Arca un modello drasticamente diverso da quello operazionalizzato in altre strutture sanitarie. All'Arca la reciprocità nelle relazioni è fondamentale per il benessere di tutti i membri della comunità. Anche se questo può sembrare ovvio per quelli di voi che sono ormai abituati ai modi dell'Arca, vi assicuro che la cura non è spesso intesa per lavorare in questo modo. Altrove, la cura si intende che deve essere fornita da alcuni e ricevuta da altri. Il modello dell'Archa è quindi radicale in molti modi e merita di essere ulteriormente esplorata.

Il progetto di ricerca che spero di condurre si concentrerà sucomprendere e comunicare le esperienze di reciprocità nelle relazioni all'Arca delle persone che ci vivono un pezzo del loro percorso. Per capire veramente queste esperienze da diversi punti di vista, chiedo per la vostra partecipazione in questo studio. L'Arca è composto da molti membri ed è importante per me per documentare le esperienze di tutti i soggetti coinvolti.

Informazioni per questo progetto di ricerca saranno raccolte principalmente attraverso l'osservazione e dei colloqui. Ho intenzione di vivere in comunità cinque giorni alla settimana per un periodo di due mesi e mezzo. In tal modo, sarò in grado di osservare e partecipare alle attività quotidiane dei soci dell'Arca. L'obiettivo di osservazione è quello di scoprire come l'assistenza reciproca nei rapporti viene messa in pratica. L'osservazione inizierà a luglio 2012.

Le interviste saranno condotte verso la fine del mio tempo in comunità, al fine di consentire il tempo sufficiente per i membri della comunità di conoscere me e viceversa. Un colloquio si svolgerà con le seguenti persone: due membri principali (con presenza di un assistente), due assistenti e due amministratori. L'intervista è destinata a durare da una a tre ore e sarà composta di circa venticinque domande. Durante l'intervista, i membri saranno invitati a condividere le loro esperienze di cura all'Arca. Le interviste saranno registrate e trascritte con il vostro permesso. E possibile recedere in qualsiasi momento durante l'intervista e si può rifiutare di rispondere a tutte le domande che saranno poste. E anche possibile recedere la tua partecipazione nel mio progetto fina quando andrò via dall'Italia. Le informazioni saranno utilizzate per scopi di ricerca e tutti i nomi di persone e luoghi saranno omessi dalla dissertazione finale al fine di tutelare la riservatezza e il benessere degli intervistati e delle persone collegate. Pseudonimi saranno utilizzati al loro posto. I membri della comunità saranno in grado di fareun controllo sulla dissertazione finale prima della presentazione della mia tesi per la verifica e la precisione.

Ci sono rischi minimi coinvolti nella partecipazione a questo progetto di ricerca. Tuttavia, interviste offriranno ai partecipanti l'opportunità di riflettere sulle loro esperienze di cura nell'Arca, contribuendo nel frattempo al piccolo corpo di ricerca già esistente su quest'organizzazione internazionale crescente. Una copia del progetto definitivo sarà data all'Arca a seguito del completamento della mia tesi di Master.

Sono molto interessata ad ascoltare ciò che si può dire le vostre esperienze di cura all'Arca e il modo in cui differisce da cure prestate altrove. Ti consigliamo di partecipare a questo progetto di ricerca.

Se in qualsiasi momento avete domande su i vostri diritti o la ricerca, o osservazioni da fare non esitate a contattarmi, Sarah Parisio, al 514.581.3507 o via email a sarah.parisio@gmail.com, o il mio supervisor Dr. David Howes nel Dipartimento di Sociologia e Antropologia presso 514.848.2424 ext. 2148o tramite mail a howesd@alcor.concordia.ca.

Cordiali saluti,

Sarah Parisio

APPENDIX E
Sample Consent Form [English version]

CONSENT TO PARTICIPATE IN *A new model for care: A case study in creating community among persons with and without disabilities*

This is to state that I understand that I am participating in a project of research being conducted by Sarah Parisio under the supervision of Dr. David Howes of the Department of Anthropology of Concordia University. Questions or concerns should be directed to Sarah Parisio at 514.581.3507 or sarah.parisio@gmail.com or to David Howes at 514.848.2424 ext. 2148 or howesd@alcor.concordia.ca.

A. PURPOSE

I understand that the purpose of the research has been as follows: comprehend and communicate people's experience of mutuality in caregiving relationships at L'Arche.

B. PROCEDURES

I understand that the interview will be conducted between July 1st and September 30th 2012 in Rome Italy. The interview is intended to last anywhere from one to three hours and will consist of approximately twenty-five questions. The interview will be recorded on a handheld Sony recorder and transcribed with your permission. I understand that it is possible to withdraw at any time during the interview. Furthermore, I understand that it is possible to withdraw my consent to participate in this research project at any time prior to the researcher's departure on September 30th. All names of persons and places will be omitted from the final report in order to protect the confidentiality and wellbeing of the interviewee and related persons. Pseudonyms will be used in their place.

C. RISKS AND BENEFITS

I understand that there are minimal risks to the psychological wellbeing and/or reputation of research participants involved in taking part in this research project. However, interviews will offer participants an opportunity to reflect on their experiences of care in the context of L'Arche while contributing to the small body of already existing research on this growing international organisation. A copy of the final project will be given to L'Arche following the completion of my Masters thesis.

D. CONDITIONS OF PARTICIPATION

☐ I understand that I am free to withdraw my consent and discontinue my participation at anytime without negative consequences.

☐ I understand that my participation in this study is CONFIDENTIAL (i.e. the researcher will know, but will not disclose my identity).

☐ I understand that the data from this study may be published.

I HAVE CAREFULLY STUDIED THE ABOVE AND UNDERSTAND THIS AGREEMENT. I FREELY CONSENT AND VOLUNTARILY AGREE TO PARTICIPATE IN THIS STUDY.

NAME (please print) ____

SIGNATURE ____

If at any time you have questions about your rights as a research participant, please contact the Research Ethics and Compliance Advisor of Concordia University, at 514.848.2424 ext. 7481 or ethics@alcor.concordia.ca.

Sample Consent Form [Italian version]

CONSENSO INFORMATO PER LA PARTECIPAZIONE AL PROGETTO

A new model for care: A case study in creating community among persons with and without disabilities

Sono consapevole di partecipare ad un progetto di ricerca condotto da Sarah Parisio sotto la supervisione del Dr. David Howes del Dipartimento di Antropologia dell'Universita Concordia. Domande o dubbi devono essere indirizzati a Sarah Parisio al 514.581.3507 o sarah.parisio@gmail.com oppure a David Howes al 514.848.2424 ext. 2148 o howesd@alcor.concordia.ca.

A. SCOPO

Sono consapevole che lo scopo della ricerca è il seguente: comprendere e comunicare l'esperienza della reciprocità nei rapporti di cura all'Arca.

B. PROCEDURE

Sono consapevole che il colloquio si svolgerà tra il primo luglio e il trenta settembre 2012 a Roma in Italia. L'intervista durerà da una a tre ore e sarà composta da circa venti domande. L'intervista verrà registrata su un registratore Sony e trascritta solo previo mio consenso. Sono consapevole di poter recedere in qualsiasi momento nel corso dell'intervista. Inoltre, sono consapevole di poter ritirare il mio consenso a partecipare a questo progetto di ricerca in qualsiasi momento prima della partenza del ricercatore (il trenta settembre 2012). Tutti i nomi di persone e luoghi saranno omessi dalla relazione finale, al fine di tutelare la privacy e il benessere delle persone intervistate. Pseudonimi saranno utilizzati al loro posto.

C. RISCHI E BENEFICI

Sono consapevole che ci sono rischi minimi per il benessere psicologico e / o la reputazione dei soggetti coinvolti a partecipare a questo progetto di ricerca. Tuttavia, l'intervista offrirà ai partecipanti l'opportunità di riflettere sulle loro esperienze di cura nel contesto dell'Arca, contribuendo nel frattempo alle attività di ricerca già esistenti su questa organizzazione internazionale. Una copia del progetto definitivo sarà consegnata alla comunità "Il Chicco" al termine della tesi di Master del ricercatore.

D. CONDIZIONI DI PARTECIPAZIONE

☐ Sono consapevole di poter ritirare il mio consenso e interrompere la mia partecipazione in qualsiasi momento senza conseguenze negative.

☐ Sono consapevole che la mia partecipazione a questo studio è anonima (il ricercatore conoscerà, ma non indicherà, la mia indentità nella relazione finale).

☐ Sono consapevole che i dati di questo studio potranno essere pubblicati.

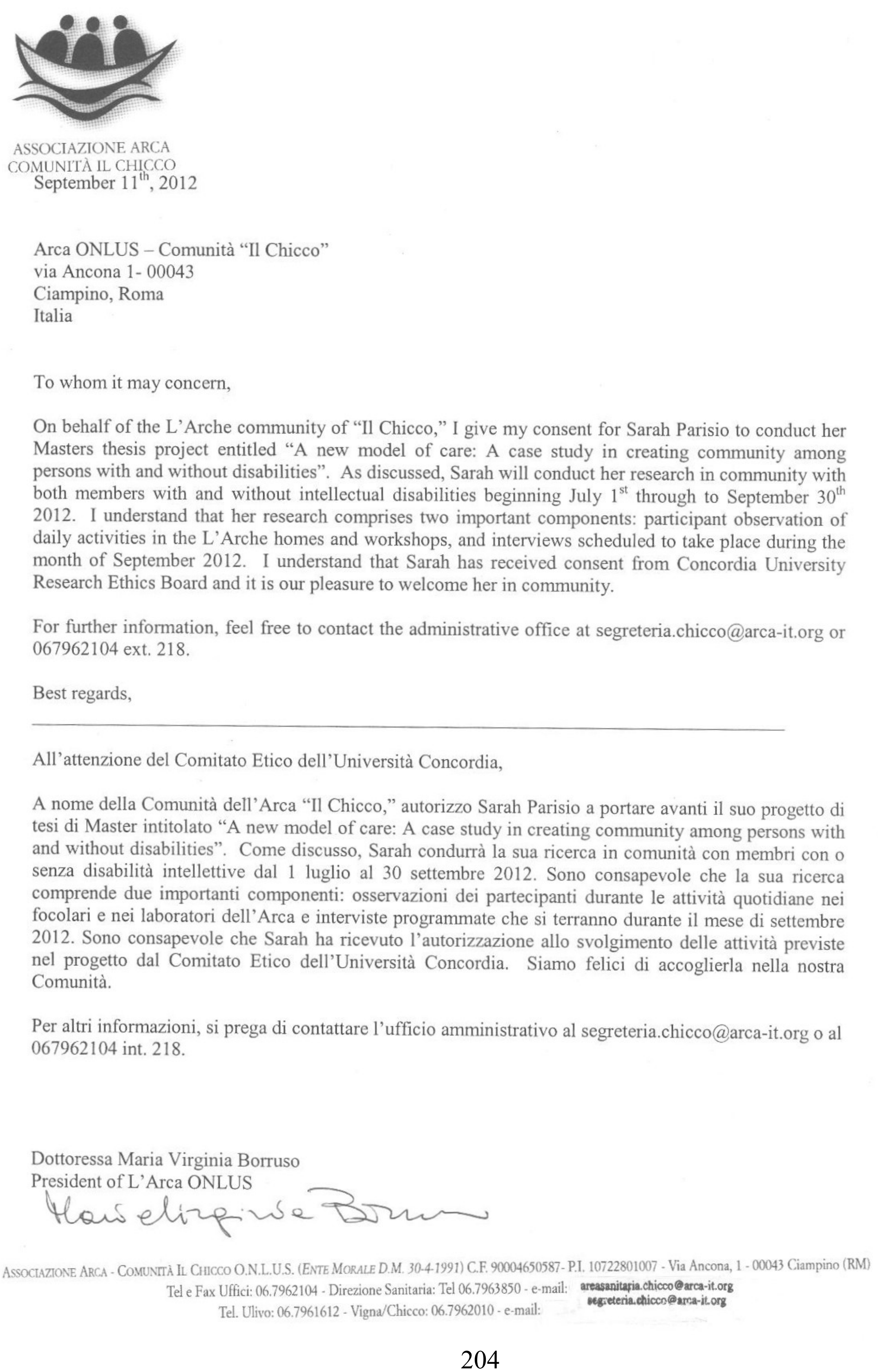
HO LETTO OD ASCOLTATO CON ATTENZIONE QUANTO SOPRA E COMPRENDO IL PRESENTE CONTRATTO. ACCONSENTO LIBERAMENTE E ACCETTO A PARTECIPARE VOLONTARIAMENTE A QUESTO PROGETTO.

NOME (in stampatello) ____

FIRMA ____

Se in qualsiasi momento avrete domande sui vostri diritti in quanto partecipante alla ricerca, si prega di contattare il Consigliere di Ricerca Etica e Conformità della Concordia University, a 514.848.2424 ext. 7481 o ethics@alcor.concordia.ca.

APPENDIX F
Letter of Consent from the President of Associzione Arca – Comunita Il Chicco



ASSOCIAZIONE ARCA
COMUNITÀ IL CHICCO

September 11th, 2012

Arca ONLUS – Comunità "Il Chicco"
via Ancona 1- 00043
Ciampino, Roma
Italia

To whom it may concern,

On behalf of the L'Arche community of "Il Chicco," I give my consent for Sarah Parisio to conduct her Masters thesis project entitled "A new model of care: A case study in creating community among persons with and without disabilities". As discussed, Sarah will conduct her research in community with both members with and without intellectual disabilities beginning July 1st through to September 30th 2012. I understand that her research comprises two important components: participant observation of daily activities in the L'Arche homes and workshops, and interviews scheduled to take place during the month of September 2012. I understand that Sarah has received consent from Concordia University Research Ethics Board and it is our pleasure to welcome her in community.

For further information, feel free to contact the administrative office at segreteria.chicco@arca-it.org or 067962104 ext. 218.

Best regards,

All'attenzione del Comitato Etico dell'Università Concordia,

A nome della Comunità dell'Arca "Il Chicco," autorizzo Sarah Parisio a portare avanti il suo progetto di tesi di Master intitolato "A new model of care: A case study in creating community among persons with and without disabilities". Come discusso, Sarah condurrà la sua ricerca in comunità con membri con o senza disabilità intellettive dal 1 luglio al 30 settembre 2012. Sono consapevole che la sua ricerca comprende due importanti componenti: osservazioni dei partecipanti durante le attività quotidiane nei focolari e nei laboratori dell'Arca e interviste programmate che si terranno durante il mese di settembre 2012. Sono consapevole che Sarah ha ricevuto l'autorizzazione allo svolgimento delle attività previste nel progetto dal Comitato Etico dell'Università Concordia. Siamo felici di accoglierla nella nostra Comunità.

Per altri informazioni, si prega di contattare l'ufficio amministrativo al segreteria.chicco@arca-it.org o al 067962104 int. 218.

Dottoressa Maria Virginia Borruso
President of L'Arca ONLUS

ASSOCIAZIONE ARCA - COMUNITÀ IL CHICCO O.N.L.U.S. (*ENTE MORALE D.M. 30-4-1991*) C.F. 90004650587- P.I. 10722801007 - Via Ancona, 1 - 00043 Ciampino (RM)
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APPENDIX G
Charter of the Communities of L'Arche

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. ...

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 of 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

- 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.
- Communities are either of one faith or inter-religious. Those which are Christians are either of one church on inter-denominational. Each community maintains links with appropriate religious authorities and its members are integrated with local churches and other places of worship.
- Communities recognize that they have an ecumenical vocation and a mission to work for unity.

2. Called to unity

- 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 centre 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.

- 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.
- The same sense of communion unites the various communities throughout the world. Bound together by solidarity and mutual commitment, they form a world-wide family.

3. Called to growth

- 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.
- The communities wish to secure for their members' education, work and therapeutic activities, which will be a source of dignity, growth and fulfilment for them.
- 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.
- All community members are invited to participate, as far as possible, in decisions concerning them.

4. Integrated in society

- 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 neighbours and friends.
- The communities seek to be competent in all the tasks they are called to accomplish.
- The communities wish to enable people with a handicap to work, believing work to be an important means of integration.

- 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.

Respectful terminology to describe the people who are at the heart of L'Arche and for whom L'Arche was founded varies from one country to another. We invite you to substitute the terms used on this website with those that are used and accepted in your country.

(L’Arche, 2012)

APPENDIX H
Mission and Identity of L’Arche

Identity Statement

We are people with and without intellectual disabilities*,

sharing life in communities belonging to an International Federation.

Mutual relationships and trust in God are at the heart of our journey together.

We celebrate the unique value of every person

and recognise our need of one another.

Our mission is to…

Make known the gifts of people with intellectual disabilities*,

revealed through mutually transforming relationships.

Foster an environment in community that responds to the changing needs of our members,

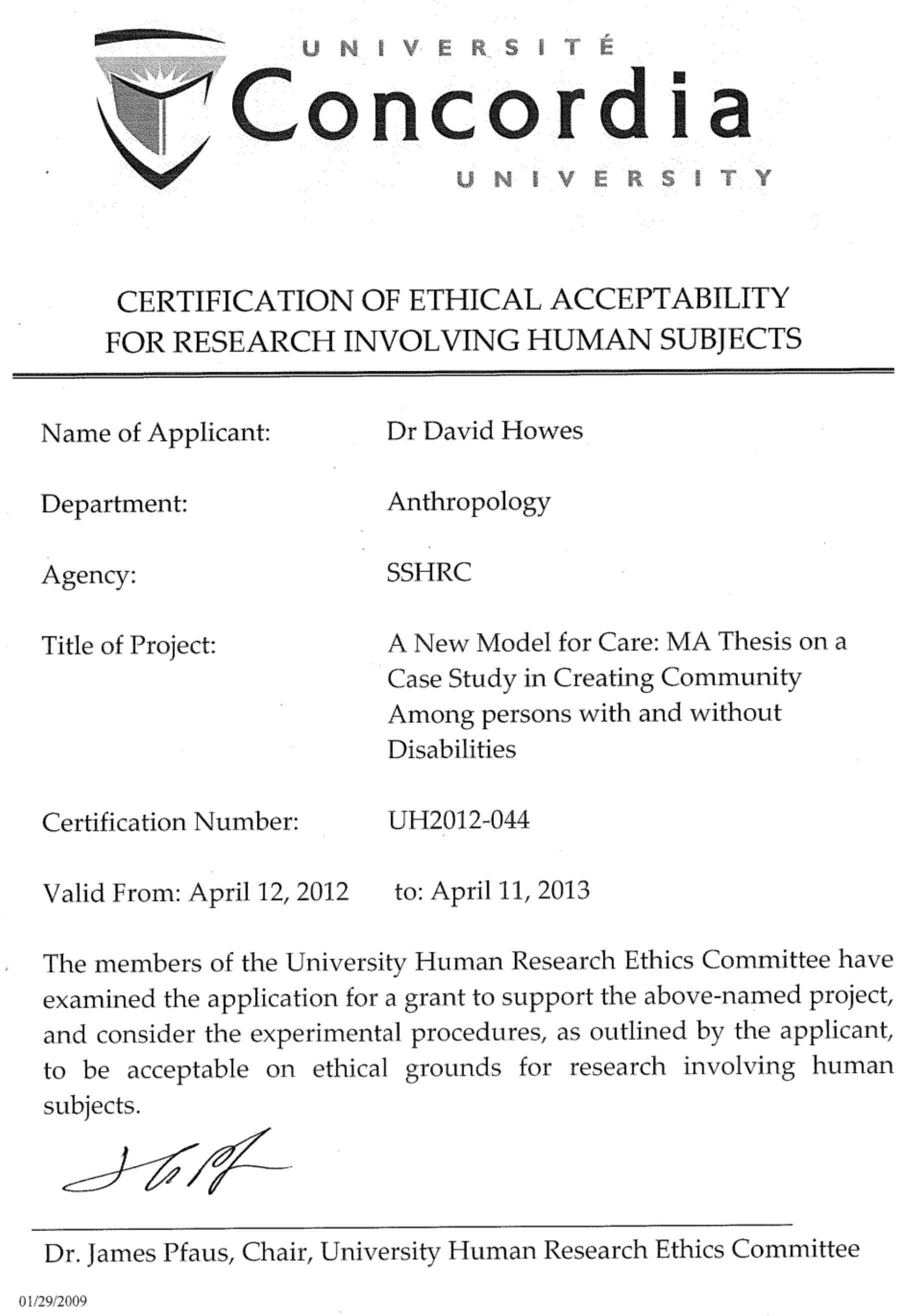
whilst being faithful to the core values of our founding story.

Engage in our diverse cultures, working together toward a more human society.

We invite you to substitute the terms with those that are accepted in your country.

(L’Arche, 2012)

APPENDIX I
Approval from Concordia University Human Research Ethics Committee



UNIVERSITÉ Concordia UNIVERSITY

CERTIFICATION OF ETHICAL ACCEPTABILITY FOR RESEARCH INVOLVING HUMAN SUBJECTS

Name of Applicant:	Dr David Howes
Department:	Anthropology
Agency:	SSHRC
Title of Project:	A New Model for Care: MA Thesis on a Case Study in Creating Community Among persons with and without Disabilities
Certification Number:	UH2012-044

Valid From: April 12, 2012 to: April 11, 2013

The members of the University Human Research Ethics Committee have examined the application for a grant to support the above-named project, and consider the experimental procedures, as outlined by the applicant, to be acceptable on ethical grounds for research involving human subjects.

Dr. James Pfaus, Chair, University Human Research Ethics Committee

01/29/2009