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A Participatory Study of the Nature of Touch at L'Arche: Understanding Protective and Risk Factors to Develop and Approach to Safe and Respectful Touch for People with Developmental Disabilities

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A Participatory Study of the Nature of Touch at L'Arche: Understanding Protective and Risk
Factors to Develop an Approach to Safe and Respectful Touch for
People with Developmental Disabilities

by

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THESIS

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Abstract

This study explored the use of touch in the L'Arche approach to care-giving for people with developmental disabilities. The intent was to explore the nature of touch, and the protective and risk factors of this alternative care setting, to promote a safe and respectful environment that enhanced protective factors and minimized risk. The author was interested in the scientific research on the value of touch, ethics in relationships with power differences, the prevention of abuse, and the prevalence of respectful expressive/affectionate touch between people with disabilities and their caregivers. The study engaged one L'Arche community in Ontario, Canada, through a participatory, ethnographic, case study design. The data collection involved six weeks of participant observation, 11 interviews and two focus-groups (N = 19). Creating an inclusive research experience was important to the author, who sought balanced participation in all research methods between residents with developmental disabilities and staff. Amongst the participants were eight staff, seven residents, and four key-informants. The findings of this study revealed that the nature of touch in care-giving at L'Arche is very complex. The protective factors included capacity-building around touch, boundaries, and communication, and the role of community and long term relationships of mutuality. Risk factors included vulnerability, lack of communication and not respecting boundaries, dual roles, cultural differences and inconsistencies amongst L'Arche communities. It is hoped that the findings of this study will be transferrable to other care settings, in order to create respectful and safe environments for people with developmental disabilities.

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Introduction

Touch is the first sense to develop and plays vital roles in human development and communication (Field, 2001; Smith, 1998). Yet, despite the critical role that touch plays in our development and well-being, North American society has become disapproving of expressive touch in relationships with power differences (Field, 2001). The abuse of vulnerable persons, such as people with developmental disabilities, by people in positions of power, such as their caregivers, is one of the reasons this disapproving attitude has developed. These high profile abuse cases have justifiably instigated a mass movement of no-touch policies. Even though such policies are meant to protect vulnerable populations from further physical and sexual abuse, these regulations are problematic for several reasons. First, it is not entirely possible to employ these regulations when providing care for people experiencing various forms of dependency, such as persons with developmental disabilities, as a degree of touch is necessitated by care tasks. Therefore, no-touch policies ultimately target affectionate or expressive touch, which then denies people the right to receive this form of touch. Most troubling of all, however, is that the abuse of people with developmental disabilities is still happening despite the no-touch policies. Therefore, my intent with this study was to explore the use of touch in relationships between persons with developmental disabilities and their caregivers. I wanted to investigate ways to promote safe and respectful touch and prevent abuse for people with disabilities. I chose to study this phenomenon in a L'Arche community, an alternative residential-care setting for people with developmental disabilities.

Overview of L'Arche

L'Arche was founded in 1964 by the Canadian philosopher, Jean Vanier. During visits to the psychiatric institution in his village of Trosly-Breuil in France, Vanier witnessed grave injustices in the treatment of the residents. This institution also accommodated people with

disabilities. Vanier realized that a great deal of the suffering of people with developmental disabilities was not due to their impairments, but rather to their “experience of social rejection – being pushed away to the margins of society” (Anderson, 1998, p. 12). Vanier was moved to respond to this injustice, and he asked two men living at the institution to live with him. They called their home L’Arche, the French word for the Ark from the Biblical story of Noah’s Ark (L’Arche International, 2008). L’Arche has grown over the last 40 years into an international federation of more than 135 communities in 36 countries. As an organization it serves over 5000 people with disabilities, who share their lives in homes, workshops, and day programs. Every L’Arche community seeks to offer a family-style living arrangement where people eat, pray, and celebrate together (Harris, 1987). This focus on togetherness and individual strengths encourages people with developmental disabilities to create a home, develop their talents, build friendships, and make the most of life (L’Arche International, 2008). In Canada there are currently 29 communities with over 200 homes (L’Arche Canada, 2008).

As a devout Catholic, Vanier founded L’Arche in the spirit of the Christian Beatitudes (Currie, 2005; Harris, 1987; O’Malley, 1992; Vanier, 1995). This teaching (found in the Bible, in the book of Luke, 6:20 – 49) says that because of their enduring experiences of anguish and pain, it is the littlest and weakest persons who have the most to teach us about what is important in life (Cushing & Lewis, 2002). They have the ability to teach others “how to live in peace with our fellow human beings by focusing not on achievements or possessions but instead on the dignity of each person” (Harris, 1987, p. 324). L’Arche is an inter-faith organization. Jean Vanier stepped down from the leadership of the L’Arche federation in the late 1970s (L’Arche Canada, 2008) but continues to live in his original L’Arche community.

For many reasons L’Arche culture and approach to care-giving and community are unique relative to the current system of social services and care-giving for people with developmental

disabilities, which is currently in transition from a medical model of care to a more consumer directed, inclusive model (Dunn, 2003). L'Arche is a place of inclusion that celebrates people with diverse physical and cognitive abilities (Sumarah, 1987; Vanier, 1998). L'Arche operates with a social justice paradigm and a humanitarian spirit (Cushing, 2003b), and it seeks to value each person's humanness and need for belonging (Vanier, 1989). Rather than defining people by their deficits and disabilities, Vanier focused on people's strengths and abilities (Cushing, 2003; Sumarah, 1987; Vanier, 1995). This approach revealed the gifts of people who were rejected by society and showed that diversity can enrich community life (Elkins, 2008). Vanier's original mission was to create a community where people with disabilities were at the core (L'Arche Charter, 1993; Vanier, 1989), which gave rise to the term *Core Member* for people with developmental disabilities residing in L'Arche communities. (See Appendix A for L'Arche Mission) Staff persons were referred to as *assistants*. Perhaps the most distinctive way that L'Arche is unique relative to other residential-care settings for people with disabilities is that L'Arche has an intentional focus on community and relationship building. At L'Arche, Core Members and assistants are supported in establishing friendships of mutuality with one another. I discuss the term mutuality below.

Overview of Touch and Care-giving Relationships for People with Disabilities

When examining the use of touch in care-giving relationships between people with developmental disabilities and their caregivers, it became apparent that there were many complex facets to this topic. First, because physical touch happens within the client-staff relationship, it is necessary to understand the roles of individuals in this relational dyad and the importance of relational boundaries. It is also pertinent to understand the power dynamics of these relationships, and how the distribution and use (or misuse) of power can contribute to appropriate and respectful or inappropriate and abusive interactions. In addition, physical and sexual abuse of people with

developmental disabilities continues to be a serious problem within the disability service sector and society in general. I will now briefly expand upon each one of these aspects and its relation to L'Arche.

At L'Arche assistants and Core Members live together often for many years, sometimes 25 to 30 years. As previously mentioned they are also encouraged to build authentic friendships of mutuality (Cushing 2003, 2003b; Vanier, 1989, 1995). Therefore, their roles within the community have a 'dual' or 'multiple' nature; that is, L'Arche assistants are caregivers *and* friends. This relational practice, known as 'relational mutuality', is dissonant with most professional ethical codes that say dual relationships run the risk of blurring ethical boundaries, thus creating the potential danger of client exploitation (Kitchener, 1988; Pope, 1990). Therefore, L'Arche's attitude toward relationships distinguishes it as a nuanced approach that needs to be explored in order to understand how the use of touch therein can be kept safe and beneficial for people with developmental disabilities.

Second, people with disabilities have historically had very little social power (White, 2005); therefore, it is important to study the role of power in the use of touch. The caregiver-client relationship implies a certain level of dependence (Wendell, 1996), and this unavoidable asymmetry of power further complicates the use of touch in this dyad (Cushing, 2003). Human interactions are complex, and power can be abused, even if very subtly (Hingsburger, 1995; Vanier, 1989). For example, it is not always possible to tell whose needs are being met by an affectionate exchange. Further, even though L'Arche assistants are encouraged to respect the power differences between themselves and Core Members through the approach of relational mutuality, it is not always possible to tell if an interaction is completely mutual. People with developmental disabilities experience more vulnerabilities than do able-bodied people, and have suffered greatly from structural, systemic, and interpersonal oppression, violence, and

marginalization (Cushing, 2003a; Dunn, 2003; Harris, 1987; Morris, 2001; Vanier, 1998; White, 2005). Even caregivers who mean well can make the mistake of violating someone through not offering choices or touching someone without first asking (Hingsburger, 1995). As previously indicated, abuse of people with developmental disabilities is a major problem in the care-giving sector (Baladerian, 1991, 2009; Saxton et al., 2001). It is estimated that as much as 100% of people with developmental disabilities will be physically or sexually abused at some point in their lives (Baladerian, 1991). While this research project is not about abuse, it is important to consider the prevalence of abuse, because understanding its root causes can help professionals and caregivers understand how to prevent it and keep the use of touch beneficial and safe for this population. Therefore, it became clear that in order to consider this topic fully I would need to explore the relational dyad between caregivers and clients with disabilities, power dynamics in this dyad, and abuse within care-giving to understand how to keep the use of touch safe and respectful for people with disabilities.

Purpose of this Study

The purpose of this study was to understand the nature of touch at L'Arche and if its unique approach to care-giving for people with developmental disabilities has created any special protective or risk factors with regard to the use of touch. The decision to focus on touch in care-giving was supported by people in leadership positions in L'Arche Ontario, who affirmed that this topic is important. Because the study was grounded in the L'Arche context, it also had the ability to provide feedback to L'Arche for future action and change regarding current organizational practices and policies on the use of touch.

Researcher Position in Relation to this Study

My interest in disability issues originates in my large French Canadian family. Out of over 30 cousins I have only one cousin who is my age, and he was born with Down's Syndrome. Because of our closeness in age, he and I were raised much like brother and sister. The experience of growing up with him cultivated an early awareness of disability and difference. This interest was further developed in my first job in high school as a personal respite worker for Community Living, an organization that supports people with intellectual and developmental disabilities. I worked primarily with one family and their daughter who had a developmental disability. Through my years of working with this woman I gained experiential knowledge of her life struggles and joys, which resulted in an even deeper interest in disability issues. After high school I decided to pursue an undergraduate degree in psychology. At this time I was instructed in my clinical and counseling psychology courses to never, under any circumstances, hug a client or person for whom one was providing care or counsel. I took this instruction very seriously and incorporated it into my schema of being a professional.

After I finished my undergraduate degree I became a L'Arche assistant and it was at this time that I developed a specific attentiveness to the use of touch in care-giving for people with developmental disabilities. At L'Arche I was immediately struck by the presence of physical affection between Core Members and assistants, such as hugging or holding hands. I saw that the use of touch is inescapable in care-giving, such as in functional or procedural tasks. I also realized that if people with disabilities were not given the option to receive physical affection from caregivers, then they most likely would not receive it at all, due to the high amounts of social isolation and lack of family contact from which much of this population suffers. I started to ask myself questions about the reasons that I was so strictly taught in my undergraduate degree that a hug was never acceptable. I saw that the openness to give or receive affection created a loving and

warm climate, but that people could also benefit from an understanding of boundaries and information about healthy relationships. Specifically, I had a difficult experience where I witnessed another assistant using touch inappropriately with two Core Members. My desire to do this research largely came out of that experience. I began to ask myself questions about how to keep the option for expressive touch open amidst the use of more functional/procedural touch and how to make all touch positive and safe. Therefore, I was interested in understanding the risk factors, such as lack of training and the dual roles, and the protective factors, such as boundaries and education, that could be employed and enhanced in the environment to understand and make recommendations to L'Arche as an organization about how to provide safe and respectful care to people with developmental disabilities.

Prior to this study there was not any research conducted with L'Arche about the use of touch; therefore, I saw my Master's thesis as an opportunity to address this knowledge gap. In collaboration with the leadership of L'Arche Ontario I designed a study that would engage one L'Arche community in a participatory manner in order to understand how to keep the use of touch safe and respectful in care-giving for people with developmental disabilities.

Review of the Literature

I will now present a review of the literature on the topic of touch in care-giving for people with developmental disabilities. I will begin with a synopsis of the published writings on L'Arche, during which I will focus on the writings of Jean Vanier and several other theorists. I will also discuss the role of mutuality and sense of belonging at L'Arche. I will then present a discussion about touch, where I will introduce a taxonomy of touch for caregivers who work with people with developmental disabilities (Gale & Hegarty, 2000). I also will discuss the literature on the necessity and benefits of touch. I will then address the abuse of persons with developmental disabilities (Hingsburger 1995; Kertay & Reviere, 1998; Sobsey, 2002; Vanier, 1998) and describe

some of the ways that abuse can be prevented in relationships of care with individuals with developmental disabilities (Hingsburger, 1995; Hingsburger & Schwier, 2000). I will summarize the basic tenets of prevention and promotion and define how I will use the terms protective and risk factors in this research. After this discussion on prevention and promotion, I will consider the literature on professional ethics, dual relationships, and boundary crossing (CPA Code of Ethics, 2000). Last, I will introduce principles from the feminist ethic of care as a complementary way to understand the ethics of relationships characterized by power differentials and the use of touch within such dyads.

L'Arche and Jean Vanier

I will now present a discussion of relevant L'Arche concepts and research. I will begin with a review of Vanier's key ideas, paying particular attention to sense of belonging and mutuality. I will also highlight several other theorists who have made substantial contributions to the writings on L'Arche.

One of the most important aspects of L'Arche philosophy is sense of belonging (Vanier, 1989, 1998). According to Vanier the desire to belong is one of the strongest needs that we have as human beings (1998). The L'Arche Charter (1993) names 'belonging' as an integral aspect of 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 . . . They have a simple life-style which gives priority to relationships". Throughout the day at L'Arche there are purposeful practices that bring people together to sustain unity. Vanier (1989, 1995) writes about the dinner table as a place of communion and argues that the daily practice of sharing a meal nourishes the relationships that create community. L'Arche is also intentional about community events such as prayer evenings and celebrations. Such practices that openly reject the individualism of Western society often cause people to think that participating in these customs

can result in the loss of individuality, but such is not the case (Angrosino, 2003; Currie, 2005; Vanier, 1998); “community is not a place where individuality is denied; it is a place where individuality is nurtured and supported in such a way that it ceases to be the destructive seed of envy and division” (Angrosino, 2003, p. 945). Vanier felt that only through community could people grow to independence and understand what it meant to be human (1998).

Community psychologist, John Dunne (1986) studied the sense of community at L’Arche. He argued that the L’Arche experience suggests sense of community is an understanding of the interdependence of all humanity, which is developed by acknowledging the charade of independence, and accepting the pain, risks, and weakness that one may encounter in mutual relationships (Dunne, 1986). His article also brings forth some of the less ideal aspects of everyday life at L’Arche. Community life can be demanding, and L’Arche does not always consist of happy times with fun and togetherness (Dunne, 1986). There is pain associated with the complex physical ailments and sometimes aggressive behaviors of people with developmental disabilities. However, despite the challenges, Dunne concludes by reaffirming the L’Arche model as an exemplar of the way that sense of community can be actualized in our society. He says that a strong sense of community in greater society demands, to some extent, the same conditions as L’Arche.

Another concept that is very important to L’Arche philosophy is mutuality (Vanier, 1989, 1998). Mutuality is about valuing the inherent personhood of the other and understanding that no matter one’s strengths or limitations, all people have the ability to contribute meaningfully to society, their environment, and their relationships (Vanier, 1989, 1998). Mutual relationships do not necessarily mean that there is equal power between all parties (Isenberg, Loomis, Humphreys, & Maton, 2004), but that value can occur even with power differences (such as those found between an able-bodied caregiver and a person with a developmental disability) through creating a relational atmosphere of inclusion, equity, and respect.

Anthropologist Pamela Cushing has written extensively on mutuality at L'Arche (Cushing, 2003a, 2003b, 2008a; Cushing & Lewis, 2002). Taking a critical position, she explains that we cannot negate the inherent power differences of these relationships. Cushing comments that this power asymmetry adds a layer of complexity when striving for mutuality. Assistants must continually “negotiate delicate power relations connected to the physics of care and to reframe dominant stereotypes of disability” (Cushing & Lewis, 2002, p. 173). She further comments on the difficulty in attempting to navigate the ambiguity of a relationship that is ultimately one of care and support but also strives to be one of friendship (Cushing, 2003b).

Cushing (2003b) offers a six-dimensional framework of mutuality in care-giving. First, mutuality is both *general and particular*; that is, mutuality is promoted as a general approach to all relationships, but it is richest within the particulars of a specific relationship. Second, these dyads are *instrumental relationships* in that the caregiver-client relationship is always initially and fundamentally one of care; while care dyads can evolve into friendships, it is not possible to free them of this instrumental dynamic. Third, Cushing emphasizes *process versus outcome*, which means that rather than being concerned with idealistic goals of perfectly mutual relationships, it is more important that caregivers are in an ongoing process of learning to be more receptive to the value of difference and the personal gifts of people with disabilities. Fourth, while Cushing is careful not to equate mutuality and reciprocity (Cushing & Lewis, 2002), she acknowledges that there are *elements of reciprocity* within thriving mutual relationships. Even though L'Arche assistants are paid, much of their discourse reflects notions of a “gift economy” (Maus, 1954, as cited in Cushing, 2003b); that is, assistants feel that giving of their time, care, and additional energy is balanced by “re-valorizing the gifts inherent in the clients’ lives” (Cushing, 2003b, p. 89). Thus, assistants see reciprocity in the “alternative currency” that they inadvertently create for Core Members, which allows Core Members to “give back” to assistants through their individual

strengths. Fifth, an integral element of mutuality is *solidarity*. This dimension encapsulates “power sharing and mutual relations as part of a moral, spiritual and political project of solidarity with those who are marginalized ... Assistants often describe their desire to make the effort to reach across inequality to cultivate common ground in relationship with others as a way of recognizing and alleviating their disenfranchisement” (Cushing, 2003b, p. 89). Seeking to reverse the perpetuation of structural inequality is essential to this kind of solidarity. Last, the sixth dimension of Cushing’s framework acknowledges *what is not mutuality: the labor of care*. It is important to remember that care-giving is work for which caregivers must receive credit. Feminists have argued that this kind of work is problematic, because it reflects tasks that are traditionally low-skilled, underpaid, and undervalued (Kittay, 1999). It is not to say that people with disabilities create “work” for others, or that L’Arche assistants are only friends with Core Members because they are paid. However, in order to prevent the further devaluing of this form of work, the labor involved in care-giving must be acknowledged. Cushing found that assistants characterized mutuality as an approach to relating to all people with mutual respect, support, and authenticity (Cushing & Lewis, 2002). Working toward mutuality merits the extra effort required, because it enriches the experience for both client and caregiver (Cushing, 2003b). She also discusses the use of an ethic of care at L’Arche, which is deeply intertwined with the concept of mutuality, as I will discuss below.

In another relevant article concerning L’Arche, Harris (1987) compared the Core Member-assistant relationship to the healing relationship of the counselor-client dyad. Harris says that even though L’Arche homes do not operate as places of therapy, there is a therapeutic quality to this form of intentional community living. While professional psychiatric advice outside of the community is regularly sought to ensure that Core Members’ and assistants’ mental-health needs are being looked after, L’Arche homes are not treatment centres. Assistants are not “professionals”, which Harris argues decreases the power difference between caregiver and client

and therefore facilitates relational mutuality. Harris also asserts that the Core Member-assistant relationship could be hurt by making it more professionalized (1987). Many Core Members at L'Arche came directly from institutions, where numerous people were abused at the hands of "professionals" (Hingsburger, 1995; Johnson & Traustadottir, 2005). Re-creating this atmosphere of professionalism within the home could be oppressive for people with disabilities. Harris (1987) argues that the mutuality promoted by L'Arche culture helps people heal from the abuse of years of institutional life. Despite the fact that people with developmental disabilities may have impaired cognitive processes, their ability and need to relate to others are still as real and important as any other human being's (Harris, 1987). Harris states that the way L'Arche encourages personal relationships is one of its greatest strengths.

In addition, John Sumarah has made a strong contribution to the academic literature on L'Arche (1985, 1987, 1989; Pottie & Sumarah, 2004). In the same vein as Harris, he asserts that because professionalism holds much power and weight in our society, the non-professional staff at L'Arche help to facilitate mutual relationships. L'Arche is not trying to "correct" or "cure" people with intellectual disabilities. Rather, L'Arche staff attempt to help people reclaim their strengths, rights to personal growth, and meaningful relationships in an inclusive environment (Sumarah, 1987).

In addition to meaningful relationships, diversity is also an important L'Arche concept (Vanier, 1998). Vanier maintains that no matter our differences there are elements that make us all fundamentally the same. We all belong to a common humanity, we all have brokenness and vulnerabilities, we need to feel understood and appreciated, etc. (Vanier, 1989, 1998). That being said, however, community is not about uniformity (Vanier, 1992). Community is about the respect and love of diversity within the context that we all belong to the same world (Vanier, 1989).

Community is about valuing the richness in difference and appreciating people “with their differences, not in spite of them” (Cushing, 2003a, p. 4).

There is also an unpublished Master’s thesis by Caroline Currie (2005) who examined the experiences of children raised in L’Arche communities. Currie found that the participants in her study had a wide range of experiences growing up at L’Arche, some that were positive and some that were not. The most tragic finding was that two of the participants were sexually abused as children during their time at L’Arche, one by a Core Member and one by assistants. This study is obviously of relevance to my study, which examined the role of touch at L’Arche. I will discuss Currie’s research in greater depth during the section on abuse.

Touch

I will address the relevance of the research and literature on touch to care-giving for people with developmental disabilities. There are several different types of touch that can be used in care-giving, so I will define the kinds of touch to which I will refer in this research. Gale and Hegarty (2000) documented how caregivers used touch with people with developmental disabilities and how clients interpreted the touch they received. In three residential-care settings, they recorded each incident of touch that occurred between a caregiver and client, and noted the type of touch used, where on the body it was directed, who gave the touch, the response of the individual, and the qualitative nature of the touch given. Their findings revealed six types of touch in care-giving relationships.

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" (p. 99). 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. Not surprisingly, functional touch was used most frequently, followed by expressive and therapeutic touch (Gale & Hegarty, 2000). Gale and Hegarty found the use of expressive touch reflected a good rapport between the caregiver and client. The responses made by clients during expressive touch interactions were mainly facial and positive. Its use to communicate and heal was therapeutic and improved individuals' well-being and quality of life. There is a scarcity of research exploring the nature of touch in care-giving, which makes the work of Gale and Hegarty valuable.

An important implication is whether support staff should be encouraged and trained to increase the frequency of "non-necessary" touch, that is, expressive touch. Conceptualizing expressive touch as non-necessary is thought provoking, pointing to the coldness and sterility of care that has characterized this field (Zur, 2005). However, even though the authors refer to expressive touch as "non-necessary", they acknowledge that when carried out professionally it is beneficial to the clients. The intentional incorporation of expressive touch could give the staff an effective therapeutic tool with which to strengthen the relationship. Gale and Hegarty (2000) conclude that "expressive touch, used deliberately and professionally, as a therapeutic medium, should be incorporated into the provision of care" (p. 105).

Over the past few decades research has increasingly focused on the effects of touch on human well-being (Field, 2001). Our sense of touch is the first sense to develop and continues to play an important function after both sight and hearing fade (Field, 2001). Because skin cannot close its eyes or cover its ears, it is a sense organ that is in a constant state of readiness to receive messages (Field, 2001; Thayer, 1986). However, "[d]espite the fact that touch is the largest sense organ (because the skin is the largest organ in the body), it is one of the most taken for granted and

the most overlooked” (Field, 2001, p. ix). The importance of touch was affirmed in a classic psychological study conducted by Harlow and Zimmerman (1958). In this study baby rhesus monkeys were given the choice between two ‘mother’ monkey dolls, one which was covered with soft terry-cloth, and the other was covered with wire mesh with a bottle with milk coming out from its centre. The babies all chose the terry-cloth mother, indicating that the nourishment associated with touch and close body contact is actually more crucial than that provided by food. Research has also suggested that incorporating a therapeutic form of touch, such as a massage, into a daily routine can greatly improve the prognosis for common illnesses such as asthma, dermatitis, cardiovascular disease, chronic fatigue syndrome, and sleep disturbances (Field, 2001; Thayer, 1986). Incorporating intentional forms of touch into everyday life also can reduce the amount of the stress hormone, cortisol. Reducing the amount of this hormone leads to increased immune system functioning (Field, 2001; Suomi, 1995).

Although many of the positive functions of touch have become increasingly clear, there is still a large problem of minimal touch in North American society (Field, 2001). Research has focused on the effects of touch deprivation and “failure to thrive” syndrome, also known as marasmus (Kertay & Reviere, 1998; Spitz, 1945, as cited in Thayer, 1986). Failure to thrive syndrome occurs when full term babies do not develop as they should, and sometimes die, because of a lack of touch (Spitz, 1945). The growth hormone, which initiates human physical development, is stimulated by physical touch in early infancy. Therefore, if an infant does not receive this critical touch soon after birth, there is a risk that a baby could fail to thrive (Schanberg, 1995). This phenomenon has been documented in orphanages where there are too many babies for the caregivers to sufficiently attend. Additionally, in a study with significantly underweight premature babies, those who received daily massages gained 47% more weight than those not massaged (Field, 2001, p. viii). In the face of research that indicates such striking results with a

simple intervention, it is strange to even attempt to grasp how North American culture became so obsessed with sterile and emotionally removed procedures of care (Gale & Hegarty, 2000).

Moreover, there is evidence suggesting that touch-deprivation may lead to violence in adulthood. The lack of sensory stimulation in childhood creates an “addiction” to touch later in life, meaning that someone may resort to violence in order to obtain the touch they are seeking (Prescott, 1971, as cited in Field, 2001). “We need to recognize that severe deprivation of touch has some of the same effects on children as abusive touch and leaves them very vulnerable to being manipulated by what seems to be affectionate contact” (Cole, 1990, p. 369). Touch deprivation is a form of physical and emotional neglect that can result in serious harm (Sobsey, 2002).

Furthermore, people with Down’s syndrome who received regular massages experienced increased muscle tone and improved gross and fine motor-skills (Field, 2001). Autistic children, who are known for their aversion to touch, also benefitted from massage (Field, 2001). Massages worked for this population because they were predictable and structured in a way that the participants felt they had control over the touch. After a ten-day period of regular massage children showed a qualitative decrease in disruptive behaviors and an increase in “relatability” (Field, 2001). The regular massages also provided an opportunity for parents to express physical affection with their children, which was very meaningful for them.

While touch is vital during the early years, there is also research indicating the importance of touch across the lifespan. A particular richness can be found in the palliative care field, which discusses the importance of therapeutic touch in end-of-life care (Blomberg & Sahlberg-Blom, 2007; Wardell, 2007). Therapeutic touch also can play a valuable role in soothing the anxieties and physical pain associated with arthritis and dementia (Simard, 2007) and cancer (Mansky &

Wallerstedt, 2006). In addition, psychological research has shown the use of touch to be very helpful in the treatment of post traumatic stress disorder, and eating disorders (Field, 2001).

A form of treatment that formally addresses the body and touch in therapy is Body Psychotherapy (BP). Originated by Wilhelm Reich (Sharf, 2004), this therapeutic discipline attempts to integrate both the mind and body to create a holistic approach to improving well-being. In BP the therapist pays close attention to the client's posture, breathing, physique, and musculature. He or she then uses this information in tandem with talk therapy techniques to create an understanding of the client's emotional well-being and identify potential directions for therapeutic intervention (Rauch, 2005; Sharf, 2004). The body psychologist uses touch with clients as a therapeutic technique by holding, hugging, or massaging the person.

When using touch in counseling and care-giving it is important to recognize cultural differences regarding the use of touch. Some cultures, namely European, African, South American and some Asian cultures engage more frequently in touching and affectionate behaviors than do North American cultures (Field, 2001). Even though touch is more prevalent in some cultures, it is nonetheless universal to some extent; thus the use of touch communicates to someone that they are a viable human being. Physical contact is the first form of communication between mother and child, and it is essential to normative human development. Through touch "a parent provides orientation, comfort and critical affective information" (Kertay & Reviere, 1998, p. 18).

The importance of touch to physical, psychological and relational human well-being and development has clearly been established. However, it is argued that another important aspect of human development of sense of self happens mainly through interpersonal relationships (Vanier, 1998; White, 2005). Thayer (1986) asserts that "our sense of self is intimately connected to the physical experience of touch" (p. 8). This relational element of parent-child interactions seems to be a significant facilitator of the development of the physical and psychological self (Kreuger,

1989). This position poses major implications for people with developmental disabilities, because the historical experience of this population is wrought with social exclusion and dehumanizing and abusive “care” practices (Devlin & Pothier, 2006; Hingsburger, 1995; Kagan & Burton, 2005). Until only very recently people with disabilities were sent away to segregated institutions. However, with the deinstitutionalization movement (Dunne, 1986; Vanier, 1998) people are increasingly being cared for in group homes or “independent” community-living apartments, where the ultimate focus on independence can arguably cause a similar form of social exclusion as experienced in the institutions. Many families do not participate actively in the life of their family member with a developmental disability, as society has taught them that this person is an embarrassment (Vanier, 1995). Thus, relationships between persons with developmental disabilities and their support staff often become primary relationships (Cushing, 2003b). This fact is an obvious issue with the disability service system and our society; however, at present, it is the reality for many people. If we apply this reality of social exclusion to the framework which says that humans develop a sense of self through familial relationships and the critical touch that happens therein, it is reasonable to conclude that such extreme marginalization strips away the opportunity to develop a sense of self. Recall Vanier’s realization that the suffering of people with developmental disabilities was due less to their impairments than to their experience of being pushed to the margins of society (Anderson, 1998). I suggest that a powerful metaphor is illuminated by conceptualizing this physical and social rejection of being “pushed away”, as the opposite to being “held close” or “embraced”, which illustrates the experience of marginalization and not receiving the essential forms of positive touch that all humans need to thrive and be well.

Abuse

Despite the fact that there are essential benefits to touch for all humans, when misused touch can cause irreparable harm (Baladerian, 2009; Hingsburger 1995; Kertay & Reviere, 1998;

Saxton et al., 2001; Sobsey, 2002; Vanier, 1998). Abusive touch is that which is coercive, not consented, or harmful (McPherson, 1990). Persons with developmental disabilities experience a reality of social powerlessness far greater than most other populations, which makes them particularly vulnerable to exploitation and abuse (Sobsey, 2002). Shame and guilt are among the psychological injuries of sexual abuse, indicating to someone that they are of no worth, arguably adding another disability to an existing one (Cole, 1990; Sobsey, 2002). One can argue that the “isolation and dependence which many disabled people experience not only makes them vulnerable to abuse, but also makes it more difficult to report” (McPherson, 1990, p. 475). For this reason, it is imperative to examine the research on the abuse of people with developmental disabilities and the response of the disability field to remedy this very serious problem.

There are a number of studies that document the abuse of people with disabilities. Because the reporting rates of abuse against people with disabilities are approximately only 20% (Cole, 1990; Statistics Canada, 2001), there is not one succinct statistic or statement that captures the nature of abuse for this population. It can be confusing and overwhelming to navigate through the following statistics on abuse, which all vary slightly. However, I have attempted to coherently document these figures in a way which demonstrates the saddening extensiveness of this issue for this population. To begin, some scholars say that people with disabilities are at least twice as likely to be physically or sexually violated as people without disabilities (Baladerian, 2009; McPherson, 1990; Powers, Curry, Oswald, & Maley, 2002). Statistics Canada (2001) reports similar findings, stating that people with disabilities are one and a half times more likely than non-disabled persons to be the victims of a violent crime, including sexual assault. Baladerian (1991) says that sexual abuse estimates for children with disabilities are four to ten times the rate for the general population. The incidence of child sexual abuse for the general population was 25% at the time of her research, which indicates that the most conservative statistic of abuse for children with

disabilities is 100%. Baladerian further comments that national statistics in the United States estimated that 39% - 83% of girls, and 16% - 32% of boys with a developmental disability will be sexually abused by the time they are 18 years old. Another analysis indicated that women with intellectual disabilities were 12.7 times more likely to be sexually assaulted than non-disabled women (Wilson and Brewer, 1992, as cited in Sobsey, 2002). In one study with women with disabilities, 73% of the participants had experienced some form of violence, 96% of which was sexual violence (Stimpson & Best, 1991). Women with disabilities are victimized more than men with disabilities (Baladerian, 2009), and in another study 83% of women with disabilities were sexually or physically violated at some point in their lives (Stimpson & Best, 1991).

When asked why they did not report the abuse, many people with disabilities replied that the crime committed against them was “not important enough” to report (Statistics Canada, 2001, p. 7). Further, 99% of developmentally disabled persons who did report abuse were assaulted by relatives and caregivers (Cole, 1990). In another study on the sexual abuse of people with developmental disabilities, 44% of perpetrators were paid staff (Sobsey & Doe, 1991). Hingsburger (1995) says that if we were to calculate the number of all the people with developmental disabilities who have been abused, and add this number to all the people who have been punished for seeking appropriate physical affection, we would have 100% of all people with developmental disabilities. These tragic statistics are overwhelming and disheartening. This population has suffered so much under the “trusted care” of family and support staff, and it is hard to know how to begin to right such a complex form of oppression.

Understanding the experience of abuse from the perspectives of those who have been abused is an important aspect in developing action. In a qualitative investigation into the abuse of 72 women with disabilities by their personal assistance providers, Saxton et al. (2001) found that a number of themes emerged when these women attempted to define their perceptions and

experiences of abuse. First of all, there was confusion around social and personal boundaries with support workers. The physical proximity and intimate nature of the labor made it difficult to tease apart social, emotional, and personal boundaries, and participants felt that these grey areas created opportunities for abuse to happen. Several participants wanted the relationship with their support worker to remain “business-like”. They felt that they could offend their worker if they did not want to be friends with him or her, which could potentially compromise the quality of their care. Therefore, keeping the relationship business-like preemptively avoided offending their support staff and having to choose whether they wanted a friendship to develop. Hingsburger (1995) also agrees that developing a support relationship into a friendship makes it difficult for the individual with the disability to say when he or she is dissatisfied with the worker’s performance, and offending the person can put them into a position of greater risk.

In addition to social and personal boundaries, power dynamics of the care relationship were important in the perceptions and experience of abuse for the participants of this study (Saxton et al., 2001). The independent-living model operates under the philosophy that the disabled person is in control of his or her own needs and care, and therefore encourages the caregiver-client relationship to remain professional. However, mainstream perceptions of individuals with disabilities are that they do not know what they need and that authority figures know best. Further, women in general are socialized to be agreeable, but women with developmental disabilities often internalize this cultural stereotype to an extreme. Their desire to please others and minimize the importance of their own needs can lead to more of a power imbalance and risk for abuse (Saxton et al., 2001).

Many participants in Saxton et al.’s (2001) study indicated that they had trouble recognizing abuse from their support workers. Some participants were unsure if a worker was being abusive if they were being rough when helping with a task or if they just were not paying

attention to the task and thus hurting them in the process. Other forms of abuse were more obvious, such as forced sexual contact, emotional, or financial abuse. There were also complexities associated with using family or friends as care providers, because being the “boss” of someone they knew well meant that the interpersonal dynamic had to change. However, not all scenarios where family members were the caregivers were negative, and some even allowed for more control.

As previously mentioned, abuse within L’Arche was documented in the master’s thesis of Caroline Currie (2005). Two out of seven of the participants in her study were sexually assaulted during their childhood at L’Arche; one participant was assaulted by a Core Member, and another by two assistants. This horrific finding is noteworthy because it documents the occurrence of abusive touch within the environment I studied. Within published academic literature and mainstream media no documented accounts of a Core Member being sexually or physically abused at L’Arche were found; however, I am aware from personal communications with members of L’Arche Ontario that abuse of Core Members has occurred, although I do not know the exact incidence or statistics surrounding past abuse. Therefore, simply because L’Arche has an empowering and respectful organizational approach to supporting people with developmental disabilities does not mean that it is immune to abuse.

Prevention of abuse starts with the recognition that it is going on with both individuals with disabilities and their families and caregivers (Cole, 1990). Many people with developmental disabilities do not know their rights. Thus it is important to educate this population about their rights when it comes to saying no to unwanted touch (Sgroi, Carey, & Wheaton, 1989). It is also necessary to teach people about their relational and sexual needs as human beings and how to fulfill these needs appropriately; people with disabilities have the same rights and desires to enjoy affection and their sexuality as do other members of society (Hingsburger, 1995; McPherson,

1990). Thus, education means teaching people about sexuality, gender and privacy issues, and social and relational skills (Hingsburger, 1995; Schwier & Hingsburger, 2000). Talking openly also demystifies taboo topics so that they can be spoken comfortably (Hingsburger, 1995).

Moreover, the North American education system does not provide adequate sexual education to people with disabilities, which Hingsburger (1995) argues is due to two contradictory cultural attitudes: First, people with disabilities are innocent, therefore, they must be protected from society, and, second, people with disabilities are predators, therefore, society must be protected from them (Hingsburger, 1995). However, people with intellectual disabilities are neither inherently sexually deviant nor innocent (Hingsburger, 1995; Sgroi, 1989). Furthermore, when we deny people education we deny them the power to identify their rights and effectively leave them unable to defend themselves: “they can’t report what they can’t say” (Hingsburger, 1995, p. 19). Moreover, when someone internalizes messages that all sex is bad, there is the risk that they will assault whenever they become aroused, because they have never been taught how to express their needs and that there is never an appropriate time or place to express their needs (Hingsburger, 1995; Sgroi et al., 1989).

Yet, focusing only on the education of people with developmental disabilities deflects the responsibility on these people to prevent their own abuse, which is a form of victim-blaming (Ryan, 1971). Thus, it is also important to educate relatives and caregivers to encourage them to talk about appropriate touch and sexuality with their family members and clients (Cole, 1990). Part of this issue is arguably about the value of relationships and the fact that if we deny people with intellectual disabilities healthy and supportive interpersonal relationships, then we rob them of their ability to discriminate between relational touch and affection that is appropriate and that which is not (Wilson, Clegg, & Hardy, 2008). Persons with disabilities often lead lives of isolation, and people who do not feel loved or loveable are particularly vulnerable to abuse

(Hingsburger, 1995). Therefore, creating a way for people with disabilities to meet affectional needs is the next great question for the disabilities field (Hingsburger, 1995).

There are a number of tools in the literature for abuse prevention. Hingsburger's number one rule for preventing abuse and promoting appropriate forms of touch is, "ask first, touch second" (1995, p. 69). Further, caregivers must listen more intently to the messages they are receiving from clients, and people with disabilities must be encouraged to speak up. The emphasis on client communication creates obvious implications for people who do not use speech to communicate. Thus, it is essential to document non-verbal persons' communication patterns to understand the behaviors that indicate they are comfortable and uncomfortable. In this way caregivers will be able to identify when people need space and when they are welcoming a physical expression of affection. Harber and Hingsburger (1998) also recommend that caregivers phase out front "bear-hugging". They argue hugging makes individuals with disabilities more vulnerable, because many people cannot differentiate between friend and stranger and why a hug is appropriate with a friend and not with a stranger. In addition, front bear-hugging is particularly intimate and when engaged in such close body contact it is difficult for a person to get away. Harber and Hingsburger (1998) instead recommend that people use hand holding or the sideways hug (where someone puts an arm around the other person), which are actions that are not as intimate or close as the front bear-hug.

David Hingsburger, a Canadian behavioral counselor for people with developmental disabilities, has done important work in the area of abuse and sexuality. He says that our society sees people with disabilities as asexual and less than human, which is a contributor to the abuse of this population. Hingsburger (1995) uses the term anti-anthropomorphization to describe the act of taking away human characteristics from human beings, which he says is the first step toward oppression, prejudice and abuse; the act of abuse can be easily rationalized if the victim is not even

human. Attempting to fix the problem of abuse against people with developmental disabilities by restricting their rights is not the answer because it does nothing to address the perpetrators, and further enables an inhumane mainstream view of people with disabilities.

Hingsburger (1995) also discusses the danger of using the word “vulnerable” as a descriptor when talking about people with disabilities. If someone is assaulted because of who they are - vulnerable - then the disability is what caused the assault and the source of the incident is somewhere inside the person. This perspective is a very insidious form of victim blaming. Thus, when we use the term vulnerable we must do so cautiously and with an understanding of the weight this term carries. However, there are aspects of having a disability that do increase risk, for example, “an individual who cannot walk or drive may find it harder to avoid or escape from a dangerous situation. An individual who cannot talk or use a telephone may find it more difficult to call for help or seek advice. An individual with limited knowledge or impaired judgment may find it more difficult to recognize danger or plan a defense. These direct effects clearly increase the risk for some people with disabilities, particularly those with severe disabilities” (Sobsey, 2002. p. 5). Thus, there are aspects inherent to disability that increase people’s risk. Yet acknowledging this reality does not have to fragment a person’s identity until they are nothing but vulnerable or at risk.

Prevention and Promotion

An important aspect of this study has to do with the prevention of harm and the promotion of ethical and respectful interactions involving touch. Nelson and Prilleltensky (2005) define prevention as any intervention or condition that focuses on reducing problems, whereas promotion is that which focuses on the enhancement of health and well-being. Vandiver (2009) defines health promotion as “any planned combination of educational, political, regulatory or organizational approach that supports actions and conditions of living conducive to the health of individuals,

groups or communities” (p. 26). However, Felner, Yates Felner, and Silverman (2000) equate prevention with promotion. These authors explain that building strengths and well-being facilitates a reduction in the degree to which conditions of risk are factors in the development of disorders; “enhancement, disruption, or modification, as appropriate, of the unfolding process [and conditions] that lead to well-being or to serious mental health or social problems” (Felner et al., 2000, p. 14).

The next logical set of terms to discuss would therefore be risk and protective factors. A risk factor is any condition related to the occurrence of a problem, and a protective factor is any resource, such as a skill or support system, that can create a safeguard or resistance against a risk (Nelson & Prilleltensky, 2005; Vandiver, 2009). Felner et al. (2000) define the concept of risk as a “conditional statement about the probability that any member of a given population or sub-population will develop later disorder” (p. 15). Risk and protective factors can be divided into environmental and individual variables. For example, environmental level conditions that could put people with disabilities at greater risk of being touched disrespectfully are unclear, or not having organizational policies, lack of staff training, and disrespectful or paternalistic mission-statements and leadership attitudes, etc. On the individual level the inherent vulnerability associated with having a disability, lack of skills, knowledge, or competencies could increase risk of people with disabilities being touched inappropriately. Possible protective factors would then include proactive and detailed policies, progressive and inclusive mission statements and leadership attitudes, helpful training for both clients and staff, an overall climate of morality and respect, an increased awareness of clients’ vulnerability amongst staff, and a commitment to building clients’ capacities. Vandiver (2009) states that individual level protective factors include self-esteem, emotional resilience, problem solving and social skills, and feelings of self-efficacy; family level protective factors include shared meals. Protective factors act in a compensatory

fashion, offsetting the likelihood that existing vulnerabilities will be activated when conditions of risk are present (Felner et al., 2000). Vandiver (2009) states that adequate health promotion programs identify current protective factors and work to support them, and address any areas where protective factors are needed. When assessing a prevention program or intervention, it is important to examine the degree to which all conditions of risk, such as vulnerabilities, have been reduced, and protective factors, such as personal competencies and skills, have been enhanced (Felner et al., 2000).

Felner et al. (2000) discuss several prevention models, such as the *blended* and *unique* models, but assert that the *transactional-ecological* (T-E) model is the most thorough approach to prevention. The T-E model is an integration of the transactional and the ecological models of development. According to the authors, the transactional model “emphasizes the dynamic, reciprocal interactions between the individual and their context, with bidirectional influence being a fundamental element” (p. 23). Thus, in the context of a care-giving environment, the interactions between the staff and clients are the result of the reciprocal effect of the environmental influence on the client and vice versa. It is these interactive and developmental processes that are the targets of change in the transactional model. But because this model is at most dyadic and considers only proximal environments and interactions, Felner et al. (2000) suggest incorporating the ecological model to broaden the focus of prevention to wider environmental and social systems. These two models complement one another by considering “systemwide conditions that distort, in pathogenic ways, all of the dyadic transactions that take place within their reach” (p. 24). For example, attitudes within the care-giving system that connote disrespect and a lack of caring for the dignity of clients could influence individual level caregiver-client interactions in an abusive manner. In contrast, system level conditions could have “significant adaptive implications for individual

behavior” (Felner et al., 2000, p. 24), and impact individual level interactions in a positive, respectful way.

There are documents in Canada which have helped to name specific strategies to improving health and well-being. For example, in Prince Edward Island’s health promotion tool, the Circle of Health (1996), parts of which are based on the Ottawa Charter of Health Promotion (1986), there are several approaches to health promotion, including building healthy public policy, creating supportive environments, strengthening community action, and developing personal skills. Engaging the strategies from the Ottawa Charter and the Circle of Health tool, and doing an assessment of the conditions of risk and protective factors of L’Arche will facilitate an understanding of whether L’Arche is promoting a healthy and safe approach to the use of touch in care-giving for people with disabilities.

Professional Ethics

Next I will consider dual relationships and use of touch in dyads with power differences, which are ethical issues addressed in almost all professional codes of ethics. According to ethical regulations, the L’Arche assistant-Core Member relationship constitutes a type of dual relationship (Syme, 2006), as assistants are often caregivers as well as friends. Further, the expressive touch that occurs within these dyads is considered a boundary crossing, because it is “non-necessary” for the completion of essential care tasks (Gale & Hegarty, 2000). Thus, it is necessary to discuss the ethics regarding multiple relationships and the use of touch.

It is also important to distinguish between ethical codes and regulations, and the moral principles that underlie them, such as respect, justice, and compassion (Walsh-Bowers, in press). Ethical codes that guide professions, such as psychology, tacitly rely (or should rely) on these values. Ethical dilemmas, then, are those which require a professional to negotiate ethical principles that conflict with one another (Walsh-Bowers, in press); for example, how to respect the

relational needs of persons with developmental disabilities within the regulations that warn professionals against dual relationships and boundary crossings, such as touch.

Before I begin this discussion on ethics I would like to clarify the reason I chose to apply ethical codes of helping professions to care-giving for people with developmental disabilities. While care-giving relationships between persons with disabilities and their support workers are not professionally therapeutic in nature, these dyads do mirror the clinician-client relationship in many ways (Harris, 1987; Sumarah, 1987). Therefore, throughout this discussion I will refer to ethical guidelines and research within the helping professions as a way of addressing the ethical issues of dual relationships and boundary crossings in care-giving.

To begin, I will address dual or multiple relationships, which occur when an individual within one role takes on a second role in the same dyad (Syme, 2006). They are common in everyday life, however, in professional contexts that involve power differentials, such as care-giving, dual roles are risky because they can blur the boundaries between what is professional and what is personal (Wilson et al., 2008). There has been a contentious debate about dual relationships within the helping professions (Sonne, 2006; Zur, 2005). The ethical codes of both the Canadian and American Psychological Associations have strict stipulations regarding the avoidance of dual relationships. In the past, individuals were warned against all forms of dual relationships with clients, because obscuring these boundaries can create contexts where the client can be taken advantage of or exploited (Canadian Psychological Association Code of Ethics, 2000; Kitchener, 1988; Pope, 1990; Saxton et al., 2001; Zur, 2005). Extreme statements such as Pope's (1990) claim that "non-sexual dual relationships, while not unethical or harmful per se, foster sexual dual relationships" (p. 688), created a culture of fear surrounding dual relationships.

It is noteworthy, however, that the Canadian psychological code of ethics acknowledges that dual relationships are sometimes unavoidable. Taking on a second role with a client does not

determine whether a therapist or support worker will initiate a sexually or otherwise exploitative relationship with that person, especially in the case of a caregiver and client with a developmental disability, who spend much more time together than two people in a professional therapeutic relationship. Thus, it may feel natural for people in a more informal care-giving dyad to develop their interactions into more of a cordial relationship. Indeed, staff and developmentally disabled clients often do build friendships (Lutfiyya, 1993). But dual relationships have been openly criticized as being synonymously linked to harm, exploitation, and sexual abuse: “all dual relationships can be ethically problematic and have the potential for harm” (Kitchener, 1988, p. 217).

While it is not debatable that dual relationships have the capacity to exploit people in the position of less power, even if they are non-sexual (Saxton et al., 2001), Zur (2005) says that the perception of dual relationships as inherently dangerous is erroneous. Multiple roles are sometimes unavoidable, especially in rural areas and small communities, which have a natural intimacy and shared connection among people (Zur, 2005, 2007); L’Arche fits within this category of the small community. In his critique of psychology’s emphasis on the danger of dual relationships, Zur (2005) says that boundary crossings such as a hug, or taking a walk with an agoraphobic client, are sometimes the most helpful, effective, and reasonable interventions. The policies and research that have created a culture of fear amongst professionals and caregivers have compromised client care because people have become more concerned with the litigious nature of the profession and the need to protect themselves from potential law suits (Field, 2001; Zur, 2005).

Psychology as a discipline claims to have a high commitment to cultural diversity (Zur, 2005). Yet it mandates adherence to an ethical code grounded in mainstream Western cultural values such as individualism, separation, and independence, over other values such as mutuality, connection, and interdependence (Zur, 2005). The focus of the professional or caregiver should

always be the client's care, healing, dignity and well-being, rather purely than the avoidance of risk. It is understandable why the helping professions have implemented regulations around dual relationships as they can lead to exploitation of the client if the therapist or caregiver is not careful or respectful (Saxton et al., 2001); however, there is also compelling evidence suggesting the dangers of such a sterile and codified approach to therapy and care.

Next I will address the ethics of boundary crossings, such as touch. The Canadian Psychological Association's (CPA) regulations are understandably strict about the unacceptable nature of therapist-client sexual relations and prohibit this kind of touch (2000, p. 18 & p. 26). However, this is the end of the formal ethical comment on touch, as nowhere in the CPA ethics code does it say how, or if, a therapist should use touch in therapy, for example, hugging a client. Zur (2005) argues that the theorists who created the mainstream no-touch policies have succeeded in immoralizing a behavior that has always been a normal part of human interactions. "The therapeutic aspects of touch in therapy have been demonized and sexualized...They have been able to pathologize what is healthy and what is considered essential to human survival throughout most of human history - a sense of mutuality, familiarity, communion, interdependence and connectedness" (p. 270).

According to Smith, Clance, and Imes (1998), touch in psychotherapy is more common than people perceive. In a survey of American psychologists, only 13% reported that they never touched their clients under any circumstances (Smith, Clance, & Imes, 1998). Therefore, 87% of clinicians use touch in psychotherapy in some form or another. In a psychotherapy session it was found that a brief and light touch to the arm broke down barriers to enhance rapport between therapist and client (Thayer, 1986). Several theorists support the employment of touch with clients in therapy, but within a number of parameters (Maidment, 2006; Smith, 1998; Syme, 2006; Zur, 2005). First, the therapist must be cautious of the power difference inherent in the client-clinician

relationship. He or she must carefully consider the motivation behind the touch and the potential impact on the client (Smith, 1998). Then, touch is appropriate, when it is a genuine expression of the therapist's feelings and only when it serves to further the growth of the patient rather than the needs of the therapist. It is important to avoid touch that is a blatant violation such as sexual touch, subtle manipulations, or that which is used to 'rescue' the client when the therapist is uncomfortable (Kertay & Reviere, 1998). The client and therapist must also have a healthy rapport before integrating touch as a part of the therapeutic practice (Kertay & Reviere, 1998).

However, Smith (1998) outlines several risks of incorporating touch in therapy. First, the non-verbal message behind the touch is not always the message received or interpreted, which can create potential miscommunications. Second, behaviors can only be understood in the cultural context in which they occur. Third, communication through touch is generally more emotionally powerful than verbal communication, thus creating the opportunity to convey succinctly a strong message, but also in a way that can be manipulated in order to fulfill the agenda of the therapist. All these elements make touch powerful but also risky. However, despite the risks, Smith advocates for the use of touch if one carefully considers and accommodates for these three factors, and only then proceeds within the parameters of informed consent, ethics, legality, good taste, and grace (Smith, 1998).

While it is easier to control and prohibit the use of touch in psychotherapy or care-giving relationships, Kertay and Reviere (1998) argue that "[i]t is critical to place the use of touch in an ethical context that minimizes its potential abuses and maximizes its potential benefits" (p. 24). As a method of communication, it is seen as too powerful and complex to impose upon it simplistic rules. The over-regulating of touch can also de-humanize the therapeutic and care-giving relationship by strictly controlling what is a very natural form of human communication (Field,

2001; Kertay & Reviere, 1998; Zur, 2005). Moreover, people will never learn about appropriate touch and affection if they themselves are never touched (Hingsburger, 1995).

New ethical orientation toward dual relationships and touch.

Several ethical theorists are taking a more balanced stance toward dual relationships and touch. Pope and Keith-Spiegel (2008) comment that: “Nonsexual boundary crossings can enrich psychotherapy, serve the treatment plan, and strengthen the therapist-client working relationship” (p. 638). These authors are acknowledging that there are both beneficial and exploitative aspects of boundary crossings, which represents a more centred opinion than Pope’s earlier stance (1990). Sonne (2006) discusses the controversy that the term “non-sexual dual relationship” has created within psychology and that there is a great deal of confusion around the appropriateness of certain boundary crossings, such a hug, or meeting a client outside the office. In the same vein as the CPA code, she comments that the APA code of ethics acknowledges that non-sexual multiple relationships are not always avoidable and do not have to be unethical. Sonne then presents a framework of therapist factors, client factors, and relational factors to consider when making decisions regarding dual relationships and boundary crossings with clients. One such factor is power, an aspect of the caregiver-client relationship that has already been established as inherently asymmetrical. Gottlieb (1993) argues that the greater the power difference between the therapist and the client, the greater the risk of a dual relationship harming or exploiting the client. This power difference should be considered carefully before engaging in a boundary crossing or taking on another role within a therapeutic or care-giving relationship. This issue is especially pertinent in the context of providing care for individuals with developmental disabilities, because this population has very little social power in comparison to others, such as caregivers. Even though L’Arche strives for relational equity, the power differential associated with the Core Member-assistant relationship means there is a risk of abuse. This asymmetry in power complicates the use

of touch in this relationship. Therefore, I suggest the integration of principles from the ethic of care paradigm to help negotiate these difficult ethical dilemmas.

An Ethic of Care

In 1982, psychologist Carol Gilligan proposed an alternative ethical framework to mainstream ethical thought, which was largely influenced by the work of her mentor, Lawrence Kohlberg. She referred to Kohlberg's theory as an ethic of justice (Gilligan, 1982), in which people develop through a linear and structured set of moral stages, the last of which is the highest form of moral reasoning (Kohlberg, 1973; Kohlberg & Kramer, 1969). In this framework moral thinking was "tested" through hypothetical and logical situations and could be resolved through objective, deductive reasoning. This model claimed that girls and women reached less sophisticated levels of moral reasoning than boys and men (Kohlberg, 1973).

Gilligan set out to study girls and women to understand their decision-making processes. She did not find that they were poorer moral judges, but that they based these decisions upon different criteria. Gilligan called her set of principles an ethic of care. She differentiated it from Kohlberg's theory based on the contention that "[w]hile an ethic of justice proceeds from the premise of equality - that everyone should be treated the same - an ethic of care rests on the premise of non-violence - that no one should be hurt" (Gilligan, 1982, p. 174). Underlying the ethic of care is the importance of relationships. Gilligan (1982) asserted that women are socialized to develop in relationships, which factored into their moral decision making process. Surrey (1985, 1987) calls this the "self-in-relation", and explains that women's experiences of the self are highly relational. Kohlberg's model that held autonomy and independence, as moral ideals, failed to represent the life experiences and moral decisions of women, which are tied to feelings of empathy, compassion, and integrity within relationships; the self and other are interdependent (Gilligan, 1982). The ethic of care says that "women's experiences of connectedness to others

leads to enlarged conceptions of self, morality, and visions of relationship” (Surrey, 1985, p. 2). The mainstream ethical paradigm that demands “aseptic objectivity in professional relationships” (Walsh-Bowers, in press), occludes the value-laden and emotionally involved nature of such relations.

Written from a feminist perspective, the ethic of care is opposed to all forms of oppression. This paradigm privileges non-dominant perspectives “not because they are more valid or accurate, but because they are typically missing from the perspective that dominates society at large” (Mahowald, 1998, p. 210). Mainstream professional ethical codes, based on Kohlberg’s work, were predominantly written by privileged, white men (McLaughlin, 2003, p. 75), which therefore privileged this population. Focusing on such values as autonomy and abstract, rational, objective thinking, creates a narrow definition of what makes someone a moral citizen. Ultimately, the values of both the ethic of care and ethic of justice are valuable. However, it is important to recognize that women have been socialized to make moral decisions on different criteria than men. Research on gender differences regarding tendencies toward care or justice found that women did tend more toward the care paradigm in ethical decision-making, but generally that women and men drew from both ethical paradigms (Skoe, Pratt, Matthews, & Curror, 1996).

Since Gilligan proposed her alternative moral paradigm, several theorists have extended her ideas to other areas of ethical deliberation. Kittay (1999) brings the ethic of care into the realm of care-giving. She discusses that care-giving and care-receiving are unavoidable aspects of every single person’s life. From early childhood to times of illness, disability or frail old age, the life cycle of a human being involves dependencies that are a normal part of existence (Kittay, 1999). Yet, our society continues to view any kind of dependency as an exceptional and abnormal circumstance. Kittay says that once our society understands dependency as an inevitable part of human life, we will appreciate the full range of human interconnection and that we cannot survive

without each other. She firmly acknowledges the asymmetry of power in care-giving, but says that it is useful to distinguish between the inequality of power in a relationship of dependency and the exertion of domination in a relationship of inequality. The relationship does not authorize the use of power except for the benefit of the client, which is about mutuality; “the character of the moral self, the asymmetry of the relationship, the partiality of its participants and its non-voluntary nature make the moral demands of the dependency relationship more amenable to an ethic of care than to a rights based or a utilitarian based morality model” (Kittay, 1999, p. 53). The ethic of care calls our attention to the unavoidable dependencies that people with developmental disabilities experience and does not devalue them as human beings because of these dependencies.

Moreover, an ethic of care stresses that people who give care also need care themselves (Wendell, 1996). Since caregiver burnout can lead to resentment and abuse (Smith, 1998), supporting caregivers in taking care of themselves is an important preventive measure in safeguarding against abuse. Allowing caregivers to look after their well-being also creates the opportunity for reciprocal care to occur within the dyad. Revisiting Cushing’s (2003b) incorporation of the “gift economy”, the personal strengths of people with developmental disabilities are valued as an important part of the relational exchange. L’Arche philosophy says that “[p]eople with an intellectual disability often have the remarkable capacity to touch others. They are particularly welcoming and spontaneous, and their sensitivity allows them to bring us together, to enrich and challenge us as human beings. L’Arche is convinced that our societies are in need of these qualities and that people with an intellectual disability can be real teachers who are able to lead us back to the essential” (L’Arche International website, 2008).

Wendell (1996) criticizes the paradigm of “independent living” as a euphemism that insults people who cannot live without a great deal of help, because autonomy is always the overall goal. The fact that complete independence is unattainable for some people calls its value into question in

any ethical or moral codes. Wendell asks, “should a society have universally applied ideals that some people are precluded from attaining because they were born with certain kinds of bodies?” (p. 149). Therefore, Wilson et al. (2008) suggest that caregivers who support people with intellectual disabilities draw on ethical frameworks that can accommodate the relational nature of their work.

Further, this model considers the role of context in ethical reasoning, whereas conventional understandings of ethics are removed from tangible ethical dilemmas as they exist in the helping professions (Prilleltensky, Rossiter, & Walsh-Bowers, 1996). An ethic of care sees ethical reasoning as contextual, relational and responsive, rather than achievable through the application of a universal set of rules and regulations based on treating autonomous individuals. Prilleltensky et al. (1996) also advocate for a process-oriented understanding of ethics, which “will promote the centrality of ethics in professional practice ... Considering that mental health treatment is inherently relational, greater sensitivity to harm and risks will be fostered by understanding actual relations between persons, their needs, preferences, values, and choices” (pp. 289 - 290). Prilleltensky et al. (1996) also suggest a more participatory model of ethics where both client and therapist together define the appropriate ethical climate in a given situation or relationship. Therefore, the most suitable approach for deciding the ethicality and safety regarding the use of touch in care-giving depends on what is best for the individual people involved, within some obvious moral and ethical principles to guide the overall dynamic. For example, the use of functional, procedural, and therapeutic touches, which are part of ‘work’ of giving and receiving care, would not be affected except for *how* these touches are being performed; that is, what is discussed and decided upon between the caregiver and the client so that both parties feel respected and safe when these touches are being employed. However, the overall use of expressive and affectionate touch, which is part of the friendship that could develop over the years of living in

community together, would be affected in an *if* and *how* way; that is, the people in a given caregiving relationship would decide if they were comfortable expressing parts of their friendship with safe touch such as a hug. Based on this “if” they would then decide how this expression would look. For example, “Are hugs okay in our friendship? Is holding hands okay?” etc.

While it is important to discuss the ethics of the individual relationships in which these specific decisions are made, it is almost more important to consider the broader environment in which personnel are making these weighty choices (Pettifor, 1996). For example, if individual professionals are seeking out the most ethical options in the best interests of their clients, but these courses of action are not supported by the organization in which they work, which is perhaps only concerned with the bottom line or volume of clients, then it is likely that the individual clients will be the ones who suffer because the organization is ultimately more powerful than the individual. Prilleltensky et al. (1996) contend that the codes and rules are disconnected from the overall social structure of an environment. If an organization is to foster an ethical climate it will need to be intentional about cultivating an environment where codes and principles are not so far removed from the overall morals that inform them (Pettifor, 1996). Walsh-Bowers, Rossiter, and Prilleltensky (1996) emphasize the major role that organizational structures and interpersonal dynamics play in ethical decision-making. Therefore, in order to promote ethical discourse and prevent harm it is crucial to comprehend this relationship between individual people and their social context.

In a case study with 14 social workers in a hospital setting, Walsh-Bowers et al. (1996) found that the participants “did not feel safe disclosing ethical dilemmas with their social work supervisors, because they believed that after sharing uncertainties, expressing feelings, and showing vulnerability about ethics, they experienced negative performance evaluations in the form of judgments of inadequate competency” (p. 324). All participants in this study suggested the need

for a safe and supportive climate in which to discuss ethical dilemmas. While these authors agreed that codes and rules are beneficial, they felt that the pressure to comply with rules “can thwart the type of communication vital for ethical dialogue, namely, free uncertainty, honest doubt, and affective openness” (p. 327). Therefore an ethical environment requires more of a sensitive and contextual application of codes and standards.

Throughout this current research study examining the use of touch and L’Arche it will become apparent whether L’Arche as an organization facilitates a social environment with an increased ethicality that prevents harm. If assistants have an internalized sense of the morals that inform the organizational practices of L’Arche, such as mutuality and respect, if there is a supportive and safe environment to discuss difficult ethical issues, and if decisions are made in a participatory and process orientated way, it would be plausible that this approach promotes some powerful protective factors which foster a safe and respectful care-giving environment for people with developmental disabilities.

Research Questions

- 1) What is the nature of touch at L’Arche?
- 2) What are the risk factors and the protective factors of the L’Arche approach to care in this community, with regard to the use of touch?

I will now discuss the way that I endeavored to answer these questions, starting with my research design and methodology, followed by my ontological and epistemological orientation and my personal standpoint. After which I will describe the sampling procedure and the recruitment strategy. Then I will discuss the methods for data collection and analysis, inclusion criteria, ethical considerations, and my research relationship with the participants in this study.

Research Design

For this study I used a qualitative design to collect and analyze data. Qualitative methodologies are more appropriate for research studies gathering detailed data and help capture depth of information in a smaller sample (Denzin & Lincoln, 2008), whereas quantitative methods are more useful in ascertaining a breadth of information in larger samples (Patton, 1990). Because I collected data in one L'Arche community and sought to understand a specific phenomenon in great depth, a qualitative design was more appropriate for this study. A qualitative design was also more suitable in this research context because it is a naturalistic inquiry method (Patton, 1990; Denzin & Lincoln, 2008). It does not attempt to manipulate the research environment to create an experimental scenario, but rather it seeks to understand the context as it is (Patton, 1990). Because the use of touch at L'Arche is a phenomenon that occurs on its own, using this methodological approach allowed me to document and understand it as such.

Some of the methods associated with qualitative data collection, such as open-ended interviews and observation (Patton, 1990), were also more suitable for L'Arche and this topic. The distinctiveness of people's nuanced experiences of physical touch at L'Arche could not have been captured by restricting participants' responses to the closed-ended, Likert style questionnaires associated with quantitative research. Rather, the dialogue that was developed in the semi-structured, open-ended interviews elicited a richness of information (Patton, 1990; Berg, 2004). Personal reflections of research participants added clarity and integrity to research results, which strengthens the validity and credibility of the research (Patton, 1990).

I also employed a participatory action research (PAR) framework. Participatory action research is a strengths based approach to research that seeks to create an equitable and non-oppressive experience for research participants and stakeholders (Boyd & Bright, 2007; Kemmis & McTaggart, 2008). In particular, PAR attempts to include populations that have been

historically excluded from research processes, such as persons with developmental disabilities (Swain, Heyman & Gillman, 1998). This model emphasizes social action and change and a higher degree of participation from stakeholders so that the researcher and participants co-create the knowledge that is gained in the research process. PAR is about power-sharing and doing research “with” and not “on” (McTaggart, 1991). Stakeholders often take positions such as research assistant, or sit on an advisory group to help guide the research process. In order to create an equitable research experience I suggested the formation of an advisory group to the Community Director. She then recruited five people to sit on the committee. The advisory group was a way to share power and control of the research with the community, and they invaluablely assisted me in developing and executing the research in the most beneficial way possible. The group was composed of four assistants, one Core Member, and one community leader. We met once before the fieldwork began and three times throughout the research process. The group operated and made decisions by consensus, discussed, improved, and approved all interview guides; and advised me on recruiting appropriate candidates for Core Member interviews.

Methodology

Throughout this research I employed two methodological paradigms, which I collectively call an ethnographic case study. I will now discuss this methodological approach and the reasons that it was the most appropriate framework for this research.

The case study is defined as a research strategy that illuminates a distinctive situation and relies on multiple sources of data, necessitating a triangulation of methods and participants (Yin, 1994). Stake (2008) says that “case study research is not a methodological choice, but a choice of what is to be studied” (p. 119). Case studies are helpful in reflecting upon specific human experiences and in refining theory (Stake, 2008). A case study methodology was appropriate for

this study, because L'Arche is a unique care setting for people with developmental disabilities, where the use of expressive touch has not been completely restricted.

I also employed an ethnographic approach as the other primary methodology of this research study. Ethnography is the process of interpreting and describing a culture (Berg, 2004; Fetterman, 1998; Geertz, 1973; Spradley, 1980). This methodology was suitable, since I was attempting to describe the specific cultural practices of touch at L'Arche. Spradley (1980) says that ethnography is not necessarily about studying people, but learning from them. The methods that an ethnographer employs during data collection, known as fieldwork, are naturalistic and qualitative in nature. Ethnographers predominantly use interviews and observational techniques, which I will discuss in greater detail in the methods section (Spradley, 1980). Ethnographic research requires the researcher to fully immerse him or herself in the particular culture during fieldwork, which facilitates a more complete understanding of the culture (Spradley, 1980). Fetterman (1998) recommends living in the culture for six months to a year. Because of the limitations of a master's degree this duration of immersion was not possible. Accordingly, I lived with the community for a six-week period, which was a reasonable amount of time in which to collect data. It was also a suitable time-frame, because I already have had a two-year immersion experience in a L'Arche community, which I have complemented with extensive research on L'Arche history and culture. Therefore, my fieldwork was not a completely foreign experience. In addition, because I focused on a specific phenomenon, the nature of touch and associated risk and protective factors within L'Arche, this study can be considered a micro-ethnography (Spradley, 1980). This small-scale version does not require as much time spent in fieldwork, as does that which attempts to describe an entire culture or society, known as a macro-ethnography (Spradley, 1980).

Ontology and Epistemology

My beliefs about reality and knowledge are grounded in the social constructivist and critical paradigms (Guba & Lincoln, 1994; Ponteretto, 2005). I align myself with the relativist approach to reality and truth of social constructivism, that “reality is constructed in the mind of the individual, rather than it being an externally singular entity” (Ponteretto, 2005, p. 129). I find this approach especially important working with diverse populations. I also appreciate that this scientific tradition values researcher-participant interaction and dialogue and that meaning and knowledge are co-created through discourse. In addition, I draw on the values of the critical tradition, which conceptualizes reality through historical power relations (Guba & Lincoln, 1994). The critical paradigm strives for the emancipation of oppressed and marginalized populations. I endeavor to produce research that is not harmful to the population with whom I am working, but is instead empowering and emancipatory, illuminating areas where further action can create a more inclusive and respectful society and improve quality of life.

Standpoint

My standpoint as a researcher is affected by several factors, including my race, gender, abilities, and biases. First, I am a white woman, and I am aware that my race has worked to my advantage in ways that I am ill equipped to fully understand. I am also affected by my gender as a woman, which has historically been a position of less power, status, and privilege than that of a man's. I am conscious, however, that being a woman gives me more power and privilege than, for example, someone who is transgendered, or does not identify with one of the binaries of sexual identity. I represent a marginalized voice as a feminist, which I feel, to some extent, allows me to empathize with marginalized groups, as I continue to grapple with my values that are in tension with the oppressive societal norms.

Perhaps most, my standpoint is influenced as an able-bodied individual. Because of my background, in my family and in L'Arche, I am conscious of the insidiousness of ableism and the unearned advantages that life has afforded me due to my able body. Even though I know I take them for granted, I am mindful of how my abilities have affected my capacity to do this research, and that I have had certain opportunities that others will not. In the way that my white skin can represent oppression, I am aware that my able body could be perceived as the symbol of oppression for people with disabilities who have been exploited by other able bodied persons. I therefore choose to be respectful with my presence, and the power that I have been afforded, and use it for the purposes of social justice.

Additionally, as a previous member of a L'Arche community, my status as an "emic" insider influenced my standpoint. I am aware that being an insider benefitted me greatly throughout this research process, as community members knew that I had an understanding of L'Arche culture, and therefore were able to trust me easier than someone who does not know L'Arche. Some would comment that my standpoint as an insider of L'Arche weakens my ability to conduct objectively rigorous research and that I should "shelf" my bias, so to say. I would reply that, yes, I need to be mindful of my positionality as an emic researcher, which sometimes makes it easy for me to idealize L'Arche as an organization. Idealizing the organization I am studying is obviously problematic, because if there were negative findings I might be more apt to cover them up or not portray them to their full extent. However, I was more concerned with helping L'Arche to be a safe and respectful organization for people with disabilities, therefore, I represented the findings of this study in a balanced and honest manner. I also used my field note journal as a way of maintaining reflexivity and "checking in" with myself to make sure that I was not glossing over any difficult issues that needed more attention.

Participant Recruitment

The first step that I took in recruiting a L'Arche community for this research was to contact the Regional Coordinator of L'Arche Ontario. After email correspondence and an in-person meeting, he authorized the research to be conducted with L'Arche Ontario. He indicated that the topic was of value to L'Arche, and he also decided which community would be most appropriate for me to work with. He contacted the Community Director to inform her of my research. I then had a telephone meeting with the Regional Coordinator and the Director from this L'Arche community to discuss the specifics of the research topic and methodological approach. The Director was enthusiastic about the topic and authorized the research.

Participants

The participants of this research were all residents and members of a L'Arche community in south-western Ontario. This community has four homes, an alternative residence for long-term assistants, and an office and community-gathering space, which are all located in nearby neighborhoods in the downtown of a city. At the time of my fieldwork there were approximately 50 people in this community, with four or five Core Members and three or four assistants in each home, in addition to day staff who support the four houses or work at the office. Each house has a house leader who is the supervisor of this house and reports regularly to the community director. The four house leaders also meet regularly as a team. The gender of the participants was mixed, with slightly more women than men. The Core Members' age range was 28 – 83 years, and the age range of the assistants was 18 – 50 years. Slightly more than half of the participants had a developmental disability. There is a Core Member Council that meets monthly to discuss and make decisions regarding pertinent community issues. There is also a leadership team within the community comprised of the community director and several coordinators, including the assistant's coordinator, and homes coordinator. The leadership team meets weekly and is

responsible for hiring new assistants, overseeing assistant training, ensuring that policies are followed, organizing community events, and issuing any punitive action such as probation and firing of assistants. In Table 1, I summarize the demographic variables of the participants who took part in interviews and focus-groups.

Table 1. Demographic Display of Participants

Stakeholder Group	Pseudonym	Sex	Years in the community	Method of Participation	Canadian or International
Key-informant (n = 4)	Joan	F	15	Interview	International
	Beatrice	F	19	Interview	Canadian
	Jake	M	9	Interview	International
	Maple	F	10	Interview	Canadian
Assistant (n = 8)	Will	M	20	Interview	Canadian
	Angie	F	10	Interview	International
	Beth	F	2	Interview	International
	Morgan	F	2	Interview	Canadian
	Drew	M	2.5	Focus-group	Canadian
	Martha	F	25	Focus-group	Canadian
	Alice	F	10	Focus-group	Canadian
	Alicia	F	5	Focus-group	International
Core Member (n = 7)	Jim	M	15	Interview	Canadian
	Sally	F	29	Interview	Canadian
	Bonnie	F	29	Interview	Canadian
	Jeremy	M	10	Focus-group	Canadian
	Daniel	M	30	Focus-group	Canadian
	George	M	5	Focus-group	Canadian
	Peggy	F	35	Focus-group	Canadian

Inclusion Criteria & Sampling Strategy

The inclusion criteria for this study varied based on the specific methods. For participant observation, I did not exclude anyone. Participants were informed ahead of time that if they were uncomfortable with me observing they could communicate this information to either me or an individual in their house, and I would not write anything down about them; however, no one indicated that they did not want to participate in the observations. For the interviews I sought a balanced number of Core Members and assistants, and a balance between males and females. I attempted to achieve a diversity of ages and ethnicities, and I interviewed only Core Members and assistants who lived in the community for at least six months. The interviews necessitated persons who had good command of the English language. The key-informant interviews consisted of individuals who made a considerable commitment to L'Arche, such as being a long-term assistant, a community leader, or someone with a particularly informed stance on the topic of touch at L'Arche, and had lived at L'Arche for at least five years. The focus-groups required similar levels of cognitive functioning and communication abilities as for the interviews. However, one participant in the focus-group, Jeremy, attends this group regularly with the support of one assistant, Jake, who communicates for him based on his knowledge of this Core Member through their long-term relationship of ten years. Based on previous research that has been done with people with developmental disabilities who do not communicate verbally, but instead with the assistance of a support worker (Sumarah, 1989), I decided that it would be appropriate for Jeremy to participate in the Core Members' focus-group with the support of Jake.

Method

Data Collection

The methods that I used to collect data were participant observation, interviews, and focus-groups. Each of these methods assisted me in obtaining a different perspective on the nature of

touch at L'Arche, and the protective and risk factors of the use of touch in the L'Arche approach to care-giving. I employed participant observation for the first two weeks of my fieldwork, during which time I recruited participants for interviews and focus-groups, which I conducted throughout in the last four weeks of my fieldwork. The reasoning behind the order in which I carried out the methods of data collection was that participant observation allowed me to derive an overall idea of the use of touch and take an immediate reading on any potential risk or protective factors. I spent some time simply "being" with people, observing daily life and establishing a healthy research relationship with the community. Thus, beginning the data collection with participant observation allowed people to get to know me, and then when I began the interviews and focus-groups there was an established trust and rapport which facilitated rich discussions and data. In addition, even though there were four homes in this L'Arche community, I considered this research study a one-group design. Because of the diversity in each of the homes I did not feel it was appropriate to conceptualize each home as its own sample group.

Participant observation.

Participant observation is one of the principle methods of qualitative and ethnographic research (Fetterman, 1998; Geertz, 1973; Patton, 1990; Spradley, 1980). It involves participating in the community life, but at enough of a distance to allow for structured and reflective documentation of daily practices, and behaviors of interest (Spradley, 1980). The participant observer keeps a journal with field-notes, wherein he or she systematically records observations (Geertz, 1973; Spradley, 1980). I engaged in participant observation throughout the duration of my fieldwork, as I lived in the community and participated in daily practices, such as meal times, daily prayer, and celebrations. I rotated between the homes and made formal observations for 2-3 hours per day, for 5 days a week for the entire duration my fieldwork. During observations I monitored Core Member and assistant interactions, and the way in which they engaged in touch with one

another. I did so in a similar way that Gale and Hegarty (2000) observed the participants in their research, wherein they recorded the types of touch they witnessed (procedural, functional, expressive, therapeutic), where on the body each touch was directed, who gave the touch, the response of the individual, and the qualitative nature of each touch given (p. 98 - 99). I took note of how the touch was initiated and the way in which people's boundaries/responses were respected. I also described the interactions and paid attention to the way that power dynamics affected the exchange. I created a template of a table that I carried with me for my field-notes as a way of keeping organized observations of these interactions (see Appendix B).

I also conducted personal-care routine observations to obtain a more complete sense of how touch was being used when Core Members were receiving more intimate care such as bathing and using the washroom. These observations were obviously highly sensitive and more private than regular recreation and meal-time observations. Therefore, I treated these observations with much thought and care, and had an additional consent process that was separate from the regular observations.

When I first began my observations I carried my field-notes journal with me at all times in order to be prepared to make observations. However, I found that it detracted from the natural flow of the interactions to constantly be writing down notes. Therefore, after my first round of observations I decided, in conversation with the advisory committee and my thesis advisor, to routinely journal and write down the observations each evening after I finished an observation period. I have a very good memory and I found it very easy to recall the specifics of each touch interaction. The one place where I did keep my journal with me to make notes immediately was during personal-care routine observations. Because the personal-care routines that involved touch moved very quickly from one task to another, I needed to immediately write down each interaction involving touch so that I would remember it accurately.

During the observations I noted behaviors that could put Core Members at risk, such as not respecting a person's boundary, or alternatively work to protect people, such as asking before touching someone. Developing a sense of resonance with participants' behaviors, means of communication, and culture; by going "beyond the words" (Wikan, 1992, p. 466) can reveal as much as a narrative or interview. There are unconscious or ritualistic aspects of persons' behaviors that they may not be able to explain, but are observable (Cushing, 2008a; Wikan, 1992). Therefore, the observations gave additional validity, substance and meaning to what the participants were telling me in the interviews and focus-groups. Cushing (2008) found strength in the use of participant observation with individuals with developmental disabilities who did not speak, "Because they do communicate in non-verbal ways, long-term participant observation allows the researcher to familiarize themselves with how to recognize what their embodied, expressive gestures or resistances mean" (p. 16). In addition, as a means of participating in this research, the observations were accessible to all persons in the community. Interviews and dialogues were not available to people who do not communicate verbally, but this did not mean that their experiences were less important than those who participated in language-based methods (Cushing, 2008). Thus, observational techniques created a more inclusive experience, as participants contributed meaningfully through their actions.

Interviews.

Personal interviews are also a data collection method of both qualitative and ethnographic research (Fetterman, 1998; Geertz, 1973; Kirby, Greaves & Reid, 2006). Interviews allowed individual community members to talk about their experiences of touch at L'Arche. I conducted interviews with both Core Members and assistants (see Appendix C for interview guides), because both perspectives were crucial to this research. The perspectives and experiences of people with developmental disabilities have been historically excluded from research data (Morris, 1991;

Cushing, 2008). However, current authors assert this exclusion has never been, and is no longer, acceptable (Cushing, 2008; Kirby et al., 2006; Klotz, 2004). We cannot understand the experience of persons with disabilities if we continue to ignore them and represent their lives through the perspectives of their caregivers. Therefore, I interviewed Core Members as a way of understanding their views on the use of touch in their relationships with assistants at L'Arche.

There were obvious ethical implications associated with interviewing persons from a vulnerable population and who also experienced a potentially reduced capacity for verbal communication and intellectual reasoning; I expand on these issues in the section on ethical considerations. As I previously indicated, I asked the community leader and advisory committee to help me identify Core Members who would be good candidates for interviews. It was important to interview people who had a clear understanding of the interview process and who knew that they were free to stop the interview at any point. Initially, I thought it would be appropriate to ask an assistant be present for all Core Member interviews to assist with any communication difficulties. However, having an assistant present during a Core Member's interview might make him or her feel the need to say the "right" thing in front of the caregiver (Cushing, July 9, 2008b, personal communication). Therefore, I left this choice up to Core Members. I called the assistant who supported a Core Member during the interview a "safe person", and indicated to all Core Members that they could choose whether they wanted a safe person to support them in their interview.

I conducted three Core Member interviews. I began each Core Member interview process by approaching the house leader to communicate that the Advisory Group had suggested a member of his or her house to be a potential interview participant. I asked the house leader to inform the Core Member about the potential of participating in an interview and ask whether or not he or she wanted to participate. I thought it would be best if a person who knew the Core Member well asked him or her individually, as the Core Member would likely feel more

comfortable being honest about whether or not they truly wished to participate with someone they knew and trusted. Three of the four Core Members suggested to me by the Advisory Group indicated that they wanted to participate, while the fourth Core Member declined. After this process I then met individually with the three Core Members who wished to participate to discuss the interview process and read over the informed consent sheet. Then I set up a time to meet with and conduct the interview. Two of the interviewees chose to have a safe person present during the interview, while one decided during the break of his interview that he could manage on his own. The Core Member interviews were between 25 minutes to 1 hour in length.

I conducted four assistant interviews during my fieldwork. I made an announcement at an assistants' meeting that if anyone wanted to participate in an interview he or she could either approach me in person or submit a written request in my personal mailbox in the community, and I would set up a time individually with that person. I distributed consent forms to assistants who wished to participate in interviews by putting the consent forms in a sealed envelope in their mailboxes, which they returned to me at either before or at the time of the interview. The assistant interviews were all between one – two hours in duration.

I also conducted four key-informant interviews. Key-informants were persons who had a key perspective on the issue of touch in Core Member-assistant relationships, such as community leaders and elders, and had been living in the community for at least five years. Key-informant interviews were also between one – two hours in length.

I performed 'member-checks' with each participant, or his or her safe person, to provide them with the opportunity to make any changes, additions or corrections to their transcripts. Performing member-checks was also a way of ensuring that participants were comfortable sharing the information they had discussed with me during the interview. Member-checks also helped

contribute to participants' anonymity because they were able to remove any particular phrases that could increase the chances that readers of this research would identify them.

Focus-groups.

I also conducted two focus-groups as a way to include the perspectives of those I could not interview due to time constraints. As suggested by Kirby et al. (2006), I used a group interview guide with four or five questions (see Appendix D), which allowed for enough time for each participant to answer meaningfully and without time pressures. I sought homogeneity in the focus-groups in order to create horizontal power dynamics. Thus, I conducted one focus-group discussion with Core Members and one with assistants (Berg, 2004). I recruited candidates for the Core Member focus-group from a group of four Core Members that were already meeting on a regular basis. The advisory committee and community director indicated to me that this group was a natural set of participants. I communicated with each Core Member's house leader about their potential participation in the focus-group and had the house leader discuss the focus-group with each Core Member. After each of the four Core Members consented verbally that they wanted to participate, I met with each person individually to discuss the focus-group process and go through the consent forms. There were two assistants present during the Core Members' focus-group. One assistant acted as a safe person for the whole group, and one assistant, Jake, regularly accompanies one of the Core Members at this group, Jeremy, and he supports this Core Member with his communication.

I recruited candidates for the assistants' focus-group by announcing at an assistants' meeting that there would be a discussion group and if anyone was interested in participating to contact me directly in person or by submitting a written request in my mailbox. I distributed consent forms for the assistants' focus-group in the same manner as I did for the interviews. Four

assistants requested to participate in the assistants' focus-group, which lasted approximately two hours.

Therefore, through the use of participant observation, interviews, and focus-groups, I structured this research to achieve triangulation of methods and participants (Berg, 2004; Kirby et al., 2006; Patton, 1990). Triangulation allowed me to attend to research questions from different perspectives and supported rigorous data collection period. These methods ensured that the data represented the experiences, feelings, and voices of the community in its diversity.

A typical day for me during my fieldwork involved getting up and having breakfast with assistants and Core Members before they had left the house to go to work or their day program. After breakfast, assistants would usually take their time away, which is personal time each assistant is allotted every day. During this time I would usually transcribe in my bedroom or conduct interviews at the community-gathering space, which I travelled to via public transit or walking. In the evenings I would travel to the house I was observing for that day via public transit or walking. I would typically be at the house from 5:00 p.m. – 8:00 p.m. to incorporate the evening meal, prayer, and recreation time. Weekends were relaxed and I usually spent the whole day with the members of my house. I took two – three hours of personal time each day on weekends to transcribe or rest.

The last half of my fieldwork was very busy, as I tried to fit in all the interviews, focus-groups, and personal-care observations, in addition to my regular daily observations. During this time there was a death in close-by L'Arche community, and many members of the L'Arche community I was living at attended the memorial services. This very sad event required me to reschedule several interviews and the assistants' focus-group, and ultimately fit a lot of data collection into a small period of time. On one day I remember doing a personal-care observation at 7:00 a.m., an interview at 12:00 p.m., another interview at 4:00 p.m., and my regular evening

observation for the day. While I thoroughly enjoyed my fieldwork and data collection experience, by the end of the six-weeks I was physically run down.

Table 2. Methods

Method	Quantity	Description
Participant	1 – 2 hours per day, 5 days	Informally for the entire research process
Observation	per week, rotating homes	1 - 2 hours of structured observation per day
Interviews	11	3 Core Member interviews 4 assistant interviews 4 key-informant interviews
Focus-groups	2	1 Core Member focus-group 1 assistant focus-group

Data Analysis

I used a grounded-theory approach with specific attentiveness to my research questions to analyze the data. Grounded-theory was originally proposed by Glaser and Strauss (1967), however, I employed the methods of contemporary grounded-theorist, Kathy Charmaz (1995, 2006, 2008). This approach to data analysis resists traditional hypothesis testing in the way that a positivist researcher would accept or reject a hypothesis through deductive reasoning. Instead, grounded-theory is an inductive and emergent method for analyzing research data. While a grounded theorist may have a particular area of interest and research questions, he or she forms theoretical conclusions or statements that are grounded in the data. Even though grounded-theory can be used as a methodological approach to research, I used it solely for my data analysis.

Grounded-theory is “particularly appropriate for discovery-oriented researchers in areas which are under-theorized” (Burck, 2005, p. 244). Because the research topic of touch at L’Arche has never been formally examined in a scholarly manner, I argue that its under-theorized status makes grounded-theory an appropriate method of data analysis. In grounded-theory the researcher should be in a “constant comparative analysis” (Charmaz, 2006, p. 5), building theory directly from the data, and then checking and refining this theory by collecting further data and comparing it to the previously collected data (Charmaz, 1996). Therefore the analysis begins while the researcher is still gathering data. “A grounded-theory approach encourages researchers to remain close to their studied worlds and to develop an integrated set of theoretical concepts from their empirical materials that not only synthesize and interpret them but also show processual relationships” (Charmaz, 2008, p. 204).

Grounded-theory involves detailed coding of transcripts and field-notes. I began this process with an initial line by line, *open coding* (Charmaz, 2006). However, I did not do so in the way that Charmaz suggests, coding the whole interview in an open manner. Within the open

coding I used a framework of attending to data that fit specifically within my research questions. I did the first round of coding by hand, wherein I used coloured highlighters to code data that fit within a research question. I then did a round of *focused coding* where I synthesized the most significant codes from the first round of coding and put them into categories and imported them into NVivo software. Next I applied *axial coding*, which is a theory-building process that specifies potential relationships between categories that emerged in the focused coding (Charmaz, 2006). After axial coding I applied *theoretical coding* where I pulled together the categories that emerged in the axial coding process and expanded on the theoretical concepts that began to emerge in the initial stages. I also applied several theoretical frameworks to analyze the data. I used Cushing's (2003b) framework of mutuality, Hingsburger's (1995) model of abuse prevention, and feminist ethics principles in addition to Walsh-Bowers et al.'s (1996) methods for increasing ethical decision making in the helping professions (Gilligan, 1982; Kittay, 1999; Surrey, 1985, 1987). Bringing in these external theories does not fit with grounded-theory, per se, but I felt that bringing them in at this later point in the analysis would shed light on other potential important characteristics of the nature of touch at L'Arche, and the risk and protective factors of the L'Arche model.

Ethical Considerations

There were a number of ethical issues in this research study that I treated very seriously. First, working with a historically vulnerable and oppressed population was a primary concern of this research. People with developmental disabilities have not been treated equitably in research (Cameron & Murphy, 2006; Cushing, 2008a; Swain, Heyman, & Gillman, 1998), which I earnestly attempted to address through the methodological approaches of this research. I attempted to engage community members with developmental disabilities accessibly in all research methods and processes.

I was particularly interested in including Core Members in the interview process. However, the reality of doing research with people with developmental disabilities required me to address some specific issues associated with conducting research with this population. In order to facilitate an equitable and accessible research experience, the limitations and needs of the population and participants were carefully considered (Boland, Daly, & Staines, 2008; Swain et al., 1998). Some of the issues discussed in the literature include concerns about communication and interviewing, the interpretation of open-ended questions, and informed consent. I will now explore these issues in greater depth.

Having a developmental disability can affect an individual's cognitive abilities and capacity for reasoning and decision making. Therefore, participants with developmental disabilities sometimes require extra assistance to understand and respond to interview questions. This concern was first addressed through my sampling procedure and order of methods. During the first two weeks of my fieldwork I did not engage in any other form of data collection than participant observation. During this time I got to know the participants, and I was able to identify Core Members who were good candidates for interviews. The Community Advisory Group also assisted me in identifying Core Members who were good candidates for interviews. I interviewed people who had a high capacity to engage in verbal conversation and a reasonable cognitive capacity to make decisions and understand questions.

In addition to the sampling procedure and order of methods, I asked each Core Member interviewee if they would like to identify a "safe person", who was an assistant from their house. This person was asked to support the Core Member throughout the interview and facilitate his or her participation by helping them to feel as comfortable as possible. There were a number of roles that each safe person could be asked to perform, and the amount or degree of the safe person's involvement in the Core Member's interview was up to the Core Member participant. For

example, if the Core Member wished to identify a safe person and preferred to have him or her present during the interview, the safe person was asked to sit in on the interview. Alternatively, if the Core Member was comfortable proceeding with the interview on his or her own, the safe person was asked to be nearby and available (in the same building) to support the Core Member, if he or she became distressed throughout the interview. In all cases the safe person was asked to help the Core Member make the transition to his or her day following the interview debriefing. Therefore, providing Core Member participants with the option of having an assistant present helped them to feel more comfortable, which made the research more accessible. Further, on an individual case by case basis, if a Core Member interviewee was seeing a personal counselor, the interviewee was asked if he or she wanted the counselor to be notified that he or she was participating in an interview, so that he or she could discuss this experience with the counselor and the counselor was aware this interview had occurred.

Another issue associated with interviewing persons with developmental disabilities is that some participants have difficulty responding to open-ended interview questions (Boland et al., 2008). Responses to open-ended interview questions can be “I don’t know”, confusion, or no response at all. Therefore, in all Core Member interviews I started each question with an open-ended phrase. If the participant did not understand, I had a number of closed-ended prompts prepared with which to rephrase the question. If it was easier to respond to the closed-ended question, I then asked if the participant wanted to elaborate or add anything else in order to provide them with the opportunity to go beyond a closed-ended response.

It was also necessary to rephrase interview questions to help participants understand, which is another issue discussed in the literature (Antaki, Young, & Finlay, 2002). Because of the need to rephrase questions, there was the danger that I might ask a question in a leading way, or that data analysis would only take into account the way the question was answered, but not how it was

asked (Antaki et al., 2002). Rephrasing or clarifying a question is sometimes a necessary process with persons who are not developmentally disabled, however, it is well documented in the literature as something which happens to a far greater extent with people with developmental or intellectual disabilities. Therefore, in order to prevent the problematic issues associated with frequently rephrasing questions from happening in my research, I employed the use of structured prompts, as indicated above. I also recorded in my data analysis whenever a question had to be rephrased in a way that I could not predict with my pre-formed structured prompts, how it affected the response, and whether or not to strike this information. However, being able to rely on structured prompts helped to mitigate this concern; further, I tried not to ask questions in a leading manner. In addition, having an assistant present who knew the Core Member well also moderated the concern of rephrasing a question in an unhelpful manner, because if a question was not making sense to a participant, the assistant was able to put the question into terms the participant understood, which helped enormously in the moments when this problem did occur.

In addition, there is an issue of informed consent when doing research with persons with developmental disabilities. Obtaining informed consent of people with developmental disabilities is a controversial issue involving a tension between avoiding coercion and ensuring that participants understand the research (Cameron & Murphy, 2007). “There is a need to protect potential vulnerable participant groups, while ensuring that the demands placed on the researcher are not so restrictive as to preclude valuable research” (Iacono & Murray, 2003, p. 49). In addition, people with disabilities might be left out of research, because they are too “complicated” to work with, or alternatively, they might be included without genuinely obtaining their consent (Cameron & Murphy, 2007). Cameron and Murphy (2007) studied the ability of persons with developmental disabilities to give informed consent. Positive indicators that demonstrated whether an individual truly understood the nature and implications of the research included high level of engagement,

such as eye contact and body language, relevant elaboration, such as verbal comments saying they understood and wished to participate, and positive non-verbal responses, such as nodding.

Doubtful indicators were low level of engagement, such as averting eye contact or seeming indifferent, overly acquiescent responses, and ambivalent non-verbal facial expressions. Therefore, when obtaining informed consent from participants, I looked for these indicators to help me understand if the individual understood the research. The use of symbols, simplified language, bullet notes, and repetition all assisted in making the research more understandable and accessible to participants (Cameron & Murphy, 2007). Accordingly, I incorporated symbols and simplified language in the Core Member informed consent process.

At the time of the research all but one of the Core Members in this community were legally able to make informed decisions for themselves. However, the written consent of six Core Members' parents or guardians was sought to err on the side of caution, because these persons were unable to clearly communicate whether or not they truly understood the nature of the research and if they wished to participate. The Director obtained the informed consent of the parents/legal guardians for the six Core Members who were not able to give consent for themselves. I provided the Director with detailed information sheets about the research and consent forms for the parents/guardians of these Core Members. Parents/guardians indicated which activities beyond the routine observations their family member had consent to participate in, which was only relevant for Core Members who participated in the personal-care observations and one participant who took part in the Core Members' focus-group.

As previously indicated, I had two versions of all consent forms (see Appendix E for Core Member Interview Consent form). One with text only, and another with simplified wordings and images and symbols (Cameron & Murphy, 2007). I will now explain more fully the process in which informed consent was obtained with the Core Members. The Core Members who could sign

their own consent forms were required to sign their own. For Core Members who could not sign their own consent forms due to physical or cognitive impairments, I gauged the verbal or body language response from the individual, according to Cameron and Murphy's (2007) indicators, in order to understand if they wished to participate.

Another issue that complicates the ability of persons with developmental disabilities to give consent is that many people are illiterate, and might not be able to read the consent forms. Therefore, I read the consent form out loud together with all Core Member participants to describe all aspects of the study to them in a way that was understandable and accessible. It was important to respect the participants' rights to know about this research, but it also had to be acknowledged that some individuals were simply not able to give full consent. These individuals were verbally given the same information about the research, and I asked for verbal consent of all individuals who could respond verbally, but parental/guardian consent was understood as the highest level of informed consent that could be obtained for several individuals.

When I began this research I felt deeply troubled about this issue of informed consent. I did not feel right about engaging people in research, if they truly might not understand what the research was about and might not be able to tell me if they were feeling uncomfortable or wanted me to stop the observation, etc. However, I found guidance in the Tri-Council Policy Statement on research involving human beings in the concept of "do no harm". The importance of obtaining informed consent is an undeniable part of maintaining the ethicality of the research process. However, I realized that people's right to participate in research that affects them should not be compromised due to the absolute need for informed consent. The main method of this research (participant observation during recreation and meal times) did not put the participants of this study at great risk. Further, this issue of participation relates to the disability movement saying, "nothing about us without us"; people with developmental disabilities ultimately have the right to

participate in research that affects them, which might require some concessions and weighing the risks and benefits regarding consent and participation in research.

A participatory approach to research increases the ethicality of the experience for people with disabilities. I attempted to make the research more equitable by suggesting a Community Advisory Group, in which a Core Member and five assistants participated. I was passionate about Core Members participating in the group not only to adequately capture a diverse cross section of the participants of this study, but also to give voice to a population that has traditionally been *told* rather than *asked* about their preferences, concerns, and questions. Having only one Core Member on the committee may appear tokenistic, and I do think it would have been better if more than one Core Member participated. However, his perspective and ideas were deeply respected during Advisory Group meetings and he added some important insights that I might not otherwise have considered. In the end I think the way I addressed the ethical issues of this research was successful, but did not always work out exactly the way I wanted them to, as with the Advisory Group and Core Member participation.

Research relationship.

My research relationship with the participants in this study was one of respect and solidarity. The term “critical friend” was helpful in this context (Kemmis & McTaggart, 2008; Evans & Loomis, in press). I was an emic researcher and a friend of L’Arche, but because I know the L’Arche story and culture, I could offer an analytical comment for the purposes of strengthening their organizational processes and practices. However, because I was an insider I needed to be extra transparent about my role in the community. While conducting this study, I was first and foremost a researcher, which involved a degree of distance, and it was important to be unambiguous about this role.

My use of participant-observation methods and the compensatory aspect of PR methodology involve researcher participation in the community, which affected my research relationship. I lived in one of the homes during my fieldwork at L'Arche, participated in meal times and tried contribute labour within the house on a daily basis. Yet, because of this higher degree of participation, I needed to take extra care to ensure that people knew I was in the community as a researcher. Because people were able to trust me easier, they may have been too open and not guarded themselves as much as they should. I also made a financial contribution to the community to compensate them for hosting me and gave honoraria to the members of the Advisory Group as a way of showing my appreciation for their increased level of participation.

Findings

The findings of this study are divided by the initial research questions: What is the nature of touch at L'Arche? What are the protective and risk factors of the L'Arche approach? To begin I will address the first research question discussing the nature of touch at L'Arche. To analyze the data for this question I open-coded interviews and my field-notes for descriptive words on what touch is like and how it is used. I also documented the various ways that touch is used at L'Arche based on Gale and Hegarty's (2001) classifications of procedural, functional, expressive, and therapeutic touch. During my research I learned that L'Arche could contribute to these classifications and I will discuss a new category of "community" touch within the expressive domain. First I will discuss the various descriptors people used to illustrate the way touch is used at L'Arche. Second I will review the different aspects of the nature of touch at L'Arche. I will also give an estimate of the frequency that the descriptions were employed. See Table 3 for a description of the main themes and sub-categories.

Table 3. Findings Themes and Sub-Categories

APA Level Heading 1	APA Level Heading 2	APA Level Heading 3	APA Level Heading 4
Findings	Descriptors	Respectful	
		Careful and Intentional	
		Unnatural and Uncomfortable	
		Gentle	
	The Nature of Touch	Functional and Procedural	
		Expressive	Community
		Therapeutic	
		Space	
		Aggressive	
	Protective Factors	Capacity-building	Core Member Education
			Assistant Education
			Boundaries
			Communication and Honesty
		Community	Relationships
			Person-Centred Approach
			Self-worth
			Mutuality
			Working on a Team
	Risk Factors	Risk Factors Specific to Care-giving	Disrespecting Boundaries
			Lack of Communication and Honesty
			Vulnerability

APA Level Heading 1	APA Level Heading 2	APA Level Heading 3	APA Level Heading 4
			Staff-turnover
			Personal-care Risks
		Risk Factors Specific to L'Arche	Inconsistencies between L'Arche Communities
			Dual Roles
			Cultural Differences
			Policy Discrepancy
			Too Boundaried

Descriptors

To begin, I will explore the four main attributes people used to illustrate the way that touch is used at L'Arche and their feelings about the way it is used. In order to answer this question I asked participants to describe how they saw touch being used at L'Arche and how they felt about it. These descriptors were complex and included respectful, careful and intentional, unnatural or uncomfortable and gentle. The following data represents the participants' descriptions and feelings.

Respectful

Most assistants and key-informants told me that touch was used respectfully, with attention to the Core Member's comfort levels. For example, the following is a segment from my conversation with assistant, Angie:

P: I feel it [touch]'s used respectfully and appropriately. And even healing, very healing. Yeah.

I: Ah, in what sense? Can you think of,

P: Well, everybody, well, I mean it's very individualized and that's very healing. Like, it's healing for [one Core Member] not to be hugged a lot, it's healing for [another Core Member] to be able to hug, come up to you and hug you, and yeah.

Here Angie is saying that it is healing for Core Members to be respected in their individual comfort levels when it comes to touch.

Careful and Intentional

In addition, most of the assistants and key-informants used the words careful or intentional to describe the way that touch was used at the community. For example, Morgan said,

It's hard to say maybe L'Arche in general, but, I guess generally you could say touch is used maybe carefully or intentionally. It's not something that's used without thought or discussion. Yeah, intentionally.

In all of the Core Member interviews participants told me that they felt good about the way that touch was used in their lives. Bonnie used the word "fine" to describe her feelings, and said

that it was important to her that people use touch gently. Jim used the word “respect”, and Sally used the word “safe”. The following dialogue is taken from my interview with Sally:

I: ... Sally, I'm just wondering how you feel, um, how it makes you feel um, here at L'Arche the way that touch is used in your life?

P: [muffled]

I: How do you feel?

P: Uh, safe.

I: Safe?

P: Yeah.

It was important to hear from Core Members that they felt fine, respected, and safe when people used touch with them.

Unnatural or Uncomfortable

In addition to these descriptions, two assistants and one key-informant identified the touch that happens at L'Arche to sometimes be unnatural or uncomfortable. Morgan discussed the difficulty as an assistant in holding oneself back from physically comforting a Core Member with a hug who also has very firm physical boundaries:

P: It [touch]'s used well, sometimes it's hard.

I: Sometimes it's hard?

P: Yeah.

I: Sometimes it's hard to?

P: Um, to set the boundaries I think.

I: Uh huh.

P: You know, if someone's crying again, it's hard because it's going against sometimes what feels, like that natural instinct, seeing someone crying and wanting to reach out to them in a physical way, comfort them in a physical way, and knowing that it's not safe for them, so intentionally setting that boundary, making that choice, and it's a good choice and it's a good boundary and it keeps them safe and it keeps them well, so it's used well, but it can be hard.

In addition, one assistant and one Core Member discussed how touch for personal or medical care is sometimes uncomfortable or unnatural. For example assistant, Drew, said:

I think there's some uncomfortable, I mean uncomfortable, maybe unnatural touch that sometimes has to happen in terms of a personal routine that I wouldn't have been exposed to before I came to L'Arche, um, in terms of helping someone bathe.

Drew expanded upon his thought by discussing the unnatural feelings associated with medical orders from a doctor. He explains that the Core Member and the assistant usually do not want to do the activity, such as stretches, but that it eventually gets done, because it is a medical order for the Core Member's health. In addition, Jeremy's support assistant, Jake, shared a story about Jeremy and his experiences with touch sometimes having to be uncomfortable:

Maybe Jeremy you can share a little story because, Jeremy remember when you were going through some pain in your stomach, um, a while ago, we needed, sometimes the assistants were wondering where you were in pain, and we tried to touch your belly and you were very clear about not to be touched there because that was the area which was hurtful and you were afraid, you were uncomfortable that maybe the touch would make it more hurtful. Um, and I think so you were very clear of saying 'this is hurtful', but 'I also don't want anybody to get close to me because it's uncomfortable'. Right? So it was that was a [muffled] when you were insecure and not clear about the pain and you were probably uncomfortable when people would put pressure on it. So it wasn't unsafe, but it wasn't comfortable.

In this passage Jake explained how assistants had to expose Jeremy to some uncomfortable touch to try to discover where he was in pain. Jeremy does not have the verbal ability to articulate where he is hurting, but it was obvious to the assistants that he was physically unwell. Therefore, assistants had to use touch to learn where he was hurting so they could help him. Thus, these are a few examples of the way that touch can be unnatural or uncomfortable at L'Arche.

Gentle

Almost all people in every stakeholder group communicated to me that touch was used gently. In Sally's interview I asked her what helped make touch safer:

I: ... is there anything special about L'Arche that helps you to feel safe?

P: Uh, yeah, safe.

I: Yeah? What helps you feel safe here?

P: Uh, uh, uh, gentle with me.

I: Hmm, people are gentle with you?

P: uh, mm hmm.

Jake also agreed that it was important for touch to be used gently in the community. For example, he said, “I think there’s something that’s very gentle. Touch has to be very gentle”. In addition, Beatrice said:

I think touch can be, but it is those little, yeah it’s respectful, it’s used as calming, you know. With people at worship service with their hand on [a Core Member’s hand] or [her] hand on theirs. I think gentle is another, gentle and comforting and respectful.

Further, in the assistants’ focus-group Martha said: “there’s a certain base, a level amount of respect and sort of gentleness or whatever, I don’t know how we word that, that kind of needs to be there”.

The Nature of Touch

I will now discuss the various aspects that characterize the nature of touch at L’Arche. First I will address the various forms of touch, and then I will discuss other relevant aspects of the nature of touch at L’Arche, specifically space and aggression.

Procedural and functional touch.

I will begin with functional and procedural forms of touch. Assistants discussed how quickly the use of touch happens via providing personal-care to Core Members. For example, Jake said, “So, for me, touch in this community, for how I feel touch is used a lot, a lot is happening in the personal-care”. Jake also described the type of touch that happens in personal-care as being a ‘hygienic’ touch, because assistants wear gloves. In addition, Morgan described much of the touch involved in various forms of personal-care:

Pretty quickly in living here as an assistant you’re using touch, functionally at least you’re using touch. So with routines uh, helping to bathe, putting, helping people putting on creams, lotions, brushing hair, brushing teeth, flossing. Functionally you’re pretty much right in there, um, and it is fairly, depending I mean, it is fairly intimate, again like with bathing, so that does happen pretty quickly.

In her interview assistant, Beth, described a Core Member’s personal-care routine in more detail:

[One Core Member's] routine probably involves the most touch of the personal-care that we do at [our] House. Sometimes you have to lightly touch her to wake her up. We help her in the shower to wash her hair and her body. After the shower, we help put her brief on. She requires a fair bit of wound care, so that involves a lot of touch in putting creams and bandages on. [this Core Member] can get dressed mostly on her own, though often needs help to pull down her shirt and to get her clothing over her bandages without tearing them off. We help her brush her hair and blow dry it. We also help her brush and floss her teeth. Overall, the emphasis is on her doing as much as she can on her own, and us helping her when she needs it. And when she does need help, we always touch her very gently, as her sensation perception is extremely high because of her autism.

All of the Core Members I interviewed did their own personal-care, except for Bonnie who received help to wash her hair. Maple and Martha talked about their approach to personal-care with one particular Core Member who requires firm boundaries to keep herself safe, but using time during personal-care to help this Core Member to receive some necessary touch. For example, Maple said:

I think there's like helping people with personal-care, even like [one particular Core Member], like she's someone you need to have pretty strong boundaries with. Um, but even like, as part of her routine at nighttime is just like putting lotion on her legs, and her arms and hands and that. And I remember I always used to think this is kind of the time where she can kind of get the therapeutic touch in a nice way. So kind of just the intention, okay it's not just slop, slop, rush, rush. I would try to choose to take that time.

In addition I was able to observe four Core Members' personal-care routines. Two of these routines were very involved and required much support on the part of the assistant, and two of the routines involved more instruction and reminding to ensure that the Core Members were doing their personal-care correctly. In one personal-care routine a Core Member was being helped by an assistant who had known her for ten years. Two examples of functional and procedural tasks that happened during this Core Member's routine were a functional kind of touch when the assistant said the Core Member's name and gently put her hand on the Core Member's hand to wake her up. The assistant continued to rub the Core Member's shoulder to wake her up while speaking her name softly. The second example was a procedural touch when the assistant swabbed the Core

Member's finger with alcohol and pricked her finger for a diabetes test. The assistant is gentle about this and asked first if she could do the finger test.

In addition to using touch to help Core Members with personal-care, two assistants, three key-informants and one Core Member discussed the importance of touch for the function of communication for non-verbal Core Members. For example, Will said, “Especially for people who are non-verbal, I think touch can mean what a word would have said”. In addition, Jake said, “But there is something about, especially, especially, *especially* with people who are non-verbal around touch in the way of communicating with them”. In both of these quotes the assistants are emphasizing the importance of touch when it comes to communicating with non-verbal Core Members. I also consistently witnessed this phenomenon in my observations. For example, there were numerous times when assistants would tap a Core Member who is hard of hearing on the forearm to indicate they were speaking. It was clear that a small touch was able to meaningfully support a communication between people to accentuate or clarify the statement.

In addition to touch being functionally used to enhance communication, most participants from the key-informant and assistant stakeholder groups discussed how touch was also used functionally to support Core Members. I divided this category into “physically supportive” and “emotionally supportive”. First I will address “physically supportive”, which meant when an assistant has to use his or her body to hold or support a Core Member to allow something to happen or protect a Core Member from hurting themselves or others. The main use of physical supportive touch that I witnessed during my fieldwork was walking with a Core Member. I stayed with the community during the winter months and the sidewalks were often very slippery. When we went outside the assistants would either hold Core Members’ hands or link arms with them to provide some physical stability. Some assistants were very passionate about not holding Core Members’ hands while walking, for the childlike implication or romantic partner image that it has.

Rather they suggested linking arms with someone, which could be perceived as less condescending or intimate. Here is a segment of Will's interview where he addressed this issue:

P: Walking with somebody who needs to be, where you're going to walk with, I've never, I always say this to assistants too, especially at [one particular] House is the most current sort of thing, you don't hold his hand, like he's an adult now, but can I just show you?

I: *Yeah, do a little demonstration. [participant and I get up, and he links my arm with his and we take a couple steps together]*

P: Because like, this is, like this sort of thing and I have my hand in my pocket and I can just sort of direct him this way.

I: *Okay.*

P: And it's guiding, but you have the free will to break away if you want.

I: *Ah ha.*

P: But if I snap my arm in if I'm worried for safety, but like it's not grabbing his hand and leading him.

I: *Uh huh.*

P: He can still take the lead, but it's more of a security and safety thing, [muffled, rustling in room] subtlety in that.

I: *Okay.*

P: And also, it's perceived differently.

Assistants told me that there was a real concern for safety while making sure that Core Members were not demeaned by small gestures that could perhaps incite an inappropriate perception. In practice, I observed people holding hands with Core Members to help them walk more than I observed them linking arms. However, in those moments I never felt as though the assistants were being disrespectful, which could also depend on the relationship and the Core Member who is being helped, to choose what is most appropriate and also what is most needed; sometimes it was simply necessary to hold someone's hand. For example, Jake said:

I think, holding hands you have to be really, is that appropriate in public? You know, people might mistake that for something different. You know, like, but then, there's too, 'I need to hold their hand' because you know, clearly, say you know, give and the person is just, okay, and so like, you know, I went with someone to a stadium with 60, 000 people and I just need to make sure that he was staying with me. So, but it in a way that it's not a restraint, but in a way of kind of making sure, okay, 'I don't want to lose you either, there are 60, 000 people around'.

So this was an important way that touch was functionally used to support someone.

Further, some assistants talked about how touch was used as a physical prompt, which is closely tied to using touch for communication. At times when Core Members were not paying attention or needed more of a cue to understand that it was time to do something different, assistants said that a small physical prompt, whether it be a brief touch on the forearm or shoulder, or as in the next quotation, linking arms with someone helped to physically prompt them into the next task. The following is a quote from Alice from the assistant's focus-group:

Sometimes as a physical prompt, actually, that's part of just reminding people like, actually with [one Core Member], sometimes she, like she's getting dementia now and she's uh forgetting, and it's like, 'okay let's go, let's go upstairs', it's like, linking her arm and 'do do do [singing]! Going upstairs!' and honestly, if there wasn't that connection it might not happen! [laughter] So, um, yeah, that's kind of a practical thing.

In this quotation Alice tells us about how she supports a Core Member to do her next task by linking arms with her and walking together and that without this connection the Core Member might not remember to move from one task to another.

Some assistants and key-informants also discussed how touch can functionally be used supportively in a 'hand-over-hand' sort of action to help a Core Member participate in an activity.

In the assistants' focus-group Martha said:

there's something around knowing that someone has kind of done something, kind of hand-over-hand or together with [one Core Member] so that we also can, there's times when I'll mix muffins with her, you know, take the bowl and help her to mix them up and that's hand over hand, so there is some of that, as well, with other people as well, not just with [first Core Member], but it is in another way allowing people to do something that they might not be able to do otherwise.

Therefore, in the hand over hand way assistants can physically support a Core Member in participating in an activity.

A form of physical support that was frequently discussed was that which is employed to protect Core Members in various situations. Four assistants and two key-informants discussed this kind of protective or intervening touch. Even though L'Arche has a no-restraint policy, there is an

aspect to this type of touch that is holding someone back from something potentially dangerous. In her interview Beatrice shared several examples of times that she physically prevented a Core Member from hurting herself, who is self-abusive and picks at wounds, and how Beatrice would sometimes try to hold her hands so that this Core Member did not pick. Beatrice also told a story of a Core Member who was receiving chemotherapy and how he did not like getting the needle, so Beatrice would hold him while the nurse was putting in the needle to prevent him from knocking it out. She also shared this brief thought, "It's just that, you're trying to stop someone, like you know, like [a Core Member] wanting to run into a subway when the subway was still moving, I mean you have to, that's when you have to be physical". Jake also discussed in his interview how he has had to physically hold someone back in the past. He said:

I had to hold someone back who was running after a car, and then you know in the first couple of seconds I was holding him and then I was able to re-direct the person towards somewhere else, but there was a restraint and so, it's like, yeah okay, restraint, it's actually better to prevent the person from hurting or harming themselves.

Therefore, despite the no-restraint policy, there are still times when assistants need to physically intervene to protect a Core Member. I discuss in the protective factors section how the safety of using this kind of protective touch is increased with communication, but for now at the descriptive level, it is important to document that this kind of touch does need to happen from time to time.

Another way that assistants functionally use touch to support Core Members is through a more emotional or psychological support. In every assistant and key-informant interview participants talked about how touch can be used very powerfully to calm or comfort a Core Member. Even though this kind of touch is very relational and I struggled with the decision about whether to categorize it with expressive/affectionate touch or functional touch, I decided that even though it is relational, the purpose of this kind of touch serves a specific function. The assistant is using touch in his or her professional role to comfort a Core Member, which I would argue is part

of the 'job' of being an assistant. In the assistants' focus-group Alice shared how she uses touch to emotionally support Core Members:

having the questions ahead of time and reflecting on the different nature of the way I'm touching people and my time at L'Arche and different reasons, like the, yeah one comforting sometimes or just showing presence, like with [one Core Member] it's just that little connection like, 'I'm here' reaching out. Yeah, so usually I reach out and she can either put her hand on top or not, sometimes she just doesn't and sometimes she just does and we can sit like that for quite a long time and sometimes that's it [laughter], nothing else is going on, you know? But um, yeah, like that's something mutual.

In addition Morgan said, "it can be physical where it's holding someone's hands if they're having a hard time or rubbing someone on the back if they're, yeah, if they're not feeling well".

Further, Beatrice shared a story from when a Core Member's father died:

When [a Core Member's] dad died and she would come downstairs and I remember just something simple like her dad's phone number was still in the phone book and his name was still in the phone book, and that was a point for her where she was, she just started to cry. And for her, she's always been this like, stiff upper chin type of person, so I mean, you can't help it but just say, you know 'Can I give you a hug?' And you know, then everybody, like [a Core Member] lined up, everybody lined up to give her a hug, you know?

Jake also shared an insight about holding Core Members' hands:

I think holding hands is very important because it's still close, but it's not like a hug, where you, kind of, you know, okay, this person can't get away. You know? But not so much [muffled]. I had an experience with somebody who was not really in a good space and just, holding, do you want to just hold my hand? And them calming down by just holding your hand.

Further, an associated form of emotional support that most assistants and key-informants discussed was what one assistant referred to as an "invisible touch". This kind of support, in the same vein as giving space, which I will discuss later, was a way of showing emotional support to Core Members who do not necessarily respond well to being touched. As Jake put it, "sometimes it's even just even the presence that's helpful for Core Members who go through something". In her interview Beth discussed that at the house in which she was currently living, not many of the

Core Members received love or comfort through touch, so she discussed other ways that they received emotional support:

At [current] House, this [support] comes mostly through presence and words of affirmation. I know that my presence is extremely important to Core Members feeling safe and comfortable, and us just being around is comfort and support for them.

In addition Beatrice reflected on this non-physical touch in her interview:

P: ... maybe love is holding them in your heart. Like, I guess what's the spirituality or the, if you want to call it the psychic touch or the heart touch, or what, I don't know what the name is

I: The emotional

P: The emotional touch where you really are connecting with someone very deeply and it's not that you're holding them or even touching them. And how is that there? And how do we, you know, I think that happens a lot, but you know, is there a way to name it?

Despite the fact that there is no physical touch happening, assistants told me that there is still a palpable connection between people. Participants talked about this form of giving comfort in relation to touch as though it was just a different expression of physically comforting people through holding their hand or giving them a hug, which is the reason I felt it was relevant to these findings. Overall, the functional and procedural aspects of the assistant-Core Member relationship are certainly more "part-of-the-job" kinds of touch. Even though assistants talked about how there was still a relational energy when using touch to help a Core Member with a task, this kind of touch did not add to the development of the friendship aspect of their relationship with a Core Member. The assistants discussed a process of distancing themselves or invoking a more "professional" attitude to employ when helping Core Members with more intimate personal-care. In sum, participants used functional and procedural touch with Core Members in a wide variety of ways, from helping them to eat dinner to personal-care and supporting Core Members in physical and emotional ways.

Expressive touch.

Next I will discuss the use of expressive or affectionate touch within the community.

Before I get into the specific examples of expressive touch I will first address the micro-cultures of each house around the use of expressive touch. The house at which I lived during my fieldwork, which I term House #1, had very strict physical boundaries for people. Later I will discuss a Core Member named “Judy” who has very specific needs around not being touched in order to stay psychologically well. Houses #2 and #3 were roughly at the same level of expressive touch; there were some Core Members with more structured boundaries, but it was not as rigid as House #1. House #4 had a high level of affection between Core Members and assistants, although there were a couple Core Members at House #4 who were not as touchy as the others. The difference in expressive touch between House #1 and House #4 was striking. I will now spend some time examining these small micro-cultural differences. To begin, in her interview Angie said:

like you move from one house to another and the rules change. Because of the boundaries, at House [#2] the boundaries were always, very boundary with [certain Core Members], and, I go into House [#4] and this woman is hugging me almost all the time, I can't get away from her! [laughter].

In addition, Beth said:

At House [#4] touch was much different. I was hugging [three Core Members] all the time, and I still do whenever I see them. There was also a lot of tickling with those guys, and also kissing on the cheek or forehead. I was very physically affectionate with the three of them, and I think that physical touch for them was a part of them receiving comfort and support.

Assistants conveyed that there is a real sense of affection at House #4, which is different than the other houses within this community.

With respect to House #1, the following is a segment of my field-notes in the first week of my stay with the community:

Tuesday, Feb. 3, 2009

It's interesting to see the differences between House #1 and House #2 in regards to touch. House #2 is much more physically affectionate. Both houses have their own culture and practices around touch. Based, it seems, on the needs and comfort levels of people in the house - very individualized.

Later on in my fieldwork I made note of some expressive gestures that I see at House #1:

Saturday, Feb. 21, 2009

I'm seeing a few gentle and expressive gestures between people here today at House #1. It's interesting because this house is known sort of as the 'boundaries house' - there are some people here who need very clear and structured physical boundaries in order to be well. But, even considering this, it's fascinating to see how people are still able to express affection with one another [lots of hand holding and back rubs in this day's observations].

These quotations and passages give some insight into the diverse mini-cultures surrounding expressive touch within the community.

I will now document the specific examples of expressive touch that participants discussed and that I observed during my fieldwork. Some of the most common examples of expressive touch that I witnessed were giving high fives, holding hands, hugging, dancing, and sitting together close or with one arm around the other person. For example, Angie said:

Yeah, like comforting, like holding hands, whatever you're doing. Like being with [one Core Member in particular] in church, and I could really feel this when I wasn't with [her] in church, and it was like, 'who do I hold onto?' [laughter] because I was so used to having an arm around her or being patted on the back, and I remember one time she wasn't there, 'this is not worship without [her] touch'. And, yeah, it's so, I get, it's not really giving her, like I get comfort in connection, I get comfort in connection from her.

In this example Angie is talking about a Core Member she has known for ten years and how their affection contributes to the latter's sense of comfort. Some of the Core Members during the focus-group discussed how they will hug friends of theirs who they have known for a long time. In Jim's interview I asked him if he ever gets a hug:

I: ... do you ever get a hug?

P: Yes, sometimes I'll get a hug. If I'm having a bad day I'll probably get a hug.

I: And is that okay for you?

P: Yeah, because sometimes I need it.

Further, in Beatrice's interview she discussed some of the expressive touch that she does with Core Members, for example:

I've been in the community so long like, I will kiss her [a Core Member] goodnight, I will kiss her on the forehead goodnight. And, just tell her how beautiful she is. You know? But if I'm teaching someone her routine I don't do that.

Here Beatrice is sharing something special about her friendship with one of the Core Members.

Further, Jake offered some thoughts on expressive touch between Core Members:

to allow touch between the Core Member and assistants too. You know, like, if somebody wants to give a hug or a kiss on the cheek and that's, you know, it's okay, it's fine. Like, if you are comfortable with that, why should we avoid that? Or why should we block that? It's the, the moment you, it's a sign of trust, it's a sign of you know, 'I like you, really you're my friend' and then that's okay too.

Thus, in Jake's opinion being able to show that kind of expression with a Core Member is a sign of trust and friendship. In addition, in Sally's interview she talked about a way that she shows affection to her best friend in the community, who is another Core Member at her house. The following segment is from her interview:

I: Okay, and how would you and [your friend] touch? If you were to touch [your friend], where, what would you do?

P: Uh, sometimes I dance with her.

Further, even when people are good friends and have known each other for years there might still not be many affectionate exchanges. For example, in Joan's interview she discusses her relationship with a Core Member and she says, "I've known her for several years and, you know, maybe hugged once or twice, so a lot of it depends on the person". Some people talked about expressive touch and mutuality, such as Morgan:

with this particular Core Member where I know that if she's having a hard day it's nice to rub her back, or just sit with her and let her, whatever, she sometimes likes to maybe rest her head on your legs and maybe if you're sitting in the room with her, just, um, yeah, so then mutuality is that not that only I can give that touch by rubbing her back or lotion on her hands or a massage but that if I'm having a totally exhausted that, she can do that too and reach out to me as well, and she can then take my hands, or like pull me in close too.

Beatrice also shares a story of when a Core Member was able to comfort her through a family crisis:

she [a Core Member] said, 'what's wrong?', and I said, 'my Grandmother's very sick', and her mother had died shortly before and she went, 'your Grandmother died?' and I went, 'no no! she didn't die!', but she right away without anything, came a hugged me and cried with me.

These are some examples of the ways that touch is used expressively in this L'Arche community. The use of expressive touch is very individualized, and even though there are guidelines and rules around respect and touch, assistants told me that they are encouraged by the leadership team to do what feels natural when it comes to showing physical affection. Because individual Core Members' needs are so diverse there was not one general approach to showing affection.

Some assistants talked about Core Members who have a more difficult time receiving physical affection, and that assistants try to deliver a gentle form of expressive touch through an activity or functional task. In the assistants' focus-group Martha talked about how she takes time in washing one particular Core Member's back and Maple talked about how she takes time with the same Core Member putting on her lotions. Maple also mentioned another Core Member who has similar boundaries strict around touch and the use of a task to help her receive some of that expressive touch:

P: ... there's someone like, [one particular Core Member] like getting into her personal space is really very scary for her. It's really an unsafe place. Even at the Valentine's day party she was happy to let someone do her nails and do her makeup, so that's kind of like a safe way to

I: Okay, so, um, almost through the task or something.

P: Yeah, and I think it's how it can be, for people who touch is a very like, broken and painful past, it's that kind of healing ways sometimes it's kind of task and care.

In addition to finding individualized ways for people to express affection, another important use of expressive touch was to express playfulness. I saw a lot of playful touch happening in some of the houses, especially Houses #2 and #4. For example, at House #4 during

an observation a Core Member and assistant were joking around together. The assistant was pretending to cry and putting her head in her hands, and the Core Member was rubbing her back and in an equally silly way trying to console her saying things like, “big girls don’t cry”, etc. This exchange was hilarious to witness. In addition, the following passage is taken from my journal from House #2:

It's neat to see the expressive touches that are consistently and seemingly okay, used here at this house. At one point an assistant picked up a Core Member and was carrying her around (so more rough physical play), I didn't notice whether or not she asked first, but both people seemed to be having a lot of fun, both smiling. I've been told consistently by assistants that the smile is a big indicator of whether the Core Member is comfortable.

In these examples the Core Members and assistants are being silly or joking and are using touch in both cases.

In addition to using touch for expressing play, people at the community used touch to meet and greet people. In the Core Members’ focus-group Jake discussed several ways that Jeremy uses touch to greet his friends:

Jake: I think Jeremy you have [muffled], Jeremy when you say hello to someone, this is one of your greetings right? The two fingers? [Jeremy and Jake touch their two index fingers together]. So you have several greetings with people around, like you can show right Jeremy? So we have the handshake, another [muffled], that took actually some time to learn, um, a handshake and to do certain touches with the hand.

Jeremy: [makes some sounds]

Jake: yeah. I think you feel comfortable with the two finger, I think that’s also how you greet [another Core Member] at work.

In addition, in his interview Jim discussed some of the ways that assistants greet him. The following passage is from our dialogue:

I: ... how do assistants greet you when you come in the door?

P: They say, ‘Hello Jim’

I: Hello Jim. Do they ever give you a hug or a handshake or a high five?

P: sometimes they give me a high five and sometimes they give me a handshake.

I: How do you feel about that?

P: It’s good.

Further, during one of my observations at House #1 I made note of two Core Members greeting each other in the morning at breakfast. One of the Core Members reached out her hand to shake the other Core Member's hand and said, "Good morning, my friend". At the time I made note of how respectful and caring this gesture was.

Community touch.

Another way that people at L'Arche use touch in an expressive way is what I term a "community touch". These are interactions involving touch which happen in a community occasion or involve multiple people. The most important example of community touch that happens at L'Arche occurs every day when people hold hands around the dinner table to say grace before dinner and pray after dinner. For example, during Angie's interview she commented about holding hands at dinner:

Every night at the dinner table we hold hands and pray. Everyone, I can't think of anybody in this community that does not hold hands to pray. And that is every day, that is just a part of living together.

Holding hands at the dinner table to pray was something that I documented daily in my field-notes, because I participated in it. Therefore, touch was used in this community sense as well, which I argue is part of the overall category of expressive touch. There was also a sense of acceptance and care during this prayer time, illustrated well by an interaction I had with a Core Member who explained that before he came to L'Arche no one had ever held his deformed hand, which was now a daily practice for him.

In addition, during my first weekend in the community there was a birthday party for a long-term assistant and the following field note is my entry after this party:

Saturday, Feb. 7, 2009

Today was very interesting and exciting, and I learned so much about the nature of touch at L'Arche, and in particular its relationship to celebration and community. Tonight was a long-term assistant's birthday party. There were 2 hours of skits and songs - so funny, touching and human. I saw touch being used in so many different ways. First of all, there

was so much expressive touch. Touch used to greet one another with a hug, a handshake, etc. Touch used to be affectionate - people putting their arms around one another's shoulder or sitting and holding hands. Dancing - wow - there was about an hour of dancing after all the skits and people holding each other's hands and dancing together. In particular, this was a way to include people in wheelchairs and dance together ... overall, such a joyous event and touch was truly an integral part of the celebration. It would not have been the same if people hadn't been as comfortable to be so free with each other.

Thus, my experience at this assistant's birthday party was another example of the way that touch is used in a community way. I will explore the implications of this form of touch more in the discussion section. In sum, expressive touch is a significant part of the ordinary routines at the houses in this community. Expressive touch in the context of friendships was used to show affection, greet one another, be playful, and facilitate a sense of community.

Therapeutic touch.

Next I will address therapeutic touch. Even though I observed this category of touch the least during my field work, it did take place with a few Core Members. Some of the Core Members received relaxation massages from assistants and some needed to do stretches and exercises on a regular basis to maintain their mobility or range of motion. I will now share some quotations from assistants, key-informants, and Core Members regarding their involvement with therapeutic touch.

As already mentioned, some Core Members receive stretches and massage from assistants to help them extend and soothe their muscles and relax. Martha mentioned this in the assistants' focus-group: "With [one Core Member] we have started trying to help her a little bit more with stretches and massage and stuff, so that aspect is kind of coming into it". In addition Morgan discussed how massage and stretches are used with this same Core Member:

Yeah assistants use touch therapeutically. We have a Core Member who we had a massage therapist come and show us how to help her relax with massage. So when it's a quieter morning we will use, help her with a massage, um, it's pretty clear when she's enjoying that and when she wants that, because there are times when she's definitely not interested

and not open to receiving that. And again with that same Core Member, therapeutically using touch with stretches with her, so helping her with her stretches.

In addition, Beth said the same for one of the Core Members living at her house, “We help [a Core Member] do stretches every night. Sometimes massages are given, but not very often, and if so, just shoulders or hands or feet, depending on who it is”.

In his interview Will discussed therapeutic touch in the community:

There’s a couple Core Members who benefit a lot from physiotherapy that’s done in the home, so just sort of teaching the body awareness and how to move comfortably and pick up things and strengthen their legs for balance and things like that. And a lot of it is done through watching, and maybe guiding, so maybe taking their hand when they need to, hand over hand, and that’s sort of touch without taking over.

Further, Jim discussed how he has benefitted from some classes on how to fall properly if he is ever in the situation where he loses his balance or slips:

I’ve been just to a fall clinic and they’ve been showing me at the fall clinic how to use different, different exercises and different ways to use my body. And the assistants are very good, sometimes they show, they try to show me and try to help me through it.

I also documented in my field-notes several instances when assistants used touch therapeutically with Core Members. Some examples included an assistant and volunteer helping a Core Member to stand up from her wheelchair and walk with the help of an assistive device or helping her to use a stretchy exercise band. Another interesting observation of therapeutic touch with this same Core Member occurred during a personal-care observation when she was pointing out areas of her body where she was in pain and the assistant gently laid her hands on those places to soothe or comfort her. With another Core Member during a personal-care routine an assistant gave her a massage on her legs and arms. In sum, these quotations and observations illustrate the various ways that touch is used therapeutically at L’Arche.

Space

Next I will address the concept of space, a concept discussed by most participants in every stakeholder group. Even though space obviously means not touching another person, I felt it was an important part of the nature of touch, because participants told me that it was a reflection of relationship and connection that was about respecting another person's body. For example, Beatrice said, "I think there's a lot of respect for people's personal space and need for space. So I think space is not a bad thing. That's another way of respecting and loving people". There is also a reality where some Core Members do not like to be touched at all. During Will's interview he said:

some people you actually can't touch at all because the way they react. I don't think there's actually in the community who, [one Core Member] a bit, um, but, there's not really [muffled] no touch in this. And that's sort of a hard thing too, because you want to figure out where that's coming from, and there are Core Members in other communities where it makes it hard even to do the personal-care.

The concept of space is an important aspect to the comprehensive picture of touch at L'Arche.

Aggression and violence.

Several assistants and key-informants discussed that some touch that happens in the community from Core Members is aggressive or violent. For example, during the assistants' focus-group Martha said, "I think we can't be fair, or it's not totally honest to talk about touch at L'Arche without saying that there is violence. You know? It's just part of the reality that we live".

In addition, Jake said:

There's a lot of touch coming from Core Members toward an assistant, you know, and so, and that is maybe touch which might be hurtful. And how do we deal with that? And so there is something around if somebody hits someone or is aggressive, you know, like, it happens and we have all the procedures of what we do if that, you know, protocol. But for me it's very important that there's the conversation [with the Core Member], you know to say, 'I don't like that. It happened, and, um, but let's try not to, and let's try to find ways how you can articulate yourself not by hitting me'.

Jake is describing a bit of the process that happens in the community when a Core Member is violent. I also use this quote later to talk about communication, but in the overall description of touch at L'Arche it helps to capture part of the way that violent touch is handled.

In conclusion, the nature of touch at L'Arche is complex. Participants said it was respectful, intentional, and gentle, but sometimes uncomfortable. They also said that functional and procedural touch is displayed in a variety of forms, there are numerous ways of showing expressive touch, and the community uses touch therapeutically with Core Members. Participants articulated that an important part of touch involved giving space yet also acknowledged that sometimes physical aggression is part of their reality.

Protective Factors

To begin I will discuss the various factors that can work to protect people with developmental disabilities regarding the use of touch, after which I will explore the risk factors. To address the protective factors of the L'Arche approach I analyzed the data as previously indicated by way of grounded-theory and looked for conditions, events, and attitudes, either already present or potentially present at L'Arche, which could support the conditions that protected Core Members and ensured they were being touched respectfully and safely. I discovered throughout the analysis that many conditions, attitudes, or events could be conceptualized on a continuum of protective factors and risk factors. For example, I will discuss "communication skills" as a powerful tool to protect people. However, "lack of communication" can be equally detrimental and increase risk, which I will discuss in the risk factors section. The main themes that I will discuss in the protective factors section are capacity-building and community.

Capacity-building.

First I will address skill or capacity-building within L'Arche. By this term I am referring to any circumstance or condition wherein people in the community learn new knowledge to keep

Core Members safe and ensure that they are receiving respectful touch in all aspects of community life. Within this sub-heading I further divided it into educating Core Members, educating assistants, and boundaries and communication skills, which are taught to all community members.

Core Member education.

Five assistants and two key-informants discussed the importance of teaching Core Members about boundaries, how to use and receive touch respectfully, and how to keep themselves safe. For example, in the assistants' focus-group Martha spoke of the value in relationship classes that the community used to do with Core Members. During these classes, which were broken into men's groups and women's groups, the facilitators would teach the Core Members about the body, relationships, sexuality, and touch. Martha said that they taught the Core Members about the 'Circles' tool of relationships and intimacy (see below) during these training periods. In addition to Martha, Angie another assistant explained:

Yeah, well, I think we teach the Core Members the language too, they know what a boundary is. The people I lived with in [previous place of employment], shoot, I didn't even know what a boundary was [laughter] until I came here, like, what are these people talking about? So, this, we give them knowledge and power to not only stand up for their rights and boundaries and protect themselves, but also how to treat other people respectfully.

In addition Jake explained how Core Members use the Circles tool in their daily interactions:

we need to teach Core Members that it's not appropriate that you hug a stranger on the street. You know, and then, but it's appropriate if you meet someone who you know, that's okay. You know, so we go through that with Core Members too, and for Core Members, how that is difficult for you to understand, but for some that is *the* [emphasis added to reflect tone of voice] tool that helps them to be healthy in their relationships because you can say, 'which circle is so and so in?' and then they say, 'oh, like' and then, so you go [muffled] what circle would you say, you see a stranger, you see someone at work, you see someone you see on a daily basis, and then they'd recognize and say, 'okay, so this is this circle' and what touch is appropriate? You know, and to help them to understand that some touch is inappropriate too. Um, so yeah, I think it's a great tool.

Assistant education.

In addition to education for Core Members, the community has training for the assistants. The first training that assistants receive is an orientation program, which usually happens in the first week that they arrive in the community. This program involves giving the assistants information about the L'Arche approach to community and care-giving, including respectful interactions involving touch, boundaries, and teaching people about how to provide personal-care for Core Members. The assistants then will spend the first week or two learning about the Core Members with whom they live and how to provide care for them. All of the assistants and key-informants discussed orientation with me. One key-informant, Maple, explained:

yeah, so we do the circle and the boundary thing, so that's kind of more, almost, emotionally how you deal with touch. And then, the first week when people are here we kind of do role playing and we do a whole morning discussion. So basically, um, people take turns helping someone floss, you'd floss and brush somebody's teeth and have it done to you. Helping someone wash their face. Going for a walk blindfolded in a wheel chair, so you really get kind of what it feels like to be vulnerable, and in order to let people in. And I know we very intentionally talk to people, like, when you're helping someone with personal-care it's a very, very intimate thing.

Another assistant, Morgan, said:

Yep, as part of probably my first or second day here we had the circle map, which is the, where people are in relationship with yourself in the centre, and then maybe God as well, and then you know, a partner and very close friends, and friends and acquaintances kind of working out from there. So, that was used with boundaries around touch and also as getting into relationships emotionally. But it also falls into touch as well and remembering that you are just meeting people.

During assistants' orientation they learn personal-care training and the various aspects of providing respectful personal-care. Three assistants and one key-informant discussed the process that is used to teach new assistants personal-care routines, which involves spending a week or two getting to know the Core Members, observing the care routine several times, and then finally being able to do a routine on their own. For example, Maple said:

like, we give people time, so we don't say, 'okay, so you're here today, you'll learn a routine tomorrow'. People who are here for their first week are just watching, slowly getting to know people.

In the assistants' focus-group Martha said:

I think basically we do a lot to make it safe and the fact that there's lots of people around, the fact that we're watching people three times of four times hopefully before they actually do a routine on their own.

Assistants are also taught about universal precautions as a way to increase the respect and safety when using touch in personal-care routines. Angie explains it well in the following quotation:

in orientation when new assistants come we're told and taught to use gloves when we're doing any kind of personal-care. And that is, it's for the universal precautions, but it's also the respect and boundaries thing. Some people don't get that but, yeah, I get it, that when you're helping someone with a personal-care routine it's not affectionate, it's functional. And, to try to keep making that clear to new people. And there's a question, how do we safeguard Core Members, I think that's one way we safeguard against abusive or uncomfortable touch.

In addition, Maple said:

we're very much like, people, for personal-care that you wear gloves and some of that's universal precaution, but also I think it puts a boundary there too, 'this is something I'm physically helping you with' which is very different than the type of touch that would be seen as different as that.

During personal-care training assistants are also taught about the L'Arche specific policy that says men only help men and women only help women in personal-care. I was told by assistants from several L'Arche communities that this policy is often perceived by other agencies as archaic and overly conservative. Most other agencies are not as strict about men only helping men and women only helping women. During their interviews three assistants and two key-informants discussed this policy and how it applies to keeping people safe. For example, Morgan said:

P: with the intimate routines it's women who are assisting female Core Members, and men who are assisting male Core Members, so,

I: And that can help keep people safer, is that the?

P: Yeah and that would help keep people safer, for sure that would help keep things safer.

In addition, Jake said the following about this policy:

I don't know if it's in every L'Arche community but it's, you know, male assistants help male folks in the house, which is for me a very, which I didn't experience working at [previous place of employment]. Definitely not. Which is very important. I think ... because it makes it safer on the side of the assistants and the Core Member you don't, you know, like you don't get the assistant, if a female Core Member says a male assistant, 'touched me here, there' it could be a completely different scenario, you know, which, so I think that's where L'Arche right away says to avoid that we say personal-care, we really make sure that intimate personal-care, this is covered by the appropriate female or male assistant.

This policy could prevent a situation where a male assistant could be accused of touching a female Core Member in an inappropriate place on her body. However, Drew discussed that just because men are helping men and women are helping women does not automatically create a safer situation. He explained how this issue is also linked to sexuality:

There's a respect level that has to happen regardless of the sex of the person because, I mean there's male with male, and female with female, and that's kind of there for a reason, but the reality of today is that not everyone is sexually oriented to the opposite sex, and so like, you know what I mean? There might be, so, if a Core Member is expressing that they're homosexual or whatever it might be, but if we're sending, we are, we would be sending females with females and so, or males with males or whatever it is, and so, that still, it, on paper or whatever, we say males only help males, or females only help females, it doesn't necessarily, like it implies that there's a safety net but it doesn't, you know what I mean? I think the safety net has to be within the respect that people give to that side of things

Drew is suggesting that a personal-care routine is not safer, because an individual is being helped by a member of the same sex, but that a stronger approach starts with a baseline of respect.

During personal-care training, assistants are also taught that personal-care routines are not a time for visiting, joking, or hugging a Core Member. For example Morgan said:

in my experience with L'Arche it [touch] has been used in a safe way, and also, because in the moments I think when people are most vulnerable is during personal-care routines, that's definitely when, when people would be most vulnerable, it exposes the most intimate part and there is this clear thing about, we want to live relationships with people, we want to be a home and house with close relationships, but during a personal routine it's, that's

not the time to build the friendship, that's not the time to be joking, like when you're helping someone to bathe that's not the fun time to be, I don't know, like splashing water at someone, like that's functional I guess, and when people are getting silly just a reminder, 'can you keep yourself safe'.

By honoring the Core Member's vulnerability and teaching people that a personal-care routine is not a time for relationship building or fun, the assistants can help create a respectful interaction between themselves and the Core Members.

In addition to teaching assistants that personal-care routines are not a time for visiting, two key-informants and one assistant discussed the importance of how assistants are taught to use consistency in helping Core Members with their personal-care. That is, there is some flexibility about certain things, such as the timing of the routine, but there is a structure to every Core Member's personal-care routine that should be respected. For example, here is a segment of my conversation with key-informant, Joan:

P: ... especially in personal routines, um, we do, we try to do everything the same in terms of sequencing. So, a) it's easier to learn and teach, and whatever, uh, b) it's just consistent. It's consistent for the Core Member and knowing what to expect or whatever. And so I think that, um, we would be able to pick up on, if there was a change in the sequence. So that's another thing just off the top of my head. To investigate that
I: So to pick up in a change in sequence um, so like a, if you're with someone and helping them, and then you go to do something and you can tell something's off or how could you
 P: Or the person would say, "aren't you gonna do this" instead of that. Or, when I was this morning with [one Core Member], she said sometimes to me, "I'm gonna have my breakfast now", um, and she kept doing that and it lead to a conversation with the whole team around okay, what are we doing? Who's doing what, and why is it different? And, so, now it's clear and she still asks for her breakfast, um, but I think with some people, especially the people who are non-verbal, um, those subtle, we're in tune with the subtleties to the point where a change in, routine might, or hopefully it would be noticed.

Joan is indicating that by keeping personal-care routines consistent and structured the assistants can actually increase the safety and respect of helping a Core Member with his or her personal-care. If an assistant was being abusive or using touch disrespectfully during a personal-care routine it would be out of the structure of the routine and hopefully the Core Member would indicate this situation to another assistant, either non-verbally through an action or verbally, as Joan explained,

by asking for something different. Maple also communicated that keeping personal-care routines consistent helped the Core Members to feel safe:

keeping to that routine is really important for people. And I think as someone kind of new coming in sometimes you may not totally get that at first, 'oh what's the big deal if she wants to have her bath like two hours later than she usually has? Oh, it's not a big deal'. Or, um, it can be really little, minute things ... but that routine can help keep people, the things that, I think that maybe people going through in time, and I think touch is a big part of this, that, and well, abuse, so like, out of control. That these things that they can control help them feel safe and stable and that they can live in the present time and not go back to that place of completely out of control.

Maple is suggesting that the potential abuse Core Members may have experienced in the past has created the need for consistency and structure so that they can have some control over the events of their day to help them feel stable and safe.

In addition to personal-care training, assistants are taught what to do in order to deal with situations where there is the potential for certain Core Members to get physically violent. Within L'Arche there is a no-restraint policy, because restraints can be very dangerous for the people being restrained. Therefore, the assistants are taught other ways to work toward preventing a violent out-burst from happening. Four assistants and one key-informant discussed a course that all L'Arche assistants are required to take called Crisis Prevention and Intervention (CPI). Assistant Beth says:

We were also trained a little about touch in terms of not restraining Core Members in Crisis Prevention Intervention, a course every assistant is required to take when they arrive, and to have a refresher course each year thereafter. We are taught not to restrain, so I think it's probably best to follow this even when the situation is frustrating or there seems to be no other options. Restraining is not the most respectful, safe, or appropriate way to handle the situation. Restraints typically aren't gentle, and Core Members should be touched gently. Often calm verbal reassurance can help people calm down.

Key-informant, Maple, also shared her thoughts on CPI:

The real key for us is, when you get to know people well, is learning the beginning stages of when they're uncomfortable. And maybe sometimes we miss some of that, or it takes a really long time to get to know people for those really early signs, because most people

don't go from being, 'I'm okay' to completely freaking out. There are a lot of steps in between.

Another assistant, Angie, spoke about the importance of CPI. She noted that as opposed to trying to physically control Core Members, becoming sensitive to their early signs of agitation and dealing with the situation at that point are much more empowering. CPI is empowering, because before a Core Member has lost control and he or she is showing signs of increasing distress, assistants can give Core Members choices and allow them to decide what would help them best to calm down. By taking this course of action the environment becomes safer for the individual Core Member, who is supported in dealing with his or her feelings in a healthier way. The environment also remains safe for his or her roommates who then do not have to execute emergency protocols for when an individual does lose control and becomes violent. Here is a segment of Angie's interview in which she discussed CPI:

P: as a policy we don't do any kind of physical restraints. Yeah.

I: Okay.

P: That's a policy. And, I worked in agency, until I came here, doing take downs and, a lot of physical restraints. It's very [muffled].

I: Yeah. And could you speak on the difference that it makes, maybe within the home environment, or, what in particular is good about the non-restraint policy?

P: Well ... when I first came here I used to think, 'oh yes, this is because the Core Members are a little more verbal', but no, it's not. We don't do that with anybody. It's more of a, more of a, uh, preventive, like seeing the signs of aggression, like preventive, CPI.

In addition to training around crisis prevention, several assistants and key-informants discussed the importance of on-going training that happens throughout an assistant's time with L'Arche. A number of assistants referred to talks that professionals had given to the community around abuse statistics, boundaries and safe touch practices. David Hingsburger, whose work I frequently cite in my literature review, has given several presentations to this community and other L'Arche communities. In reference to one his presentations, a key-informant, Beatrice, said:

I think there's this openness in L'Arche to learn, so I think when David Hingsburger talked to the community about, you know, what are the issues, big changes happened. You know? Or you know, using circles, and circles of, where are you in that circle or whatever? Or the willingness to have people even judge or disagree with us was there because it was more important that we protect people's vulnerability.

Angie also discussed the impact that a professional's presentation had on her role as an assistant.

Below is part of our dialogue:

P: we had [a professional], came at one assistant's meeting and she talked about abuse in the population. And the fact that, the different kinds of abuse, and the fact that at that time like 90% of people with disabilities had been abused. And I know that that's a low number
I: it's a conservative estimation, yeah.

P: It's 100%, and just the, uh, the impact that that had on me and wanting to honor them and respect.

In addition to professionals giving presentations to the community members, many assistants and key-informants discussed how the community will often seek advice from outside professionals for certain situations or queries. For example, Beatrice discussed in her interview that in the past she started to use massage with one Core Member, because she noticed that this Core Member responded well to it. However, she also called in a behaviorist to observe her doing the massage and give pointers that might help keep the interaction safer for the Core Member. Several assistants and key-informants discussed the work that this particular behaviorist has done with the community and that her input has been very useful.

Boundaries.

I will now discuss boundaries, which is the third sub-category within the theme of capacity-building, as a protective factor to increase safety and respect in using touch with Core Members at L'Arche. Three assistants and one key-informant discussed that it was at L'Arche where they themselves learned about boundaries. For example, one assistant in the focus-group, Alice, said:

I know the orientation process, just making it really explicit what boundaries are, what space is, a lot of assistants I know, myself included, learn a lot about that here. You know,

that's transferrable actually to our other relationships. Respecting our own boundaries as we're learning to respect someone else's boundaries, it helps to make it safe.

Three assistants and one key-informant discussed how boundaries are a part of orientation. Even though it may be difficult to understand, assistants are asked to trust why certain boundaries are in place. One assistant and two key-informants even said that at first boundaries may look cold or unloving, but really they are in place to help keep certain Core Members safe. For example, Maple said:

in the first week of orientation when assistants come we do the whole circle with people and we really try to tell people, 'you may not get why some of these boundaries are in place right now, and it may seem really weird, and we don't want to give away people's full history, but we're just really asking you to respect that and in time you're gonna understand things differently when you get to know people'.

In addition to discussing and learning about boundaries, one assistant and two key-informants told me during their interviews that the assistant's comfort level with regards to touch was just as important as the Core Members. Morgan discussed how she will redirect a person sometimes, because she is not always comfortable receiving a hug:

For another Core Member who likes hugs and I'm not always comfortable receiving hugs all the time, again just when she reaches out for a hug just holding her hand instead, taking her hands in my hands, so that it's redirected.

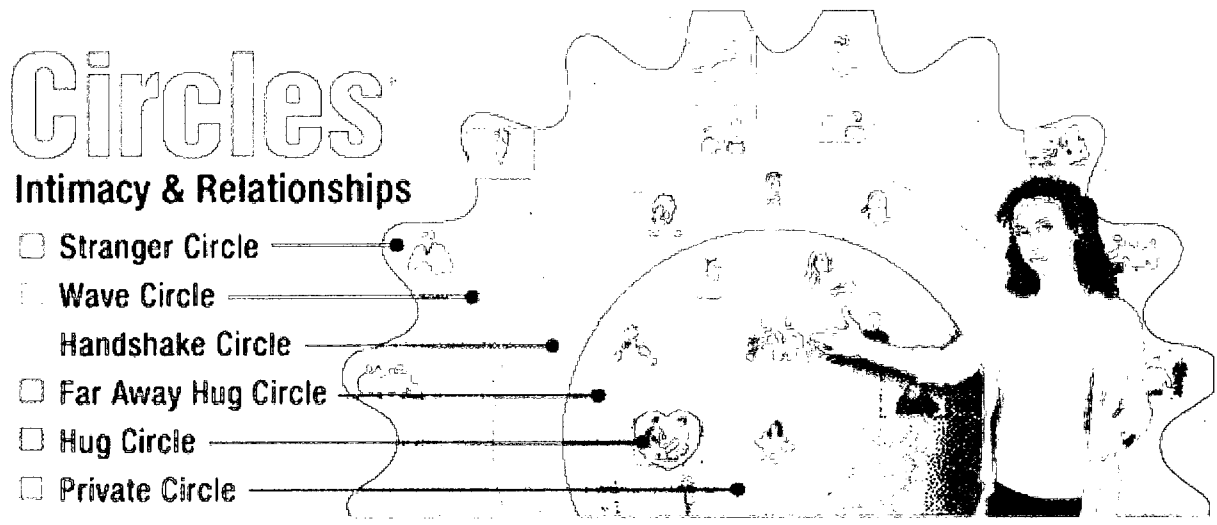
Jake discussed the importance of respecting assistants' comfort levels in relation to both expressive and affectionate touch, and also helping Core Members with personal-care. He said:

And then again, it's all about how I feel in it, if I'm comfortable and then I'm like, 'it's okay'. If an assistant says, 'no I don't feel comfortable' I think that's important too. I think there is something, asking the Core Member, 'are you comfortable with being helped by an assistant?', and then also ask the assistant, 'are you comfortable helping the Core Member?' Because you're asking 20, 19 year old[s] to enter, to be invited into very personal space, um, to be prepared for that and to take the skill away.

In sum, people in the community were telling me that they felt supported in establishing their own comfort levels and personal boundaries around touch.

As previously discussed, the community uses an educational tool to help teach both Core Members and assistants about boundaries and safe touch. This tool, which is called “Circles”, is a visual map or representation of the different kinds of relationships that any given individual could have, and then the types of touch that are appropriate for those relationships. (see Figure 1.) The tool is part of a broader life-skills curriculum for people with disabilities that was developed by the James Stanfield Company in the United States. During my field work every participant group, either in formal discussions during interviews or informally during my observations, talked about the Circles tool and how it applied to their role in the community.

Figure 1. Jim Stanfield's Circles Tool



For example, assistants discussed how they used the Circles tool to support Core Members in keeping their own boundaries, and how learning the Circles to support the Core Members helped them to learn about boundaries too. In addition, during assistants' orientation the community leaders use the Circles diagram to help the assistants understand where they are in relation to the Core Members. Key-informant, Joan, explained this function of the tool:

I: ... you mentioned mutuality and I'm wondering how talking about mutuality and the use of touch um, might help prepare assistants?

P: Yeah, so it connects to the circles a little bit, so we, we talk about mutuality being when you know, when people have the same understanding of what kind of relationship they have. So whether it's a good friend, an acquaintance, whatever, um, and that, that people when they first come into the community, like really they're just beyond stranger, you know, and they're really still out here [participant is pointing to a outer circle in the 'circles' tool] after a couple of weeks

I: Mm hmm.

P: but, then the functional part of their role [of being an assistant] means they start sometimes being here [participant is pointing to the very close circle of the 'circles' tool] in terms of physical relationship

I: so they're very close?

P: yeah, and, and so that's, um, just something to be aware of, we just talk about it ... it's a functional part of the role, it doesn't add to or connect with the mutuality of the relationship, you know? Um, and so outside of any function, there's the expectations on people are still that touch is over here [pointing again to outside circle of 'circles' tool]

I: Okay, so touch is back out in the, I guess that's the acquaintance?

P: yeah, acquaintance or friend, yeah. So, over time the use of touch, um, you know, the touch that's more around care, uh, affection follows the depth of the relationship. You know? I think that there's always a piece of the function that's outside of that.

According to Joan, the Circles tool can help assistants to understand the requirements for touch in their functional roles within the community. One of the risk factors that I will later discuss is that some assistants believed that the intimate nature of personal-care routines sometimes gave new assistants the wrong impression about the nature of their relationship with Core Members; that is, they would often become overly and inappropriately affectionate with Core Members within a short amount of time in the community. Therefore, using the Circles tool in this way to help assistants understand the functional touch required of them could help prevent unhealthy physical

affection with Core Members, because it teaches assistants that they are still just getting to know people.

The Circles tool is also very useful for the Core Members. Many Core Members are able to articulate who is in which circle and the touch that is then appropriate based on that relationship. Numerous Core Members also use this tool as a way of identifying their closest community of friends. The people who have been identified in their closest circle have known the Core Members for many years and are often the group of people who are called upon to help a Core Member, if he or she is going through a difficult time. This was how many Core Members discussed the circles during daily life, by saying, such and such a person was in their “circle”. One key-informant, Jake, explained the Circles tool in his interview:

You know, I don't know if you know the relationships circle, but you know, green, yellow, red, it goes through different stages and it explains to you, you know, who is in what circle. Like the closest circle is maybe your partner, and what kind of touch is appropriate and then with other people? And then we need to teach Core Members that it's not appropriate that you hug a stranger on the street. You know, and then, but it's appropriate if you meet someone who you know, that's okay. You know, so, we go through that with Core Members too, and for Core Members ... that is *the* [emphasis reflects tone of voice] tool that helps them to be healthy in their relationships because you can say, 'which circle is so and so in?' and then they say, 'oh, like' and then, so you go [muffled] what circle would you say, you see a stranger, you see someone at work, you see someone you see on a daily basis, and then they'd recognize and say, 'okay, so this is this circle' and what touch is appropriate? You know, and to help them to understand that some touch is inappropriate too. Um, so yeah, I think it's a great tool.

All of the Core Members whom I interviewed were very articulate about their understanding of boundaries as a way to keep touch safe. For example, Jim and I were talking about what kinds of touch would be appropriate for meeting people on the street; here is a segment of our discussion:

I: Um, so, say, when you're out on the street and you run into a friend, or say you're at church and you see a friend, um, how do you greet them?

P: With a handshake.

I: Hmm, with a handshake. Um, would you ever say hello to somebody with a hug?

P: No, not unless I really knew them.

When Jim said, “No, not unless I really knew them” this sentence spoke volumes to me. It suggested that he understood the intimate nature of hugging someone, and that a hug is really only appropriate to exchange with another person you know well, and especially not a stranger. Further, during the assistant’s focus-group, Martha discussed how some of the Core Members at her house have articulated their boundaries in the past. She said: “two of the women at [our] house have come home from work kind of saying, ‘this happened and I wasn’t comfortable with it’ and, you know? And we explored the situations and followed up.” Therefore, because the Core Members had understood that something was happening that violated their boundaries in one way or another, they had the knowledge and courage to come home and discuss it with other people in their lives who could help them deal with it. These are powerful examples of people with developmental disabilities who are aware of their own rights to such a sophisticated degree that they are standing up for themselves and articulating their feelings on situations that are very difficult for many people. A very powerful example occurred between two Core Members during an observation period. The following segment is what I recorded in my field-notes with some reflections afterward:

I am sitting in the living room with a Female Core Member in a wheelchair. This Core Member sees another female Core Member walk into the living room. The Core Member in the wheelchair reaches out a hand to greet her friend. The Core Member coming into the room gently and tenderly tells the other Core Member that she needs space and doesn't want to take her hand. She repeats this a couple times patiently until the other Core Member puts her hand down. There are no assistants in the room, it's just myself and these two Core Members.

- This was a very interesting exchange because it communicated several things at once.

#1 - the Core Member in the wheelchair was comfortable enough in her friendship with her roommate that she reached out her hand to express a greeting (this Core Member also has very few words, so shaking hands is one of few options to say hello).

#2 - it expresses the comfort level of the other Core Member to articulate her boundaries. She did this politely and with care for her friend. But this suggests that she felt safe enough to be honest and honor her own feelings and physical boundaries.

These two Core Members demonstrated that they were both comfortable keeping their boundaries, but they were also comfortable being honest with each other; honesty is another major protective factor, which I will discuss later.

During the Core Member focus-group one participant, George, said that safe touch to him meant a 'contained touch'. One of the safe persons present during the focus-group followed up with George and asked, "what does that mean when you say contained touch?" and George replied, "well, very secure touch". I asked George what made touch secure for him and he replied, "like whether it's on my hands". That is, the hands are a safe place for him to receive touch. Then he replied that assistants ask first before touching him. In addition to honesty, asking first was a protective factor that each stakeholder group discussed, which I note below.

I also wanted to understand whether assistants had a good sense of how to protect non-verbal Core Members and how to respect their boundaries. Overall, five assistants and three key-informants discussed this issue in their interviews. The following quotation is from Angie's interview:

if they don't speak, non-verbal, like body language, if you shy away. I worked with basically non-verbal people in [previous work-place], a lot of non-verbal people so I don't even think about, like, the body language thing is fairly instinctive now, like I've been trained by years of experience that I don't think about. Like, 'okay, she's frowning, I'm not going to touch her', I just, I know it. So I guess, that's a heads up.

Another assistant, Beth, had much to say on how assistants can tell whether Core Members who do not communicate verbally are comfortable:

I think you can tell by their body language. If a Core Member is not comfortable being touched, you can feel it through the point of contact. It's obvious when a person hugs stiffly or maybe even backs away from touch. [A Core Member] often is very tense when approached by someone for a hug, for example. When I hold [another Core Member's] hand, I can typically tell how she is doing and whether or not she's wanting to have that point of contact or not.

Beth also said:

Non-verbal communication often speaks volumes louder than any words. Anyone's non-verbal communication during physical contact should inform a person of whether or not that person feels safe.

Morgan also knew how to tell if non-verbal Core Members were comfortable being touched:

We had a volunteer who went to, I don't know if it was their arm, or just something, to go for a hug, I'm not sure what it was for the Core Member who was non-verbal and they didn't know them particularly well and the Core Member actually went to hit them [chuckles], pretty clear and non-verbal indication that it wasn't welcome. [laughter] Um, but I mean, facial expressions I know with, um, yeah with a Core Member whose non-verbal here, she will often if you ask her, you know, during a massage or, where does it hurt, like where is it sore, where are you hurting, she will point, and she uses [not sure of word] to indicate that something is hurting and she's pointing and welcoming then you to be helping massage that area for her. Um, and she's also very clear when she doesn't want the massage, you know? She's pretty clear with her body language, with turning away, um, or yeah, it could be spitting or making a grumpy face that it's not a time where it's welcome.

In addition, Beatrice discussed that this type of knowledge really only comes with getting to know someone and then being able to sense a shift in their mood or body language. Overall, assistants and key-informants indicated that they understood how to interpret non-verbal Core Members' body language, which helped them know when touch was welcome.

Several assistants and key-informants discussed the importance of setting clear and firm boundaries with some Core Members. They discussed how some Core Members are not able to internalize the Circles tool and distinguish between what is appropriate for a stranger and what is appropriate for a friend. Morgan described it this way:

as a Core Member where you're someone who really wants to be hugging people all the time, but if it's not safe because they can't set boundaries the same for everyone, and if they hug one person somehow it's okay then to hug everyone, and it gets them into unsafe situations.

Throughout my time with the community many assistants and key-informants discussed with me the boundaries and physical-touch protocol for one particular Core Member who needs very strict boundaries in order to stay healthy. For the purposes of this discussion I will use the pseudonym

“Judy” to refer to this Core Member. In my field-notes I recorded a conversation that an assistant at Judy’s house had with me:

Tuesday, Feb. 17, 2009

I have been noticing today the specific differences in the use and acceptableness of touch between the different houses. Touch at this house [house #1] is very structured and defined boundaries are enforced. For example, one assistant indicated to me in conversation after dinner that one of the Core Members [Judy] cannot receive touch above and beyond holding hands at prayer, or else she will become physically aggressive. It is so important for touch to be structured in a way that allows her to be well, and boundaries must be firmly adhered to.

Another way that this Core Member has been supported in her needs for strong physical boundaries is what people called the ‘pinky shake’. In sign language putting two pinky fingers together is the sign for a hug, and this sign was adapted for Judy to safely express physical affection with her closest friends. Key-informant, Maple, describes this scenario further:

P: ... For [Judy] have you seen her do, like, the pinky shake?

I: Yeah.

P: Yeah, that’s basically the sign language for hug, and people who are in her closest circle, especially [muffled], because over time we learned, she desperately wants to have someone who can be really close to her, but it’s almost, kind of, I don’t know if you’ve done the circles, but like that purple circle in the middle, where you can only be by yourself. It’s almost like she wants someone to come into that space and heal all her loneliness and no person can ever do that, so she tries to pull them into that and can’t handle it, and violently pushes them away. And it can get really extreme and sometimes I feel really bad for her because I think life must be incredibly lonely. For, even like, for someone to touch her on the shoulder, like, you might think it’s this totally benign and harmless act, but she’ll just obsess about it and then really act out in a way that’s really quite detrimental to herself, and like other people. So, just like for her it needs to be, like no touching. And that seems to be the one thing that she can handle. So it’s like really trying to learn how to provide comfort with words and supportiveness.

During my time with the community I came to understand that Judy had very serious physical boundaries in place to help keep her safe and healthy. Through my observations it was apparent that these boundaries were difficult for both her and others at times, but everyone understood that she needed them for important reasons. She was also very good at keeping her own boundaries and would often communicate with other Core Members and assistants, if she needed space or if

another person was too close to her.

Many assistants and key-informants discussed how respecting physical boundaries fit into the broader picture of showing respect. One assistant, Morgan, spoke about how showing respect in broader ways translated into a general respect of the Core Member's space and body:

assistants show respect by listening, listening to what they're [Core Members] saying, what they're not saying. You know, helping someone with their evening routine and if they're not ready yet, you know showing respect by, "okay well do you want to do this in maybe another 5 minutes? We can do your routine" or, yeah respecting where people are at, what they're showing with their bodies, if they need space, like not trying to be joking with them or whatever, but respecting that need for space, and backing off. Um, yeah, and the language that we use that's very, yeah, using respectful and inclusive language. And treating people as they want to be treated.

Overall what Morgan is talking about are very basic tenets of being respectful. In an observation I recorded an interaction that between a Core Member in a wheelchair and an assistant. In this interaction the assistant asked the Core Member where she wanted to go once she was done eating her meal. The assistant gave the Core Member a few choices and based on her energy levels she asked the Core Member if she wanted to take a nap. The Core Member said, "yes", and then the assistant pushed her wheelchair to her room. This interaction may seem simple and insignificant, but it was how the assistant gave several choices and waited until the Core Member responded before pushing her wheelchair. The assistant showed respect for this Core Member's boundaries by not touching her before she first listened to what she wanted to do.

Communication.

The last few codes within the theme of capacity-building have to do with communication skills. Throughout my field work I learned that it is inadequate to teach people about boundaries, if not taught concomitantly with the ability to communicate with one another about those boundaries. As I have indicated briefly throughout the first part of this analysis, the ability to ask or inform an

individual about touch and be honest with one another is extremely important in maintaining safe and respectful touch practices.

Arguably, the most important aspect of communication with regards to touch is asking and informing the individual to whom the touch is directed. All Core Members, assistants and key-informants discussed the importance of asking or informing before touching. This protective factor is consistent with the literature that says to ask first and touch second (Hingsburger, 1995). For example, key-informant Jake said:

So, in the personal-care, for me it's very important for me that people are aware of the touch that is happening, or that they are, or you are wanting to do. Like, 'Is this okay that I help you with this?' and then the Core Member either nods or says yes or if, you very quickly realize if they don't want it either and to be aware of it and to not force it then. You know, I think that's very important, no touch can be forced.

In general, assistants and key-informants told me that it is important to ask Core Members before they touch them, regardless of the nature of the task, whether it is to help someone with a functional task or to give someone a hug. For Core Members who do not communicate verbally, the assistants talked about asking or announcing out loud what they are doing so Core Members are aware of what is happening to their body. For example, assistant, Will said: "Announcing it. 'I'm going to wash your face' or, 'I'm going to wash your hair'. So they're not just, 'whoa!' you know. Or even asking permission, 'you're upset, can I hold your hand?'"

In addition to Will's thoughts, I observed repeatedly that assistants asked or informed Core Members before touching them. Recall the example of the assistant asking the Core Member in the wheelchair what she wanted to do before pushing her wheelchair somewhere. Further, during an interview with Core Member, Bonnie, she indicated to me that asking and communicating were important in helping to keep touch safe. The following is a segment of our discussion:

I: So I'm just wondering, uh, what makes touch comfortable or respectful for you?

P: It's to ask.

I: To ask first? Yeah, I think that's a very important one, isn't it?

P: Mm hmm.

I: Is there anything else that helps to make touch comfortable for you?

P: Um, is to say I don't want to be touched here or there.

I: Hmm, mm hmm, so to tell other people what's comfortable for you?

P: Yeah.

In addition, during Jim's interview I asked whether assistants ask before they touch or hug him, and Jim replied:

Oh yeah. Yeah they [assistants] wouldn't just go up and hug me for the sake of hugging me. They would say, "Jim, do you want a hug? It looks like you need a hug today, or it looks you had a bad day" or something. They would never just go and do it randomly because they know that that could lead to problems. So they would always ask, because it would be like me doing it to them. So, you know, we've got to respect each other. And if you don't, then L'Arche isn't L'Arche.

I noticed in my observations that, when it came to more routine tasks, assistants did not always ask Core Members before they touched them. Common examples of this scenario were assistants helping a Core Member to eat a meal or helping a Core Member to do up a jacket zipper before going out. For example, Jake said, "the communication is very important, then over time it becomes a routine, therefore, I think you don't have to say it I think every time". With more routine tasks such as helping a Core Member to eat a meal, assistants did not ask before every single spoonful, etc. Despite the fact that some tasks become routine and therefore do not necessarily require a verbal notification, there were times that I witnessed assistants helping Core Members with routine activities that I still felt could use a verbal indication, an observation that I will discuss under risk factors.

In addition to asking and informing Core Members before touching them, assistants and key-informants told me that it was very important for information to be passed along about Core Members so that new assistants or volunteers understood Core Member's specific needs and limitations. Beth said:

Respect and boundaries are often topics of discussions. People in the community are very careful that information about touch and boundaries is passed on to new assistants within the first couple of days.

In addition, Morgan said:

it's pretty clear where people's boundaries are and what the struggles are, and what people are carrying, so those conversations do happen pretty quickly.... Yeah, it's just getting to know someone, and there's direction from people who know her [a Core Member] better, like when I was in my first months here the people on the team were really good at saying, 'okay, when [same Core Member] was just making this kind of noise, that's what she uses when, you know, when her stomach is hurting and you know, so she probably would need some prune juice, would probably be good if she stretched out after dinner' like, they, were good at in the moments when things were happening, where helping to name and identify that.

Further, key-informant, Joan, had the following to say about communicating information with other assistants:

we need to, I guess ... literally give voice to what we know to be true about this person [a Core Member]. So, you know the little subtleties that you might pick up on, I might be missing and so it would behoove you to you know, to say, 'I think so and so was saying, you know, blah blah blah, and doesn't really like whatever' and you know? I think we as assistants kind of owe that to each other.

In addition, Jake also had an important comment on this protective factor:

And so that always had to be covered and talked about very early on, because yeah, because touch is one of the things you do pretty much from the first moment you enter the door. A handshake is a touch, right? So, uh, and therefore, right in the beginning, I remember ... in one house I said 'yeah, some people might just not shake your hand and that's okay, you know, like because there's a reason for it and just for them, you know, they maybe don't know you and they need, like they have their own personal boundaries where they feel comfortable enough to do that, and if it does not happen you should not feel bad about it'.

Jake was describing giving newcomers information "up-front" about personal boundaries that different Core Members might have. For example, during probably the first hour of my first visit to house #1 one of the assistants told me very straightforwardly that I should not touch Judy, unless she offered to shake my hand to say hello. So from first-hand experience, I know that important information about people's needs and limitations is shared with newcomers.

The quote from Jake also relates to giving and receiving feedback, being honest with each other, and not taking things personally. Assistants and key-informants told me that giving feedback to each other about how to be appropriate or respectful was an important way to ensure that touch was used respectfully and safely with Core Members. Key-informant, Beatrice, said, “the willingness to have people even judge or disagree with us was there because it was more important that we protect people’s vulnerability”. Beatrice also explained that an assistant’s ability to receive feedback is a good way to gauge whether an assistant is appropriately placed in a work position at L’Arche. She explained to me in her interview that, if assistants used touch in an inappropriate or disrespectful way, but were able to receive feedback admit that they were wrong, apologize to the Core Member, and change their behavior, then it was okay for them to stay in the community. Beatrice said, “if someone can take that feedback and make the shift, then that’s great. If they can’t then, it’s okay. Go, because it’s not safe for you to be here”. Three of the four key-informants discussed the importance of not taking feedback personally when it is given. For example Beatrice also said:

you know, try to keep our egos in check, because I think, yeah, so I was just lucky too, because I lived with some people too who were on that same vision that it wasn’t about just being nice to each other, it was about being as best we can

Jake talked about not taking things personally in relation to when Core Members communicate a physical boundary to others: “‘Why doesn’t he want to hug me?’ he said no, so he said no. Sorry, swallow it, but, get moving on”.

Jake discussed in his interview the process for giving feedback or reporting if something wrong happened:

if anything happens in a way that touch is used, if I would observe touch where I feel like uncomfortable with, and I always go with my gut feeling, that is the moment that I would say that I have to talk to, you know, so ‘we have a grievance’. You know, like you can say, you know, like, ‘I observed this, I’m not sure really what this means, but I just want to make you aware of it’ and of course, normally I would go to leadership and they would

say, 'what did you see', and so I trust the experience and they would say, 'okay, let's talk about it'.

In this passage Jake identified what he would do if he saw someone using touch inappropriately: He would talk both to the individual and to leadership and there would be discussion about what took place. This openness and communication are important factors in protecting the use of respectful touch.

In the same vein as giving feedback, most assistants and key-informants indicated the value of being honest and transparent regarding any incidents that occur where touch is used inappropriately or un-gently. For example, several assistants and key-informants discussed that, although the community has a no-restraint policy, there are still times when assistants need to protect a Core Member in a way which could be perceived both by the Core Member and outside witnesses as a restraint. Some assistants mentioned experiences like holding back a Core Member from running into moving public transit, into the street, or from picking at a wound. In every situation where assistants brought up that they had held someone back in a way that they were using their strength to protect the Core Member, they said how important it was that to talk about it afterwards with other assistants and the leadership team. Maple and Jake discuss this issue in their interviews. Maple said:

there are times when I feel I, I could be helping, or I'm trying to block her [a Core Member] and the emotions are, you know, and I feel like I'm in this wrestle with this person, um, which, I mean that hasn't happened a lot, but um, it when that would happen I would go and talk with uh, with [the community director].

Jake had the following to say about communicating with others about these difficult situations:

I think the restraint policy is good but where does it come into play and what is a restraint and what is not? So that sometimes, I find, like, you know, and I told someone, I had to hold someone back who was running after a car, and then you know in the first couple of seconds I was holding him and then I was able to re-direct the person towards somewhere else, but there was a restraint and so it's like, yeah okay, restraint, it's actually better to prevent the person from hurting or harming themselves I can, um, justify it in a certain way. But I called right away and explained it because I didn't feel good about it either. But, I didn't know

what else to do. This person was kind of running after the car and, he's pretty strong and quick, you know, so, but that's when it was important for me to talk to someone and just say and to be okay. I wrote an incident report and so it's all there and people know. So I think it's important if ever you are in a position where you might have, myself I feared I might have hurt someone, I hope I would always call, 'this is what happened, I don't feel comfortable'. You know, um, so then it's either, 'okay, let's talk about it' and yes, you know you did something actually that wasn't okay, and not to feel too bad about it, it can happen and you can work on it'. Or to be, 'you know, that's okay. You did it because you had a reason behind it'.

Assistants also discussed how it is important to be honest with oneself and one's fellow assistants about any difficult feelings experienced while providing care for Core Members. The type of care-giving that occurs in L'Arche communities is demanding and can evoke complex emotions. Maple very clearly explains this issue:

I think we talk to assistants a lot too, like, 'when people are really aggressive with you it's normal to have feelings inside and not feel really loving toward that person and it's really important actually that you articulate that to people, if you're feeling that way and that you can be honest. It's not okay to act on it, but it's really normal to feel it'. So I think if people aren't willing to be honest that way and kind of work on their own issues I think things can become really unsafe.

In the assistant's focus-group Drew shared a similar experience:

I think, yeah, there's something to that, that we have places where we can be honest with each other and kind of let that out, and not, not let it take a grip over people. I think, like you're saying, if you don't have a place to share it, it starts building inside of you and it starts saying like, 'I'm the only violent person here, I take, or, I have aggression towards someone I'm supposed to be caring for and I can't do that and this is too much for me'. And once you kind of, if you have the honesty and you find out, 'oh, the community leader felt that way?' Or, you know, a 35 year assistant also felt that way? You know, like, 'oh, maybe I'm not the spawn of satan', or whatever, you know what I mean, whatever places we end up building ourselves into, but I think, yeah I've been touched by how people are willing to share real, raw, honest experience, and that makes for a lot healthier, I think that might be another part of protecting the safety.

Both Maple and Drew are referring to very difficult emotions to communicate with others, but in both cases they are expressing that by talking out loud about these complicated and painful kinds of emotions that it can actually increase the safety and respectfulness of the environment for Core

Members. This protective factor obviously relates intimately to community and working on a team, which I will discuss in the section on community.

In addition to discussing difficult emotions that arise from being aggressively targeted by a Core Member, Jake talked about communicating with Core Members if they are aggressive and informing them that their actions were inappropriate:

There's a lot of touch coming from Core Members toward an assistant ... that is maybe touch which might be hurtful. And how do we deal with that? And so there is something around if somebody hits someone or is aggressive, you know, like, it happens and we have all the procedures of what we do if that, you know protocol. But for me it's very important that there's the conversation [with the Core Member], you know, to say, 'I don't like that. It happened, and, um, but let's try not to, and let's try to find ways how you can articulate yourself not by hitting me'.

In sum, Jake indicated that communicating to Core Members about their inappropriate behavior is just as important as giving feedback to assistants.

In addition, communicating with Core Members about their day can also improve the safety of a given situation. For example, some assistants and key-informants mentioned that they learned about something that had happened during a Core Member's day at work. Because the Core Member had discussed the incident with them, they were able to follow up with the Core Member's place of employment and make sure whatever was going on stopped.

Another way to communicate that assistants felt increased the safety and respectfulness of touch was to develop a word that communicated to others that the speaker of the word needed space or another individual needed space. This is what Martha had to say in the assistant's focus-group:

Martha: I love our behaviorist, who comes from [an agency in the city] you know, and I really, she's great. But, one of her things is that you have to come up with a, as a team, with a word. She said it doesn't matter what the word is, you know, it could be elephant, it could be whatever,

Drew: safe word

Martha: yeah, but just, and that word means that, you know, either I need space, or I think you need space.

Here Martha described creating an anchor word as a way to communicate that someone in a house needs to take some personal space.

Jake also discussed the importance of communicating honestly with others if an assistant accidentally makes a bruise on a Core Member. The following segment is taken from his interview:

We have to be aware that, even by, and that I actually learned at [previous place of employment], by helping somebody to stand up, just if you put your hands on their wrist and you put a light touch on it you can create a bruise very quickly. And so, to make that, to be like we still need to help the person up and they need to be gentle, but if that happens you know it's clear that everybody knows like, why is that bruise there. Um, I think that's something, not to cover anything up, I think that would be the worst if that happens if people are not speaking up. Like, 'I helped her up and she I grabbed her a bit strong because she was tripping to the side and now I realize that she has a big black bruise on her wrist'. Some people might say, 'oh well what were you doing?' you know, so, um, I think that's important to be aware of that, especially elderly people they get bruises quite quickly. If that happens to say it, to say 'this happened', because that, I think it's the transparency that's important and, I think, not to be, to be hard on yourself. You know, it happens. We can't put everybody in a cotton ball and hope they don't hurt themselves.

Another way that communication can be a protective factor that assistants, key-informants and Core Members talked about was the importance of listening to Core Members and what their needs and feelings are. For example, in Bonnie's interview she and her safe person, Joan, were discussing how Bonnie's personal-care routine changed a few years ago to involve assistants helping her to wash her hair. Bonnie is an individual with broad and more structured personal physical boundaries. She and Joan recounted the process they went through to discern if Bonnie would be comfortable with an assistant touching her head and hair every time she needed to wash it. The following dialogue is taken from Bonnie's interview:

Joan: But, um, before that you didn't always have someone helping you wash your hair, right? And so it took some time to, for you to feel okay with that, and we needed to have some meetings and talking through what that would mean and what it might feel like to have someone touching your head, right?

Bonnie: Mm hmm.

Joan: So, um, was it, I don't know, did you find that helpful to be able to talk about it ahead of time?

Bonnie: Mm hmm, yeah, yeah.

Joan: and I think we also said we could evaluate it, so if it wasn't working we could talk about that too.

Bonnie: But it's working fine now.

Joan: Okay, good.

In addition, Maple discussed a time when communicating with Core Members and asking for their feedback regarding a certain situation was relied upon to help create a more respectful environment:

I remember living at [one of the] house[s], and telling, everything, everybody was a bit out a control, things were crazy. I remember we kind of came up with this idea, what can we do to make the house a peaceful place? And, we kind of realized, I think people just needed some boundaries and limits set and that wasn't happening at that time, and uh, just basically kind of feel like pulled on people's life experiences, 'you guys have lived in community for a really long time and you know what makes it work and doesn't make it work. And we want our home to be a peaceful place where everybody can feel okay, so what do we need to do to make that happen?' And I remember that the Core Members were so engaged in this dialogue, like I was really surprised at kind of what came out of it and people were saying things like, 'well, if I'm having a hard time I need to go to my room to yell because it scares other people' maybe like too much teasing, or no name calling because that upsets other people. Um, and just people just keeping their physical boundaries so other people can feel safe, like wearing a bathrobe, keeping your door closed. It kind of seems like very basic stuff, um but it really helped people feel comfortable.

In addition to including Core Members in important discussions and hearing what they have to communicate, one assistant and two key-informants also discussed the power dynamics of the Core Member-assistant relationship, and the importance of acknowledging the inherent power difference. For example, in the assistants' focus-group Martha said:

People are dependent on other people, and what does that bring into the relationship, you don't want them to be mad at you, so? But, yeah, no certainly we try to do what we can around, sort of, you know, helping people [Core Members] to be able to express those concerns. Yeah, but again it's, yeah, some people are able and some aren't.

In addition to Martha's thoughts, Jake also had some thoughts to offer on the subject of power:

we are always, as assistants, always slightly in a power relation, and the power relation it's shifted, it's not equal. And I think we try to get it as equal as possible, but we know it's not, we know because there are limitations in the Core Members that, I think, there's reality and I think we need to accept that, um, but we shouldn't play it. You know, I

shouldn't play the power, I shouldn't say, you know, 'now I can do this to you because', and then I'm fine because you are not able to respond to that.

Jake articulates the value around accepting the literal power difference between assistants and Core Members and trying to make it as equal as possible, without ever misusing the power that an assistant has. He also discusses what happens if an assistant ever were to become abusive toward a Core Member:

if there's violence that occurs from assistants to Core Members then, I think, we have a policy that if it's serious enough it's the moment to leave, right away. You know, I think it's immediate termination around sexual abuse, physical abuse. And I think that's absolutely necessary. Because again, you know, like we are welcoming folks who have probably lived horrible things in their lives and once they're here and they think they're in a safe haven, like, what that one event could all destroy, you know is just so much. It could destroy years and years and years of L'Arche by letting somebody live out some kind of abuse for a longer time or even you know, so, yeah, we have to be, they would be very clear about that. There can't be at all, never.

In sum, the first main theme of capacity-building is an important protective factor in creating a safe and respectful environment for the use of touch. The types of skills that participants told me help to create a safe and respectful community are education and training, boundaries, and communication.

Community

This protective factor is obviously much more specific to L'Arche, as part of this organization's mission is to foster community amongst its members. In their interviews participants from every stakeholder group talked about how various aspects of community can increase the safety and respectfulness of touch at L'Arche. The protective factors within community that I will address are relationships, mutuality, and responsibility. I will start with a quote from Morgan's interview. Morgan described a time when a Core Member's father died and how this Core Member, who usually requires stricter boundaries, was able to receive emotional comfort from physical affection, perhaps only because this Core Member lived in community:

Being in the community, being surrounded by people means that they know people for a long time who can then use touch in different ways. People who have been friends with for years and it's okay you know, to hold their hand and it's okay to give them, you know, a hug in that situation. So, and it keeps people safe too because you can't totally wipe out a touch completely and, um, that would be really emotionally, whatever, yeah they [this particular Core Member] needed it, certainly more touch, during that time when they were living that [the death of a parent]. And the fact that they had a community and close friendships and people who knew them really well and who were able to offer that physical comfort and people that they could feel safe with, you know? Someone who they've lived with 10 to 15 years, it's okay to go and hug them and to be crying whatever, holding their hands, and I think somewhere else, maybe if the community wasn't there and maybe strictly following policy then whoever was on duty or whoever was in the house at that time and couldn't offer that support, I think that would really have made them unwell when they needed that.

In this quote Morgan noted the way that being in community with someone for many years can help keep touch safer when supporting people through difficult times.

Relationships.

In addition, several participants from the assistant and key-informant stakeholder groups commented that developing relationships with Core Members was an important part of the training they received on how to use touch respectfully with people. For example, Angie said:

I mean, every person, every Core Member's different. Some Core Members I wouldn't, I would ask before I even shook their hand. Like depending on their boundaries, and there's a process, I guess the training I received was getting to know each Core Member that I have lived with.

Several people from the assistants and key-informant groups spoke about the value and safety that come from the long-term assistants' group. For example, in the focus-group, Martha said, "I think one thing that happens in L'Arche that doesn't necessarily happen in other places, is that people get to know each other for 15 or 25 years and you know people transfer information". In addition, Drew said the following:

with the Core Members that might be the safety net, you know the long-term assistants, the deep committed relationships and the transfer of information so that, you know, that safety of touch might not be breached.

Further, in his interview Jake discussed the development of his understanding of Core Member's needs during his tenure as a long-term assistant:

but also because of the years I've been around I know with every Core Member there's a different kind of touch. So I know with some people, okay, that person, I won't hug, and that person I can give a pinky, and that person I can give a high five. So over the years you learn what's possible, and over the years you also learn what this person likes, and over the years it goes through stages.

Many participants in the assistant and key-informant groups mentioned the value in knowing people's stories; knowing people's struggles increases safety concerning the use of touch, because assistants know how to support Core Members accordingly. For example, Joan said:

it also helps to know people's stories, like ... what in life is going to trigger what for everyone? I mean, we can't, you can't anticipate everything, but I think, first of all it's community so five brains are better than one when it comes to remembering ... history is important and that too comes with relationship, being able to have lived through some things together, but also to know what type of thing um, might affect someone more.

Joan is saying that by knowing people in relationship assistants can better understand their needs and limitations and support them more appropriately. For example, Will said: "some people know they're loved by being touched and other people know they're being loved by being told. Not everybody needs both, some people need more than the other". In a similar vein, Joan said:

I mean there are so many variables, you know, people are so different, somebody, you know I can name three people off the top of my head who emotionally the negative impact does not exist if they're touched a lot, you know, in caring healthy ways. Um, but I can name three people who for whom it would be very, very damaging.

Joan and Will are assistants who have been with this L'Arche community between 15 and 20 years, and their knowledge of people's needs and limitations comes from years of experience in getting to know Core Members.

Person-centred approach.

Along with knowing Core Member needs, most assistants and key-informants told me that it was important to use an individualized or person-centred approach and always put the Core Members' needs first. For example, Beth said:

Safety and appropriateness depend on both the giver and the receiver, and I think that L'Arche does a pretty good job of promoting this. We are taught which Core Members it is safe to touch and which ones it is not. Safe and appropriate touch can include holding hands, high fives, hugging, kissing, arm around the shoulder, pat on the back. It varies so much from person to person, and I think that each assistant needs to figure out what touch is appropriate in each of his or her relationships with Core Members, within the rules of the community around respect and boundaries.

In addition, Morgan commented that the type of touch an assistant could use to comfort a Core Member depends on the person:

it can be physical where it's holding someone's hands if they're having a hard time or rubbing someone on the back if they're, yeah, if they're not feeling well, depending on who that is, and what's welcome. It depends on the Core Member and how you know them, yeah, how they receive comfort and support, what's good for them.

Further, Beth also said:

It [touch]'s careful and safe. The focus definitely is on respecting the needs of Core Members, while promoting their health and well-being. Though relationships and touch are mutual, the emphasis is on what the Core Members need or want, which is important in keeping them safe. Because there has been such abuse of touch in our society, everyone is very, very careful to take all measures possible to ensure that Core Members are safe and treated well.

In addition, Beatrice had similar sentiments regarding her relationship with one particular Core Member:

I come from a very touchy feely family. Like we kiss each other, you know goodbye and hello. And, um, so I remember going through a real journey too of, kind of, feeling sad that I couldn't be cozy, fuzzy, warm, cozy with her [a Core Member]. Um, but realizing that was *my* concept of love, and it wasn't necessarily what love *is* [emphasis reflects tone of voice]. And it wasn't a love that would be helpful, in the end, for her. But, something that had a boundary, but humor, and warmth, and care was there.

It is clear that Beatrice and Beth choose to respect the needs of Core Members first, even though in their interviews they expressed that they are both people who are comfortable expressing and receiving love through physical affection.

Assistants and key-informants discussed the importance of being aware of what they need to be well and how to meet their needs for physical affection. Some assistants discussed how they have people in the greater community such as friends, family, a loved one or partner who they could go to if they needed a hug, etc. However, there is a potential risk with international assistants. L'Arche routinely welcomes assistants from other countries and people whose natural support-systems are far away could find it more difficult to achieve this same sense of wellness, if they lack meaningful connections outside of the L'Arche community in the city. I discuss this issue further in the section on risk factors.

Moreover, people from the key-informant group spoke often about how it takes years to develop a strong friendship with Core Members; therefore, the type of expressive/affectionate touch that is then appropriate because of that deep and committed friendship looks different than that of a Core Member and assistant who have not known each other as long. For example, Joan discussed how she explains this concept to newer assistants: "I realized I'm pretty close with [two particular Core Members], that's taken some time, but um, uh, like sometimes I've said, you know, 'I can do this [hug a Core Member] because I've known people for a little longer'". In addition, Daniel, a Core Member who took part in the Core Members' focus-group, talked about a special friendship for him and how he often greets this friend:

Joan: How do you greet [friend]? Not a handshake.

Daniel: Oh, sometimes a handshake, sometimes, depends.

Joan: Sometimes you give him a nice hug.

Daniel: That's right.

Joan: Yeah. Why do you give [friend] a hug?

Daniel: Because we're really, we're actually like a small family.

Joan: Yeah.

Daniel: We see each other month to month, year to year.

In sum, participants reported that taking years to develop a friendship and creating room for affection within that friendship increase the safety and respectfulness of the use of touch.

Self-worth.

Participants from every stakeholder group talked about how stable and respectful friendships can contribute overall to Core Members' sense of self worth. For example, during his interview Jim said, "I think it's good when I reflect because it makes me realize that I have people in my family and people in my home that really do care". Further, Jake shared some of his thoughts about how L'Arche fosters a sense of self-worth:

Coming to L'Arche, and you know, the first time you're uncomfortable. You know, there are ten people telling you that you're a nice person. Like, 'really? Okay, thank you'. Which is important, and it's not happening only then, I think it happens on a daily basis. So it's just, like, little comments you know, 'you're a good person', you know I think for Core Members I think it's very important because they have probably heard for a long time in their lives that they're not a good person, and that they are a burden, you know, like, 'we don't want to live with you'. And they were, they were sent away from their families. To actually hear on a daily basis or a regular basis that 'you're a good person', 'we love as who you are', that's important.

Joan shared a moving story about a Core Member and the way that developing self-worth through friendship and community impacted her ability to protect herself:

I think the relationship part of L'Arche, the community part, the years and years and years, year to year of getting a consistent message of worth. Getting a consistent message of, um, trust and home and self-worth is, you know, shouldn't be underestimated. So, um, I think a very powerful example is a person, a Core Member in the community, um, several years ago was abused sexually by somebody outside of the community, um, on the person's way home from work. And yeah, it was pretty excruciating, it was pretty devastating for those of us, yeah, for her and the people around her. Um, and she, so, we were intentional again, it had been, but I mean this person's quite vulnerable to something like that, and so again we well, yeah, I guess I could say we were intentional but I don't, I don't know that, you know, going over the circles again, or whatever, I mean that might have had something to do with it, but it was more I think the community stuff, the stuff about um, her worth being told to her again and again and people saying, again and again, 'you didn't do anything wrong, you did nothing, you didn't do anything wrong', and 'you did the right thing'. So anyways fast forward to last year, and this person came home crying, um, because she had been approached by someone again and had you know, taken a few steps with this person

and had interacted with this person, consented to interact with this person to some level and then, and then said no, and kept saying no and kept, and then got up and left. So just the, um, that she was able to do that. I mean on one hand it was a really awful thing and scary for her again the second time, but it was actually also a thing to celebrate because she found her voice and she found her get up and go, literally, so I think that has to do with community because I really don't think that if she was living somewhere else without that input that that would have turned out the same way.

Working on a team.

In addition to self-worth, several assistants and key-informants discussed the value of working on a team and how this approach to providing care for people with developmental disabilities can increase the safety and respectfulness of touch. For example, Maple said:

if she's [a Core Member] having a bad week and you're the only person that's helping her and she's constantly ... kind of hitting and yelling, and I think people are going to have emotional responses to that for their own dignity and it's really normal. Yeah, so I think if we don't have that support and we don't have plans in place, like, okay 'you need to take space' or, 'we need to tag team and you need to switch' then I think touch can end up, just because of human reactions, yeah, I think that's a place where abuse could happen.

Mutuality.

In addition to working on a team, every key-informant and assistant that I interviewed discussed the importance of mutuality in helping to keep touch respectful and safe. Beatrice offered some other thoughts on mutuality:

L'Arche is interdependent I think, I think it's a really good thing that we offer. There's also something about mutuality and friendship that I think, um, that I think helps you be in there with somebody in a way that you might not if you were just kind of, being clinical with them.

Jake also had some reflections on mutuality and the use of touch at L'Arche:

L'Arche is, I think it's a model of living kind of as a family. You know? And if you transfer it to the family, you know, every family wants their children to be safe. You know, and that their family members to be safe [muffled], so that's the goal. The idea, yes, there's dysfunctional things happening, there's abuse happening in families so, but I think L'Arche tries to live the ideal picture of mutual relationships and in mutual relationships I don't want to hurt the other person, I don't want to hurt my friend. Like that's just not, that would be contradictory. That would not be mutual. So I think because you're living a really high ideal about mutual relationships we are giving a statement on violence and any hurtful

touch is not allowed in this house, in this community. Um, we are a non-violent community.

Joan also discussed mutuality in her interview:

it takes some time to get to mutual. I think our relationships between Core Member and assistants are much more about caregiver and care-receiver at the beginning, um, and even maybe between assistants it's more about my relationship to someone vis a vis my role at the beginning, and then so, mutuality takes time. I think mutual is about, yeah, it's about giving and receiving and also both people understanding or thinking of the relationship in the same way.

Joan explained that when people think about a relationship in the same way there are less misunderstandings and miscommunications. Concerning the use of functional touch in a Core Member-assistant relationship, being clear about people's roles and responsibilities therein and preventing miscommunications increases the safety and respect of the use of that touch. In addition, Maple said the following about mutuality and the use of touch:

Yeah, I think it's the thing with mutuality, and I think it was what I was talking about earlier, we all have our feelings and our perspective and I think there's a place for people to express that, um, but it's also in a way, it's not just saying 'this is who I am and this is what I want' and kind of forget everybody else in the world. It's saying 'but yes I do have an impact on other people in the world that I live in and I want to be the best person that I can possibly be so I can give who I am to the world'. And I think, yeah, so I think that really helps people be aware of themselves, but also their impact on each other. And I think if you did that I don't think we would use touch in an abusive way ... I think that's pretty fundamental. And I think everyone is held up to that standard based on their ability. Like, I don't think anyone would say, 'well, so and so just can't help that they're punching people'. Like again, it's okay, like [Core Member's name], like, 'no hitting, I need to take space from you right now'. So I'm not just sitting there helping her and she's pounding me and pounding me. Yeah, so, I think it's kind of that accountability and seeing ourselves as valuable human beings but also seeing that everybody else has a place.

In sum, according to Maple, mutuality is also about realizing one's impact on other people and trying to become the best person possible to one's ability. If people are continually encouraging each other to be the best they can be, according to her, touch would be used safely and respectfully. Jim had similar reflections to Maple. In his interview when I asked him what helped him feel safe when assistants used touch with him, he replied:

P: Uh, what makes me feel safe is because I know I've got my place and they've got their place, and we share a lot of other places, but basically we try to get along with each other. And if one person's doing something wrong, they'll tell him, and if another, but you know, it just, it just makes it better for that person to understand that they're doing something that they shouldn't be.

I: *So that honesty?*

P: Yeah.

In addition, Jake talks about mutual commitment, which relates to self-worth and also to helping someone to be the best he or she can be:

And it's so clear that we are saying 'we are not turning away from you because you have been in a rough time' you know. 'We are here for you, we support you'. And that's again the commitment level, and it's the friendship level. You know, it's like, to make sure to them, 'you are my friend, I will go with you through the valley no matter how long it takes because I would do the same with the friends I have [back home]'. You know, so I am not turning away from this person because of one argument, or one bad day. But I think, I realized Core Members very quickly question that. You know, are they still, do people still like them? And to reassure, 'yes, we do'. You know, yes. But we need to work on this because this can't happen, you know, like, how can we make this better? How can we prevent this from happening again?

Jake and Jim are both talking about that sense of mutual responsibility and honesty and helping one's fellow community members to be the best they are capable of. Therefore, there are some concrete aspects about the L'Arche approach to living in community and building long-term relationships that many participants told me worked to protect the safe and respectful use of all forms of touch in care-giving for people with developmental disabilities.

Risk Factors

I will now address the risk factors that I discovered during my field work. As will become apparent, not all the risk factors that I describe occurred currently in the community; some of the risk factors were events or conditions that occurred in the past and had already been addressed. In addition, some of the risk factors that I document were potential scenarios or circumstances that could more easily compromise safety. Assistants and key-informants expressed concern about some of these situations because they had witnessed them happening within the community. I will

differentiate between risk factors that are particular to care-giving, conditions which will be relevant to most care-giving scenarios, and those which are more exclusive to L'Arche.

Risk factors specific to care-giving.

Throughout the analysis I realized that there were risk factors that could be specific to L'Arche, and risk factors were specific to care-giving in general. That is, because I was witnessing or learning about a potential condition that could put people at greater risk did not mean that it was specific to L'Arche just because I was in a L'Arche community. Therefore, I had to probe the data to understand which factors were specific to L'Arche and which were specific to care-giving more broadly speaking. While I am aware that this study is about L'Arche itself, it would feel irresponsible to only address those risk and protective factors specific to L'Arche. L'Arche is unique compared to most other residential-care settings, which is why it is important to address how its distinctive approach and philosophy could affect how people are either safer or less safe when being cared for. However, L'Arche is also a part of a broader system of residential-care-giving. In order to increase the usefulness and general relevance of this study for the broader field, I will also address those risk factors and protective factors that I do not feel are specific to L'Arche itself.

Not respecting boundaries.

The first and perhaps most important risk factor that participants from all stakeholder groups discussed was not respecting boundaries. For example, Maple said, "I think if people just don't get kind of the need to set some limits sometimes I think our folks can be pretty unsafe". Maple also shared a story in her interview of one Core Member who needs stronger boundaries and what happened in the past when those boundaries were not honored:

The boundaries need to be really in place because sometimes being able to distinguish between friend and stranger and what goes on at work and what goes on at home. And, if people don't set those limits with her [a Core Member], like, I remember a young assistant

once thought it was really funny to call out names with her and she would just get really silly and funny, and then at that point she was still traveling on her own and I found her like on [a busy] corner screaming out body parts to complete strange men. Like, I get how that makes her very vulnerable and unsafe out in the world. Or if, and even things like tickling and giving a hug, like that can seem really, kind of benign at home, not a big deal. Then there was an incident at work where one of the guys that she was kind of like slapping his bum and tickling and she was doing the same thing back to her, which again, that puts her in a really vulnerable position. So sometimes like those boundaries need to be there, yeah, just to keep her safe.

In addition, Beatrice talked about how, when she first came to community almost 20 years ago, some of the practices that were happening then could have made Core Members unsafe:

I came to community at the, just sort of pre-David Hingsburger coming to the community and doing this huge talk about boundaries, and what happens to, what's the statistic of people who are in institutions, or um, I think he was in the community before, but prior to that it was, you know ... you'd see someone put [a Core Member] on their knee or, uh, you know. And maybe for some male community members there wasn't clear boundaries and there were, I think some hazy moments and some situations that could have been quite, um, hurtful for children, for females.

Maple and Beatrice conveyed that in the past when people's boundaries were not always respected, the environment could have been less safe and respectful.

Three key-informants and two assistants discussed in their interviews how visitors or newcomers in the community are more likely to use touch inappropriately with Core Members and not appreciate why certain boundaries are in place. For example, Beatrice said:

I experienced so many times people would come to the house, and they'd hug [a Core Member] and they would shake my hand. And I was like, 'well why is this, uh, you know, you don't know her, and you don't know me, you were appropriate with me, you weren't appropriate with her', you know? One time there was somebody who had come over and it was her second visit, and [a Core Member] was saying that her stomach was hurting and the woman just reached over and rubbed her stomach. So after I talked to [the Core Member] and just said, you know, 'if that happens you can always say I don't feel comfortable with that', and so, I just talked with the person and I said, like, 'if your co-worker said their stomach was hurting would you go up and rub their stomach?' And she sort of was like, 'No'. [laughter] Then, perhaps you wouldn't do it with someone else.

In addition, Angie had similar sentiments regarding some new assistants in the community:

this has always bothered me, and I speak up about it too, like, when a new assistant kind of assumes, has a false familiarity with the Core Members. Like they're hanging all over them

and they've only been here three months. Like, we don't do that. I see it a lot in other communities and in new people here.

Angie also had some ideas to offer to as why assistants might become too close too quick with

Core Members and why it is inappropriate:

Logically, if you're helping someone with a very intimate routine it'd be okay to hug them or sit and hold their hand [outside of the washroom], that's logically, but it's not okay if you just met them, you're assuming a closeness that just can't be there in two weeks, or whatever. I guess that's what I was trying to say. I see that a lot with [one Core Member in particular] she likes to be hugged and likes a lot of attention, but if an assistant is here for two or three months and really gets really that close to her, really, is that fair? Like, I don't know, I don't think so.

Joan also had some insights to offer about not respecting boundaries and why it is sometimes difficult for new assistants. She said that, even though the leadership team discusses the circles and boundaries in orientation, sometimes assistants do not fully understand the purpose for boundaries until they have a negative experience with a Core Member, because they did not respect his or her boundaries. Joan says:

I think one of the reasons it [disrespecting Core Members' boundaries] might happen is because of the vulnerability of both the Core Member and the assistant. So, the assistant who's newer is typically trying really hard to fit in, trying to be helpful, trying really hard to get to know people. And you know, we focus so much on relationships, so they want a relationship, and then as I said before like we come and the first, it can be brutal the first couple of weeks because you just are like dying to do something, right? And, um, so I think that places the assistant in a somewhat vulnerable position, um, because of that desire and need, and then the Core Members might um, also be, um, kind of like a magnet I guess, you know, like they, the one attracts the other. You know? Core Members who need I guess more structured boundaries might in front of that other assistant be vulnerable to being, I guess, a physical closeness that is not healthy for them, yeah. So yeah, how do we, we try to prevent it by doing the circles thing, by trying to really be clear about why, but to some extent it really, it's hard for people to get it unless, until, um, it becomes clear in other ways, like they need to live something more difficult I think, unfortunately. I mean, not always, sometimes with enough warning and enough insight you know, they can kind of step back.

This quote suggests that Joan deeply analyzed why new assistants might go to the affectionate point too fast in their relationships with Core Members. In addition, Will commented that the

affectionate touch that happens between Core Members and assistants is important, but that if not done properly it becomes a problem versus something that can be positive. Will said:

Or you can become too attached, you know, it can go both ways, where it's not a healthy relationship. Like, we've got, we've had some situations where assistants are just a little too icky close, it's not a healthy closeness.

I will briefly explore some of the examples of assistants not respecting Core Members' boundaries that I witnessed during my observations. The following paragraph is a documentation of such an example:

One of the big uses of touch at one of the houses is picking up a Core Member to help her get into her wheelchair. She does not have the use of her legs, so assistants have to help her get into and out of her chair by picking her up. One assistant on either side, each with one arm under the Core Member's leg, and one arm under her arm.

I haven't seen any assistants ask or verbally inform this Core Member that they're going to pick her up to put her in her chair, or likewise move her from her chair into her seat in the van (she also needs to be picked up from her wheelchair to sit in the van). While she is probably used to being physically assisted regularly, these interactions could be more respectful even if assistants informed her of what was coming next. "I'm going to pick you up and help you into the chair". Overall though, people are very gentle when helping her. It could also have something to do with the fact that this Core Member is non-verbal. Maybe people internalize this and unconsciously assume they don't need to communicate as much.

In another instance with the same Core Member I observed an assistant approach her to help her adjust in her chair so that she was sitting up more comfortably. The assistant did not inform the Core Member of what she was doing. Rather, she just picked up the Core Member and adjusted her. While the Core Member appeared to be more comfortable after she was adjusted and did not react negatively to being picked up, it could have been more respectful if the assistant had simply said something like, "You look a little uncomfortable, I'm going to help you adjust in your chair so that you're more comfortable". In addition, several people in the community talked about the wheelchair being an extension of someone's body; that is, it is just as disrespectful to touch someone's wheelchair without asking as it is to touch her or his body. Even though there seemed to be a good understanding of this concept in the community, what I witnessed with the previous

Core Member suggested that it is easier to blur physical boundaries with Core Members who are in wheelchairs. In the assistants' focus-group Drew had some insights on this issue:

If I were to push [a Core Member not in a wheelchair] into his room it'd be a much different scene than to take [a Core Member in a wheelchair] to take space and try and wheel him into his room. And I think sometimes, that touch, sometimes it gets blurred because it's not um, a body to body, you know? It's not flesh to flesh ... I think that's a chance for it to get unsafe touch because it's not your first nature to kind of see someone's wheelchair as their body.

Here Drew identified the possible risk factor involved in assisting people in wheelchairs and the need to be extra deliberate about viewing their chair as a part of their body.

In addition, Beth discussed her views on how sometimes the restraining kind of touch involved in protecting a Core Member from hurting himself or herself can be too much and can cross the same kind of body boundary where the assistant is no longer being respectful:

I think just [muffled] not physically restrain a person, and like trying to hold a hand over her [a Core Member's] eyes, and she was trying and obviously because she wants to see the blood [from picking at wounds], but, and I know that is part of it, but it still didn't feel right to see her struggling against that hand even though that they're [an assistant] trying to help her because they don't want her to pick because she's hurting herself, so it's hard, it's kind of a hard line, but yeah, I would still probably say that it's best not to be trying to restrain her arms or, yeah, or even trying to help her make healthy choices, you just have to know it's going to happen and do your best and help clean it up.

Beth is commenting on the complexity involved in supporting Core Members from hurting themselves and the ease with which a line can be crossed. In addition, Will talked about the role of power and vulnerability in not respecting a Core Member's boundaries while engaging in that protective or restraining sort of touch:

And it's true it can happen so much with somebody whose less vulnerable, whether you're thinking that it's for your own safety or whatever, you can be forcing somebody to do something, and with a Core Member you can cross that line so fast. And so there have been times where it's like, 'I could have handled that a little bit better', or, 'no wonder so and so hit me, it's because I wasn't respecting them in that moment and time, and this is what they were trying to do'.

Lack of communication and honesty.

The communication that is required to respect another person's boundaries is an important aspect of helping people to stay safe. Therefore, a potential risk factor in using touch in care-giving occurs when assistants are not communicating either with each other or to Core Members about what they are doing and how they are using touch. For example, Joan said:

like sometimes I've said, you know, 'I can do this because I've known people for a little longer', but I don't always say that so it's confusing to folks when people are trying to learn very quickly how to be with someone.

Here Joan is referring to the expressive touch that is a part of some of her relationships with Core Members, because she has been in the community for approximately 15 years. She tries to remember to communicate information to new people, but sometimes she does not. In this case the potential risk involved with not communicating in a way seems due to simple human error or forgetting rather than malicious intent. However, it still places the Core Member in a position more vulnerable to risk.

In addition, in Sally's interview I was asking her what she would say if she wanted to communicate that she was uncomfortable with someone touching her. She replied, "I don't know". I provided a couple examples of things she might say, "Maybe could you say, 'I'm not comfortable with that?'" to which she replied yes and nodded. However, after reading over this interview I was not left with the impression that this Core Member could really communicate that she was feeling uncomfortable, disrespected, or unsafe, which could increase the risk of unsafe touch.

Moreover, Will discussed one particularly heart-breaking story of an assistant's inability to communicate about a difficult experience:

There was one situation where an assistant was here for X months, and left really quickly, just vanished. And three years later I got a letter from him, and in the letter he said, 'I've only reached this point recently where I can actually talk about why I left, and it was

because this Core Member had just pushed all my buttons and it got to the point where I could overpower this Core Member and I scared myself and I had to leave'. And I knew because that Core Member did push people's buttons, he had some less than endearing qualities, but he could easily overpower him to get violent and this former assistant saw that potential in himself and it scared him. So basically he just had to leave, but for him to take 3 years to reach that point ... I mean it's sad that he couldn't go to anybody at that point and say, 'I'm' you know, yeah.

In this situation the assistant was not able to communicate with his team of assistants what he was going through and how the frustration that he was experiencing caused him to confront his own potential for violence. In the assistants' focus-group Drew had an insightful comment to offer:

We need to be honest with ourselves and I think L'Arche is really good at that. Like, sometimes it's this ideal, idealized Nouwen book or Vanier type writing, or whatever, and actually they're actually really good at breaking down themselves, you know, in their writing, you read their writing and you know, they are transparent, they talk about times when, you know, Vanier talks about, but then sometimes we glamorize it or we glaze over those hard times and see that there is so much depth so much richness, but you need to kind of put on this facade of you know, things are great and we have great relationships, we have great boundaries and yet, yeah, I know that I've lived both sides, which helps me appreciate the boundaries a little bit more.

Drew's statement suggests that living at L'Arche can be very idealized, which can make it difficult to be honest about the aspects of community life that are not so great. Even though this risk factor is about communication, it is also about unrealistic idealism, which is a risk factor more specific to L'Arche.

Vulnerability.

Vulnerability was a consistent risk factor that people from the assistant and key-informant group discussed. Earlier I addressed the vulnerability that new assistants feel and the increased risks which is involved with that. Jake discussed a form of vulnerability that comes with being a new assistant:

I had the situation once where a fairly new assistant spoke out about something which happened when I wasn't in the house, and she wasn't sure if she should say something because she was just new. You know, and this other person was around for a longer time. And it was good she spoke up because there was something going on that wasn't okay. Um, and so we needed to address that and we were able to work it out, but so I was very

grateful that she had the courage, because I think if you are fairly new you're going to think, 'oh probably that's okay, what am I supposed to say?'

Here Jake referred to when a newer assistant felt that she should simply trust what a more experienced assistant is doing by virtue of his or her longer experience. Jake discusses the courage that it took this newer assistant to speak up about something she saw.

With respect to the vulnerability of Core Members, four assistants and all key-informants discussed Core Members' inherent vulnerability as a potential factor of risk with using touch. For example, in the assistants' focus-group Martha said, "I think we do do everything we can, and I think it's just kind of to recognize that's there because our people are vulnerable there's an implied, an implied vulnerability that's there you know?" In addition, Joan said:

there's a lot of checks and balances with each other I guess. And so to the extent that that gets translated into um, anywhere, into relationships, with a new person you know? Um, into relationships with people at work, or just on the bus, you know, so, um yeah, I think people are still pretty vulnerable. So I think we have to remember to also give, continue to give people tools and educate the Core Members around what's good, what's healthy, what's not, you know?

Joan's quote indicates that the assistants try to make sure that checks and balances are brought into Core Members' relationships both within and outside of the community, but even then people are still more vulnerable to abuse. In addition, Jake discussed the vulnerability of non-verbal Core Members and how even when assistants try to be respectful of what they are communicating through body language and other forms of communication, they do not have the ability to vocalize whether they are being hurt or exactly what hurts, etc. This situation is obviously an inherent risk to providing care to people who do not communicate verbally.

Staff-turnover.

In addition, other risk factors pertaining to the use of touch specific to the broader field of care-giving include high staff-turnover and when new assistants miss orientation. For example, here is a segment of my conversation with Beatrice:

P: I'd say another thing that can make L'Arche very vulnerable is our transition, we just have such a huge transition, you know?

I: Like turnover?

P: Turnover, yeah. And I, yeah, so you don't always have people holding the story or the history or the, you know, it's not, you know, and I think that's everywhere in other organizations as well, but that, that kind of turnover can also, yeah, leave people a bit vulnerable.

Typically L'Arche assistants come for one or two years at a time, at which point some leave and some stay for longer terms. Many L'Arche communities also host co-op students who stay for four months at a time. As she points out, staff-turnover is not a unique problem to L'Arche, but it is a problem that can increase the risk of disrespectful touch, or touch that does not honor an individual's boundaries. If we recall Joan's interview where she discussed the vulnerability of new assistants and Core Members with regard to expressive touch, it is logical that the more frequent an organization welcomes new staff the more risk there would be in engaging in this kind of touch.

Further, some assistants miss the orientation program when they enter the community. Due to personal timing where they could not arrive at the community when the orientation was being taught, or because of how some assistants enter the community as volunteers first and then through casual part time work which becomes more involved over time, some assistants do not go through the formal orientation program. For example, Beth said:

Unfortunately I missed orientation week, so I wasn't actually all that prepared for how to use touch. At one point [an assistant on the leadership team] went over the circle diagram of boundaries, but that was about it. Some things were taught as I learned routines and was told about Core Members, but for the most part I just sort of observed and found my way.

Here Beth communicates that, even though she learned through conversation and observation, she did not feel very prepared to use touch with Core Members, because she missed the orientation program. Missing training is a risk factor because, even though Beth perhaps received much of the same information in other ways, she missed out on the structured program where all of the

important information is compiled into a bundle of learnings to prepare new assistants for their work term.

Personal-care risks.

Other risk factors that three assistants and two key-informants discussed was the speed with which new assistants are on their own doing personal-care for Core Members and also that personal-care routines happen behind closed doors in the washroom or Core Member's bedroom, where an assistant is alone with a Core Member. For example, Beatrice said:

But I always think like, man, you know, when you're training someone, they watch you, first it's for a while, they watch you for a while, then you watch them, and then that's it. Every time someone's in the bathroom alone with somebody, it is a huge risk that we take.

Further, Angie said:

Well, this might, might pose as a risk, I'm not saying that it does, but the fact that a new assistant comes, and they have a week of orientation and then they're thrown into personal-care routines. And, that's always made me nervous. Yeah, just it has to be like, it has to be, it's a job, so ... And it's not just L'Arche, that's not L'Arche ... It's like, in the group home I worked at there wasn't half the training we get here.

Angie and Beatrice indicated that there is a risk involved with new assistants providing personal-care and also when Core Members and assistants are alone together in the washroom.

Risk factors specific to L'Arche

Here I examine inconsistencies between L'Arche communities, the way that cultural differences can be a risk at L'Arche, discrepancy in personal-care policy, and how touch may become too boundaried.

Inconsistencies among L'Arche communities.

Two assistants and one key-informant talked to me about inconsistencies amongst the L'Arche communities in Ontario with relation to the use of touch. Beth said:

I know it does not happen in every community, but part of the international L'Arche charter says that only females help females and males help males. This is a huge factor I think in keeping people safe.

In addition, Jake said the following:

I have not lived in another community, but I've been around other community members from other communities and I've seen how touch is maybe used there, so that sometimes, maybe, I was questioning certain things.

Jake also said that he is aware that his perceptions might be inaccurate, but nonetheless he questioned practices in other communities. In addition, I know from personal experience that there are some inconsistencies between communities when it comes to touch practices and boundaries and skill building. The following passage is an entry in my field-notes about this issue:

In my [assistant] interview this morning the participant was saying that sometimes people outside the community or people who don't know the Core Members very well can harshly criticize the assistants or the community for not hugging the Core Members enough or not showing enough affection. It's so interesting because my previous experiences lead me to believe that L'Arche was much 'touchier' than maybe it is. And perhaps some communities are different, and this could be a more major learning from my work here, is how inconsistent the communities can be, which partially reflects that each community establishes its own culture, but also that some cross community conversation could be about how people are trained and taught about touch. Also, it shows that people are so respected in their individual needs for touch that out in the [broader] community people who support Core Members do not compromise on those values, despite potential criticism, etc.

Dual roles.

In addition to inconsistencies amongst the communities, two key-informants and one assistant talked about dual roles and power within the community. Recall Martha's statement in the assistants' focus-group regarding not wanting a person who is caring for you to be mad at you, and then the power dynamic of dependence that sets up in the Core Member-assistant relationship. Further, Beatrice discussed the role of being friends with one's coworkers, who might also be your superiors, and the complexity involved in negotiating aspects of that relationship:

and as assistant too, like my friend is also my community leader who has to talk to me about things that I don't want to hear sometimes. You know? Like, that's a hard, that's very difficult to live.

In addition, Jake discussed overall the issue of being friends and caregivers:

Certainly a critique I think L'Arche is hearing often [assistants being friends and caregivers]. Um, but then again I think we are living something different. We are living, we are particularly choosing to live community, and in community you cannot live, you cannot, I think you cannot be professional in the way of saying, 'I'm your caretaker, I cannot be your friend'. Community would be dead, it's just, it's not possible. Because community living is so much about mutual relationships and so much about living daily life together in all its ways. It means, so, it would mean, if I would go clearly by [muffled], someone [a Core Member] could not come here [to Jake's house] for an overnight because it would totally blur the boundaries, what's happening here. Um, so, that said, I think that in L'Arche we need to be very clear that, yes we know that that is often something criticize, but we need to be very strong in that aspect that we are living community, right? Like that's the clear goal that was, Jean in the very beginnings said, 'I want to live community with these people'. And I don't necessarily look into, 'am I allowed to do this or do that?', and what kind of law and ethics, and that goes into it, so, I think that is an important point to make.

Here Jake is trying to address some of the complexity involved in the Core Member-assistant relationship at L'Arche. He also says:

Is this relationship unprofessional? I would say no. I think it's, like, why can I not be a, because the thing is with L'Arche too though, in certain areas we are choosing to ask outside professionals to help the Core Members, so we know we have limits. In a way of, okay, like, if it's too emotion, like if someone needs behavioral therapy? Yes, we are not doing it, we are going to the outside, and say, and they [outside [professionals] don't go to parties [with the Core Member] and have a professional relationship, then it's the behavioral therapist and the Core Member, and they are not living community. So, therefore they are not going to go out to a movie, they are not, that would then be unprofessional if that person would then go over there for an overnight... I think L'Arche is doing, like, it's going kind of in the middle somewhere, like we are living it differently, we are aware of we can't fix it all, we need help from the outside, we do this, these are our professional relationships. But because we are choosing to live community, we cannot be professional. Like, we have to be professional in certain ways, but, we need to have the door open to all the other stuff, otherwise L'Arche is not possible. It's just clear, it's not possible.

Cultural differences.

In addition, several assistants and key-informants discussed how L'Arche communities host assistants from many different countries and cultural differences for international assistants could act as a potential risk factor with the use of touch. For example, Jake said:

don't assume that certain touches are okay. And I think that is very difficult, uh, particular because we welcome people from so many different cultures and I think that's something

we can work better on. Because in different cultures touch is just interpreted differently. And so, I think we need to be aware of that. And I think we need to invite people who come from different cultures to explain it to us, so that we can say, 'okay'. You know? Because, otherwise we are not welcoming them in how they, in who they are. You know?

In this segment Jake commented on the cultural differences when it comes to touch and that people's previous culture needs to be learned about and respected. But also they can be supported in understanding the new culture of touch in Canada and at L'Arche. For example, Alicia, an international assistant said:

I'd like to say, from my perspective I'm maybe different than you, like, have experience to come and maybe I can say again, from a new culture. So always, like from my culture, like this [Canadian] culture is more polite. We are different, we are more like, uh, temperamental, yeah like when we are talking we are louder, we are more touching you know? Like more touching in communication simply.

In addition, Beth, who was also an international assistant, disclosed that she had a very difficult time moving from one house that was very affectionate to another house with more structured boundaries. In her interview she said:

my family's very touchy, but I think that helps [previous] house feel so much like family too. My family is always hugging and [muffled], like we're always telling each other that we love each other, and it's true, it's kind of drawing me in because it's that aspect of touch that adds a very personal element to a relationship.

These participants are talking about supporting international assistants to know how to meet their needs for love and touch. Most assistants in the community have partners, family, friends, and their own community outside of L'Arche where they can go for a hug if they need one. However, for the international assistants who are so far away from home and really only have their friends at L'Arche, where do they go when they need a hug, especially if they come from a culture that is more touchy? Beth described her transition from the first house to the second house:

It's challenging to have touch as a love language and I don't think it's very well supported because people are so careful. Yeah, like when I was really struggling I was told to find other ways to feel love. I very much felt, and I was told that basically that I shouldn't have needs. Yeah, like I really walked away from that feeling really guilty and feeling like I had to really re-assess my life and being in L'Arche, and it was like, well, we're talking about

mutual relationships, why should I feel guilty for needing love?

Beth understood very well the need to protect Core Members because of their increased vulnerability and the importance of honoring boundaries in her interview. However, there was something about the definition of mutuality that seemingly gave an understanding of this concept which meant that both people's needs should be met all the time, which could be a potential risk factor. From my experiences in the community I do not believe that anyone disrespected her need for love, but ultimately she ended up feeling guilty for being a physically affectionate person, which is truly unfortunate.

Personal-care policy discrepancy.

In addition, there was some discrepancy in the male-male, female-female policy in personal-care routines. Beth communicated that she was “concerned for the increasing prevalence of small compromises from the original female-female, male-male initiative in the charter, which I think could potentially put Core Members at risk”. In her interview she mentioned that there was a time when she was even asked to learn a male Core Member's personal-care routine, which included his bath, which made her very uncomfortable. However, when I asked key-informant, Joan, about this policy she told me that it is rarely compromised, except for when assistants are in extreme need of more assistance in an emergency situation, and the only other staff person in the house is of the opposite sex. Joan indicated that this decision also would never be made lightly or without conversation. Therefore, it appears as though there has been a miscommunication about what is okay in terms of policies with helping Core Members with their personal-care. In this community's policy about personal-care, it says, “An assistant of the same gender should always provide personal-care. The Homes Coordinator must approve exceptions to this”. However, the policy does not specify the circumstances that make exceptions appropriate or the duration in which these exceptions are meant to occur. That is, are they meant to be brief or can the Homes

Coordinator approve a female assistant to permanently help a male Core Member, or vice versa, with his bath? It is probably because the Homes Coordinator must decide on a case by case basis. However more specific wording regarding this issue could be helpful to clarify when it is appropriate to compromise on the male-male, female-female personal-care policy.

Too “boundaried”.

Further, two assistants and two key-informants talked about how the community is perhaps too boundaried, which was a term one participant used to explain that there needed to be more of a dialogue about healthy touch. For example, Beatrice said, “I think we explored a lot about how we have the boundaries, I’m not sure we’ve explored enough about how we do the healthy touch”.

Beatrice also commented:

It’s better to be boundaried than to be too, yeah, all over the place, and warm and fuzzy. But there’s some sort of a middle ground there and I think it’s important to keep talking about it

Beth also said:

Though good touch certainly exists within the community, there is much more of an emphasis on what not to do, and in some ways it even evokes a fear around even touching in a way that is healthy or good, that maybe someone else wouldn’t approve of it. As a person who receives love by touch I’ve felt at times like I wasn’t allowed to receive love through touch from Core Members or that I had to be super careful because another person didn’t receive love through touch and would think that me hugging someone for example was not okay or something.

These participants are talking about learning how to do safe touch and boundaries at the same time.

To review, the above findings represent the data from 11 interviews, 2 focus-groups and six-weeks of observational field-notes. In the next section I expand upon these findings relate them to the literature to build additional theory and practical approaches to help caregivers to know how to use touch respectfully and beneficially with adults with developmental disabilities.

Discussion

I will now explore the major themes and categories which I have presented in the findings section. I will elaborate by tying these findings back to the literature and adding personal reflections in order to ultimately present the unique theoretical and practical contributions of this research project. For parsimony's sake I will not discuss everything that I have documented in the findings section but only those themes and categories which beg further discussion because they could be important factors in the overall contribution of this research. Therefore, I will elaborate on some of the main themes, by examining the nature of touch and risk factors and protective factors. I will first look at significant aspects of the nature of touch, and then I will discuss the prevention and promotion aspect of this study. Even though Felner et al. (2000) explain that risk and protective factors occur on individual and organizational levels, it was impossible to neatly tease apart the factors so as to present these categories separately. However, I explain how each protective and risk factor is related to the organizational and individual levels. After I discuss the risk and protective factors I will summarize the theoretical, ethical and practical contributions of this particular study and its transferrability to other care settings, and I will end by discussing areas for future research and my action and dissemination plan.

Nature of Touch

Throughout this research study participants told me that they felt touch was used respectfully, gently and carefully. They said sometimes it was hard to maintain established physical boundaries, especially when Core Members with more structured boundaries were upset, but that they understood the need to keep the boundaries. Through my observations I saw touch being used in all the ways that Gale and Hegarty (2000) delineated, such as functional, procedural, expressive and therapeutic. Within procedural and functional touch included helping people to eat, dress, bathe, administer medications or a diabetes blood test, to comfort and support, to prompt or

communicate, and also to help protect people from hurting themselves or others. Expressive touch was very individualized and included holding hands or linking arms, hugs, kisses on the forehead or cheek, tickling or other playful kinds of touch. I noticed some gender differences with expressive touch, and while I do not have any hard statistics, there were definitely more women than men being physically affectionate, although male Core Members and assistants did also engage in expressive touch. Therapeutic touch involved stretches, massage and physio-therapy type activities.

The fact that this community was able to find a way for expressive and affectionate touch to be a part of the day to day interactions was very informative. Even though a few assistants felt that the community was too boundaried when it came to expressive touch, the fact that they were, for the most part, able to achieve a healthy way of showing affection with one another was impactful. In the literature there are often more restrictive approaches (Field, 2001), such as no-touch policies, which forfeit peoples' ability to engage in this very natural form of interaction (Zur, 2007), which is important to our well-being. As I mention in the literature review, people with disabilities spend a vast majority of their time with caregivers, therefore, if caregivers were not allowed to ever express affectionate touch with clients in healthy ways, I was concerned about from whom and how people would get these critical forms of affectionate touch. And if there was such a starvation for affection, would that not then make them more vulnerable or desperate for it? Therefore, through this research I have learned that L'Arche does support its community members in engaging in critical expressive touch, but on an individualized basis and with boundaries, education and communication, which helps to make it safer.

Community touch and implications for sense of community.

In my observation notes I reflected on how various forms of expressive touch during community time contributed to a feeling of unity and mutuality. Holding hands daily around the

table was a connective gesture that focussed people on the intentionality of the communal moment. When I reflected on these moments in my fieldnotes I wrote that I felt a palpable strengthening of the sense of community (SOC). At the time I thought it was a powerful expression of the *shared emotional connection* aspect of McMillan and Chavis' (1986) original theory of SOC. However, upon deeper analysis I realized that it was possible that these moments facilitated three of the four aspects of McMillan and Chavis' (1986) sense of community theory. First, the types of community touch that I observed and experienced during my fieldwork fostered feelings of belonging and acceptance, characteristics of the *membership* aspect of the SOC theory (McMillan & Chavis, 1986). Holding hands together daily during prayer or participating in a weekly community get together supported a sense of boundaries of who belonged to the group, which is a characteristic of membership. Emotional safety is an important aspect membership, and as Angie suggested in her interview, the fact that individuals, including people who did not usually like to be touched, felt safe to reach out to their neighbour to hold hands at the dinner table, or dance together at a community event, suggests that people felt emotionally safe during these times. In a later article, McMillan (1996) reconceptualized the original SOC theory and renamed the four dimensions of this theory. The term he attributed to membership was *spirit*. McMillan (1996) stated that the emphasis was on the "spark of friendship that becomes the Spirit of Sense of Community" (p. 315). It is apparent that these habitual moments where community touch is fostered are moments that kindle and nourish friendships.

Next, according to McMillan and Chavis (1986) the aspect of *influence* has to do with feeling as though one matters to a group and the group matters to its members. The act of reaching out daily and holding the hand of the person next to you was a strong expression of people communicating that they felt they mattered to the group. McMillan (1996) re-characterized this aspect of the original theory as *trust*. This element of trust involved being clear about community

norms and processes, which helped individuals to feel a sense of stability in their environment.

The idea that each day individuals can count on the fact that before and after dinner they will hold hands and pray is an important community norm, which contributed to the trust of the group.

Most poignantly however, the aspect of *shared emotional connection* was truly fostered during this daily ritual and other community events, such as the birthday party that I cited in the findings section. Community touch fosters this aspect of the SOC framework for several reasons. First, McMillan and Chavis (1986) discuss that a shared emotional connection is based on a shared history; when participating in these ritualized events there is a real feeling that “*I’m doing what this and other communities have done every day for decades*”. In addition, according to the “Contact Hypothesis” of this aspect of the SOC theory, “the more people interact, the more they will become close” (McMillan & Chavis, 1986, p. 13). Therefore, the frequency of these daily prayer interactions or weekly community worship meetings fosters this aspect of SOC. In addition, a tangible spiritual bond is fostered by this act of holding hands at prayer time, and according to McMillan and Chavis (1986), spiritual bond is an important aspect of shared emotional connection. McMillan (1996) later renamed shared emotional connection as *art*, and said that art represents the transcendent values of a community. He said that the basic foundation of art is experience, and in order to have this experience it is essential that people in the community are in regular contact with one another. This contact needs to be of “high quality” (McMillan, 1996, p. 322) or have deep meaning, which then allows the experience to become part of the community’s collective heritage. It is clear that this aspect of daily life at L’Arche represents a meaningful form of physical and psychological contact, where relationships are strengthened and spirit is nurtured. In sum, all of these aspects of community touch work together to facilitate a strong sense of community. As previously discussed, Dunne (1986) stated that the L’Arche model was an exemplar of the way that sense of community can be actualized in our society. He said that a

strong sense of community in greater society demands, to some extent, the same conditions as L'Arche. This form of community touch appears to be one of the ways that L'Arche facilitates a strong sense of community amongst its members.

Prevention and Promotion

Discourse of respect.

The assistants employed a general discourse of respect regarding the use of touch with Core Members, which indicated to me that these respect practices are habitualized in the assistants' daily routines and fostered from the organizational level. Assistants asked first before touching most of the time and were easily able draw on their knowledge of how to show respect to Core Members. During my observations assistants were very open with Core Members about discussing if they were comfortable and communicating when they needed space. In addition, it was quite clear to me that Core Members felt respected regarding the use of touch, which was most striking in Jim's interview. The confidence with which he stated that assistants would not hug him without asking first was very meaningful and indicated to me that this individual felt deeply respected in his home and community when it came to the use of touch. To Jim, a respectful environment was synonymous with L'Arche. Prilleltensky et al. (1996) state that an organization's ability to foster an ethical climate is affected by whether it cultivates an environment where ethical principles are not so far removed from the overall morals that inform them, such as respect, justice and compassion. It was more than apparent from the data that this L'Arche community was able to foster a respectful and ethical environment where individuals felt honored and safe.

Communication as a protective factor.

In addition, with regard to communication as a protective factor, even though communication is something that happens at the interpersonal level, it was apparent to me that this

L'Arche community supported and taught people how to talk to one another about difficult experiences and seek advice and support from one another. For example, several assistants told me that if a Core Member is being repetitively aggressive toward an assistant, sooner or later the assistant's patience will run out. Therefore, if assistants are having a hard time and they honestly communicate to others and reach out for support, not only can this communication help the assistant to feel better but also it helps keep Core Members safer because it mitigates the likelihood of assistants being unconsciously (or deliberately) rough, or worse, with Core Members because they are angry. The extent to which honesty and open communication skills are supported and taught within an environment has a direct protective impact in that environment. Openness and honesty are even written into this L'Arche community's standard code of conduct policy, which suggests the significant status in which these values are held.

Communication as a protective factor relates to a feeling of safety that is discussed in Walsh-Bowers et al. (1996) research with social workers. These authors found that it was important for social workers to feel safe to ask questions, reveal their vulnerability and to seek advice from their colleagues and supervisors. I wonder what would happen if these L'Arche assistants had to pretend that the difficult situations they experience did not exist, or feared judgment from people in leadership positions? There would unquestionably be more stories like the one Will shared in his interview, of the assistant who left the community abruptly because he was extremely frustrated and upset, and felt that he could not talk about it.

Specifically however, when angry or aggressive feelings are toward a person for whom one is supposed to be caring, a person with a developmental disability, a person who is more vulnerable, these feelings are not only difficult to acknowledge, but then acknowledging them can make one feel, as Drew put it in the assistant's focus-group, like the "spawn of satan". The truth is I cannot think of a caregiver who has not gotten frustrated when faced with an aggressive client,

Jean Vanier admits to experiencing these feelings himself (Vanier, 1989). But there is an image that comes along with being a L'Arche assistant, and the descriptions of violent and aggressive do not capture this image. I have heard people use words like sacrifice, martyr, and angel to describe L'Arche assistants. Even though I believe that most L'Arche assistants, myself included, firmly object to these descriptions, there is an aspect about L'Arche assistants that is idealized, which I would argue to be a risk factor associated with L'Arche. When people feel as though they need to live up to unrealistic standards, and they are pushed to the point of breaking and have no safe place to talk about it, they are more likely either to hurt someone because they are so frustrated, or to just up and leave, as did the assistant in Will's story. This risk factor has to do with breaking down excessively idealized images of staff and also creating safe spaces where people can be open with one another about what they are struggling with, and not worry about appearing unprofessional or incompetent (Walsh-Bowers et al., 1996). Aggression is not unique to L'Arche, but perhaps the excessive idealism associated with being a L'Arche assistant can make it more difficult to be honest with one's fellow teammates when those aggressive or angry feelings boil up inside. Acknowledging this issue of idealism with assistants could help them to be more open with any difficult experiences or feelings they may encounter, thus helping to protect the safety of the environment for Core Members. The extent to which a L'Arche community fosters this protective policy of open and honest of communication amongst its staff can act in a compensatory fashion, reducing the likelihood that existing vulnerabilities will be activated when conditions of risk are present (Felner et al., 2000).

Mutuality, friendships, and power.

Moreover, some participants discussed the complex power dynamics of care-giving relationships at L'Arche which very often evolved into friendships through years of living in community together. As Martha pointed out in the assistants' focus-group, because conflict is

almost inevitable in any friendship, what if your friend, who is also your caregiver, is mad at you? In the literature this ethical issue of dual relationships is argued to put the client at risk (Kitchener, 1988; Pope, 1990). This issue also relates back to the business approach that is discussed by Saxton et al. (2001), where participants stated that they wanted their relationship with their support worker to remain “business-like” to preclude the possibility of offending their caregivers by not having to choose whether or not to be their friend. However, the data suggests that not only are assistants cognizant of this issue and the power dynamics of their dyad with Core Members, but that they care about empowering Core Members and being the best caregivers they can be. In Jake’s interview, he discussed the power differential between assistants and Core Members. He said that the assistants try to decrease the power difference as much as possible, but he admits that it will always be there. Therefore, the ethics of the L’Arche approach to care and friendship with Core Members need to be reconsidered because L’Arche communities do not just provide “treatment”, they are also intentional communities of care. As Jake put it in his interview, in this community they tried to live an ideal of mutuality, and in mutual relationships people do not want to hurt their friends. It seemed as though this community had achieved a balanced way of living community life as friends in a way that fostered mutuality and honored power differences so that power was not misused. In Cushing’s (2003b) framework of mutuality, she says that it is very difficult to navigate the ambiguity of a relationship that is one of care, but also strives to be one of friendship. It is a complex and ambitious undertaking, but this community appeared to be walking all of these “grey areas” with grace, respect and communication. And for the most part, when people made mistakes they apologized and tried again. Further, as Beatrice discussed, if assistants were not willing to apologize or accept their faults, then they would potentially be asked to leave the community.

An ethic of care is thus appropriate for relational ethical decision making, such as that which is found at L'Arche. By making ethical decisions in a discursive and participatory way, caregivers can focus on the less apparent inequities that are embedded into the composition of their relationship with Core Members, thereby fostering mutuality within the dynamic. In previous research, it was found that assistants characterized mutuality as an approach to relating to all people with mutual respect, support, and authenticity (Cushing & Lewis, 2002). Working toward mutuality merits the extra effort required, because it enriches the experience for both client and caregiver (Cushing, 2003b).

Moreover, there were several aspects of Cushing's (2003b) framework of mutuality that applied to the use of touch at this L'Arche community. First, elements of reciprocity within the Core Member-assistant relationships were fostered through expressive and comforting touch. Assistants talked about how, when they were having a bad day, a Core Member might reach over and hold their hand or rub their back. In addition, Angie discussed the importance of the physical connection she had with a Core Member at church, and how this caring touch contributed to her sense of comfort during worship. This capacity to reach out and give back to the assistants through touch was an important way that Core Members contributed to the mutuality of their relationships with assistants. The "alternative currency" that assistants created for Core Members allowed them to "give back" to assistants through the ability to use comforting and expressive touch.

Second, that Core Member-assistant dyads are always initially and fundamentally instrumental relationships was evident in this community. In the data it was clear that assistants were cognizant of aspects of their care regimen that would only ever be instrumental, such as personal-care routines. Assistants talked about how they supported Core Members in maintaining their boundaries during personal-care. They did not allow for any playfulness during this time, because this could bring the care routine from a functional place to an expressive one.

Acknowledging this aspect of their relationship also was important to the safety of the environment, because it allowed for people to be clear about their roles and responsibilities to one another.

Third, solidarity is an integral element of Cushing's (2003b) framework. As previously discussed, this dimension encapsulates "power sharing and mutual relations as part of a moral, spiritual and political project of solidarity with those who are marginalized ... Assistants often describe their desire to make the effort to reach across inequality to cultivate common ground in relationship with others as a way of recognizing and alleviating their disenfranchisement" (Cushing, 2003b, p. 89). The community form of expressive touch that was found within this study appears as a particularly powerful example of touch that exemplifies solidarity. The act of holding hands during daily prayer seemed to call people back to the intention of Jean Vanier's original mission of L'Arche and indeed, cultivate a common ground of equity between the Core Members and assistants.

Last, Cushing's framework reminds us of what is not mutuality: the labor of care. She says that it is important to remember that care-giving is work for which caregivers must receive credit. The way in which assistants were supported in looking after their own emotional well-being was an important aspect of this characteristic, which I will discuss more fully in the following section.

Caregivers taking care of themselves.

Another way that this organization employed a feminist ethics approach was by supporting caregivers to take care of themselves (Wendell, 1996). Research shows that when caregivers continuously put the needs and wants of clients before their own it can lead to caregiver burnout and resentment, which is a leading contributing factor in abuse (Saxton et al., 2001). Through this honest and open approach to communication in the community, assistants are supported in naming when they need a break, when they are tired, when are frustrated, etc., and if needed a team

member will step in for them. This strategy to caregiver well-being is obviously deeply connected to working on a team. However, if an assistant was working on a team that did not care about open communication or ensuring that assistants took care of themselves as well, then this situation would not be healthy either. Therefore, organizational circumstances that foster a respectful and safe environment when it comes to the use of touch in a care setting include working on a team that supports caregivers taking care of themselves.

Flexibility around routinized tasks.

In situations that were more routinized and repetitive, such as helping a Core Member with eating, the assistants did not always ask prior to touching a Core Member. Even though the general rule is to ask before touching (Hingsburger, 1995), I feel that this is an example where this rule could be more flexible; the Core Member most likely expects what is next, such as another bite of food. In my fieldwork I noticed that once the task of helping someone to eat had begun there was an understanding between those two people about the rest of the task. There was meaningful eye contact between the two people and sensitivity on the part of the assistant of how the Core Member was doing and if he or she was communicating anything non-verbally. Personally, I also think it would be annoying if the assistant were to ask the Core Member before every single bite of food. Therefore, while the general rule of “ask first, touch second” is a safe way of approaching the use of touch with people with disabilities, for daily routine tasks people told me that the importance of asking each time became more flexible. In addition, as people get to know each other they develop more sophisticated methods of communicating with each other, which could affect the way that assistants communicate with Core Members during these routine tasks. Therefore, meaningful eye contact and reading body language could take the place, to some extent, of verbally asking or informing Core Members.

Incorporating feedback.

Assistants and key-informants discussed the importance of not taking critical feedback personally. These data indicated that it is more important to protect Core Members than it is to coddle fragile egos or people who did not understand how to use touch respectfully with people with disabilities. It was as though the participants were saying that there was always a space to make minor mistakes, to talk about issues and change future behaviour if an assistant had made a mistake. However, if the assistant could not take the feedback and incorporate it into his or her way of being an assistant, then as Beatrice said, “go, because it’s not safe for you to be here”. This idea dispels a lot of the “warm, fuzzy, everyone’s welcome here” feelings that one often gets when thinking about L’Arche. This protective factor communicated to me that these assistants are serious about providing safe and professional care to Core Members, and if there are assistants who do not resonate or agree with these values (which is not always possible to know from initial interviews) then the leadership team does not hesitate to call people on their behaviour and potentially ask them to leave the community.

Community as a protective factor.

In addition, L’Arche as an organization is arguably as much about community as it is about providing care to people with disabilities. The data revealed several ways in which this organizational philosophy acted as a protective factor. First, the data indicated that assistants are asked to be honest about their difficult feelings and rely on their team of assistants to support them. Recall when Maple explained that when Core Members are being aggressive it is easier to react with anger, and possibly aggression, back toward that Core Member because of the human reaction it evokes. However, if there are several team members in the house at the same time, and assistants are taught to rely on their team for support, they can simply remove themselves from the situation if they feel angry, and allow a fresh person to take their place. Therefore, having a

community and team of assistants around Core Members, versus only one caregiver, can protect the safety and respectfulness of touch. Second, the virtue of having a group of people around can increase the safety of an environment because there is a norming process and a sense of mutual responsibility; having more people around, such as a community, is safer. Third, through years of relationship, long-term assistants have an internalized knowledge about Core Members, and as Joan put it in her interview, “five heads are better than one”. When it comes to supporting Core Members and being able to respond appropriately, for example, to a Core Member who is being aggressive or not respecting someone’s boundaries, if there are more long-term assistants present they can step in and help, or offer advice based on their years of experience and knowledge of Core Members. Therefore, it is clear that these aspects of community can act to protect Core Members and buffer conditions of risk.

It was apparent that community could act to help Core Members stay healthier in regards to use of comforting or supportive touch, such as the story Morgan shared in her interview. The particular Core Member that Morgan referred to usually follows a strict boundary policy where she is not touched expressively very often. However, losing a parent is not a regular experience, and since this Core Member lived in community when her parent died she was able to receive physical comfort, such as a hug, because people in the community had known her for so long. Her roommates and friends in the community understood what she needed to be emotionally well, which were hugs and comfort, outweighed a particular approach to her day to day life that kept her well, which was a restricted amount of physical touch. Morgan was saying that if this Core Member lived elsewhere, in another agency group home, etc., perhaps whoever was on duty in the house at the time would not have had the history with this Core Member to know that it was okay to be flexible during her time of hardship so that she felt the comfort and support that she needed. Morgan’s statement is a comment on the power of community and long-term relationships. This aspect of

community as a protective factor relates to feminist ethical reasoning, which happens in relationship and in context.

However, it is important to also consider potential risks of long-term relationships, even though they did not surface in the data. For example, perhaps long-term relationships could make it easier to blur boundaries between caregivers and clients, and people might discount inappropriate affectionate behavior because “they’ve known each other a long time”. In addition, what about a long-term relationship that is physically or sexually abusive, but other people in the community do not know that it is abusive? Even though there are concrete processes and checks and balances to prevent abuse, if L’Arche as an organization encourages assistants to stay for lengths of time such as 20 or 30 years, hypothetically an abusive relationship could go on for a very long time. I think the chances of this occurring are slim, but it is important to consider in order to move forward in an informed manner. Ultimately, however, the data revealed that long-term relationships contributed to increased safety in the community.

Self-worth.

Moreover, several participants discussed the ability of community to contribute to people’s sense of self-worth, and how the impact of self-esteem acted as a means of people knowing that they deserved to be treated respectfully. Self-esteem is well documented in the literature on prevention and promotion as a valuable individual level protective factor (Felner et al., 2000; Vandiver, 2009). Most powerful is Joan’s story of the Core Member who was able to stand up for herself outside of the community and say no. A healthy sense of self-worth acts as a protective factor because if people know that they are worthy of being treated respectfully and with dignity, then they will be more likely to advocate for themselves if in a difficult situation.

Vulnerability as a risk factor.

In addition, vulnerability was an individual level risk factor for both Core Members and new assistants. Acknowledging the vulnerability of new assistants as a risk factor could prevent inappropriate expressive touch from developing in these newly formed relationships. In her interview Joan points out that during the first few weeks of being at L'Arche, new assistants do not do much in the way of working or helping Core Members because they are still learning. Further, so much emphasis is put on relationship building, and for newer assistants who obviously would not have a relationship with Core Members, there can be an inner vulnerability of feeling inadequate for not having deep relationships, in addition to not feeling very helpful. New assistants may unconsciously accelerate the time that it takes to establish relationships with Core Members so that their relationships appear the way relationships do between Core Members and long-term assistants, which sometimes involves expressive touch. Therefore, an appropriate course of action could be to inform assistants in orientation very frankly that they will probably feel less than adequate and also not very helpful in the first few weeks of their time in the community. The orientation and training of assistants needs to foster awareness that the closeness of the relationships between Core Members and long-term assistants does not mean that their relationships are "better" or that they are "better" assistants, but that each assistant is on his or her own particular journey with L'Arche. Perhaps it would also be helpful to give assistants a timeline framework of when it is appropriate to start incorporating certain forms of physical affection into their relationships with Core Members. Not that natural expressions of affection should be so prescribed, but essentially participants were telling me that it is inappropriate when new assistants are overly affectionate with Core Members and that this issue happens often enough that people brought it up in their interviews consistently and independently of one another. Therefore, a framework of expressive touch that has guidelines and a timeline could be helpful for new

assistants to prevent them, in their vulnerability, from misusing affection with Core Members as a way to feel that they are adequate community members and that they belong.

Moreover, there was also the vulnerability of new assistants with regards to their trust of long-term assistants. Recall in Jake's interview when he discussed the new assistant who spoke up about something that was happening at his house. Going against the implicit authority of those who have been in the community longer creates a space for increased risk when it comes to touch, because it requires new assistants to trust and act on their own judgment when they have been asked to observe and learn from those who are more experienced. This action also forces newer assistants to potentially forfeit in their minds the relationship with the person whom they are effectually 'turning in' at a time when they are trying to get to know people. It is impossible to say whether other new assistants have not spoken up for similar reasons, but new assistants' vulnerability in this regard is certainly a risk factor to consider.

In addition, while it was okay for routinized tasks to sometimes evolve to the point where assistants did not need to ask the Core Member before every single touch, there were still routinized tasks that could benefit from more consistent verbalizing or asking first. For instance, the example of the assistants helping the Core Member into and out of her wheelchair multiple times daily but never verbally informing or asking her. This example struck me as an interaction involving touch that could be more respectful and that could honor Core Members' vulnerability more. It was obviously not abusive or hurtful, and the Core Member never appeared distressed or uncomfortable. But these body boundaries could be respected more by first communicating with the Core Member. As a participant observer I was sometimes one of people to help this Core Member into and out of her chair, and every time I said something like, "Okay, we're going to help you out of your chair now" while the other assistant was present. The assistants did not seem to pick up on the fact that I was communicating this information to the Core Member. The bottom

line is that people deserve to know what is going to happen to their bodies before it happens, and this risk factor embodies a disconnect between respecting boundaries and communication. There was an increased vulnerability for this Core Member because she was someone who did not communicate verbally.

In addition, throughout this research I learned that Core Members who are quieter and more reserved by nature, such as Sally, are more vulnerable and need more continuous education, conversation and reminding about how to keep themselves safe. I did not get the sense that Sally really knew the words to use to tell someone if she was feeling unsafe or uncomfortable. Therefore Core Members may need more regular skill development and maintenance when it comes to self-advocacy and boundaries.

Same-sex personal-care policy.

In addition, there was much discussion around the same-sex personal-care policy as a way to protect Core Members. I had several reflections on this policy. To begin, most Core Members have come from institutions where abuse rates were extremely high. It is known from research that women with disabilities have much higher abuse rates than the general population (Baladerian, 2009; Saxton et al., 2001), and that the majority of perpetrators are men (Stimpson & Best, 1991). By acknowledging a probable history of abuse, I think this policy honors the most vulnerable people in the situation, which statistics tell us are women with disabilities, followed by men with disabilities (Baladerian, 2009). The same-sex policy is not perfect, as Drew points out, because it does not automatically imply safety. However, when I thought about it, if I was a woman with a disability who had been sexually abused by a man, I would want a woman to help me with my bath. This policy evens out the power differences that would be found between two individuals, when one of those individuals is already in a more vulnerable position.

However, when I further considered the policy I saw that sexuality was relevant. When assistants help Core Members with personal-care the Core Member is often naked in the bath or shower; in our society the naked human body is sexualized and associated with arousal. Therefore I think this policy is also attempting to prevent assistants from becoming aroused if helping a Core Member of the opposite sex, and likewise prevent Core Members from becoming aroused if being helped by an assistant of the opposite sex. However, Drew suggested that in order for the female-female, male-male dynamic to be a safer approach personal-care, there needs to be a certain baseline of respect, because an individual of the same sex could just as easily violate an individual; if the policy is only about removing a potential opportunity for sexual arousal between people, it does not take into account the possibility for same-sex arousal or abuse. However, it would be an invasion of privacy to ask assistants their sexual orientation before matching them with a Core Member. And what if an assistant was bisexual? Would that mean that they would be prevented from helping Core Members with their personal-care routines? The absurdity of this issue is clear, therefore, I believe this policy is not solely about sexual arousal, but I think it is a part of it. My sense is that it is more of an attempt to respect the most vulnerable people which statistics tell us, are women with disabilities, and then men with disabilities. The policy is not foolproof, which is important to recognize, because implying safety through so simple a policy could create just as many risks. However, the policy in conjunction with an overall philosophy of respect helps it be a protective approach to care and touch.

I also feel it is necessary to mention that when I was doing this research I was informed by members of L'Arche Ontario leadership that it was the only agency out of over 30 agencies in the province that was not being investigated for sexual abuse charges. It does not mean that it has not happened at L'Arche, because I know through other conversations and also through Carolyn Currie's (2005) research that it has. However, this male-male, female-female personal-care policy

is one of the palpable differences in personal-care policy between L'Arche and other agencies in Ontario. Could it contribute to a reduced rate of abuse? Without doing a major study of the other agencies in Ontario we cannot know, but I could not help wonder if this policy had anything to do with this difference in abuse rates. There are clearly other differences between L'Arche and other agencies in Ontario, the most obvious being the important status of community and friendships in this organization, but also that this organization is known for having staff and residents who stay for decades, which affects the long-term stability of the organization.

More discussion of healthy expressive touch.

Moreover, several assistants discussed how the community had become quite good at supporting boundaries, but that they were not sure if it engaged enough in teaching people about how to touch expressively in healthy ways. From my observations I could see that there was certainly not a lack of expressive touch, and I did not feel that the environment was cold or sterile of affection. My observations told me that people interacted in very mature and open ways that respected people's boundaries. However, perhaps including more discussion of how healthy expressive touch can be incorporated into assistant-Core Member relationships would benefit the members of this community.

Transactional-ecological model applied to L'Arche.

As discussed in the review of the literature, Felner et al. (2000) argue that the transactional-ecological (T-E) model is the most thorough approach to prevention. This model, which integrates the interactive and developmental aspects of the transactional model with the multiple levels of analysis of the ecological model, is thought to be a strong approach to prevention and health promotion. Felner et al. (2000) emphasize that interactive and developmental processes are the targets of change in the transactional model, and that system-wide conditions affect these individual level interactions in a positive or negative way. Since I do not have any data from the

overarching system of care-giving and the way this system impacts L'Arche, I would only be able to speculate on the specific effects this system has on L'Arche policy and practice. However, I do have meaningful data from several levels of analysis such as the individual, micro-system and the organizational levels (Dalton, Elias, & Waldersman, 2007), which would allow me to comment more directly on the transactional aspect of this environment. Perhaps an area of future study would be to engage a L'Arche community while also studying the broader system of care-giving to put together a more concrete picture of the way that the system affects the organization and individuals. However, for the time being it is possible to comment that the interactive and developmental aspects of this L'Arche community are constructed in a way that supports a respectful and largely very safe environment.

The developmental aspects of the environment, such as evolving skills and competencies involving training, communication, self-worth, and the reciprocal interactive nature of the relationships and iterative protective nature of community, create a setting that puts the safety, health and dignity of people with disabilities first, while maintaining a climate that supports caregivers in sustaining their own health as well. The reciprocal nature of supporting caregivers to care for themselves through the team and community approach is then an aspect which leads to a stronger and healthier environment for all community members when it comes to the use of touch. Further, according to the Ottawa Charter (1986), and the Circle of Health (1996), creating supportive environments, building healthy policy, and developing personal skills and capacities are valuable strategies to health promotion. I document the specifics of how this community has created a supportive environment through its open and honest communication policy and practice, which I would argue is also supported through a strong sense of community and respect. I also detail how this community takes an empowering and proactive approach to helping its members develop personal skills and competencies, such as learning about personal-care, boundaries and

tools, such as the Circles tool, that support Core Members in advocating for themselves. There are risk factors associated with this environment, such as cultural differences, staff-turnover, client and new staff vulnerability, dual roles, inconsistencies between communities, and sometimes a lack of communication or respect for boundaries. Yet, according to the literature protective factors work in a compensatory fashion, offsetting the potential vulnerabilities created by the risk factors (Felner et al., 2000; Vandiver, 2009). The overwhelming energy and commitment dedicated to cultivating a supportive environment, helping people to develop personal capacities, creating respectful interaction and honoring first the needs and limitations of the Core Members, indicates to me that even with the risk factors, which through building awareness and further education could become less precarious, this environment is safe when it comes to the use of touch.

Therefore, there are several aspects of this environment which could become aspects of a practice-based promotion approach to incorporating the use of safe touch in care-giving for people with disabilities. This practice-based approach will be a useful contribution of this research and will hopefully be transferrable to other settings that involve not only people with disabilities, but also general relationships of care that are characterized by power differences. I will discuss this approach in the next section on practical contributions of this research. The transferability of these protective factors to other care-giving settings would involve several target areas for intervention. First a focus on developing skills and capacities involving training, communication, and self-worth would be important areas in which to put resources. Moreover, illuminating the dynamic nature of the relationships, putting the safety, health and dignity of people with disabilities first, and creating an environment that supports caregivers in sustaining their own health, are all powerful areas to increase the safety and respectfulness of an environment.

Contributions of this Study

I will now discuss the theoretical, ethical, and practical contributions of this study.

Theoretical contributions.

Theoretically there are the implications I discussed for sense of community theory and the use of community touch as a means of facilitating SOC. As I discussed before, there are elements to the use of touch in a community capacity that have a direct ability to impact most of the aspects of McMillan and Chavis' (1986) original theory of sense of community. This finding can make a strong contribution to the literature on SOC and the value of appropriate and respectful expressive touch such as hand holding, hugging, or dancing as a means to facilitate SOC.

In addition, and most obvious, this research can contribute to the theory around touch. Throughout the review of the literature I discuss the importance of critical affective touch (Field, 2001) for human wellness. I was concerned about how staff in the disability field addressed this issue for people with disabilities to ensure they receive this critical touch. During my field work I was moved by how staff at this L'Arche community were not only conscious of the importance of critical touch, but also that they made sure Core Members were receiving it. It was obviously easier for Core Members who were comfortable receiving traditional expressive gestures such as holding hands, having an arm around their shoulder or giving hugs. However, assistants were also able to help people with more complex boundary needs to receive important touch. Assistants talked about how they took time during personal-care to apply cream, help an individual wash or with a massage, and that through these *tasks* they were able to help people receive critical touch. For individuals who could hardly be touched, such as Judy, the staff came up with creative solutions, such as the pinky shake. Therefore, this finding has the ability to contribute to the literature further knowledge about the various ways in which staff that provide care for people with developmental disabilities can facilitate their clients' attainment of critical expressive touch.

Moreover, the data indicated that even people who have difficulties receiving touch still need touch, provided in a manner that involves a lesser degree of physical contact.

Another contribution of this research in the theoretical area of touch is around Harber and Hingsburger's (1998) approach to safe touch practices. Harber and Hingsburger (1998) argue that it is important to help people with developmental disabilities to stop hugging, and that it is inappropriate for a caregiver and client to hug. They contend that hugging is a particularly intimate boundary crossing that is too risky and makes the person with the disability more vulnerable. Harber and Hingsburger are correct that many people with developmental and intellectual disabilities are unable to cognitively internalize the social difference between a close friend and an acquaintance or stranger, and the reason that it is okay to hug a friend but inappropriate to hug a stranger. Therefore, Harber and Hingsburger suggest phasing out all hugging behavior as a way of protecting people with disabilities. According to these authors, if people know that hugging and close body contact is inappropriate, they will be more likely to protect themselves from someone touching them inappropriately or abusively. However, in my research I found data to the contrary of what Harber and Hingsburger are suggesting and I believe this finding is an important potential contribution of this research. During my fieldwork I witnessed assistants and Core Members giving each other hugs in what I thought was an appropriate and respectful manner. I also saw a lot of teaching occurring in the community that increased the safety of hugging, such as teaching the Circles tool and boundaries. In my opinion, it is safer and more humane to approach this aspect of human interaction by embracing the "grey areas" and not taking a restrictive approach, such as no hugging at all. While a "no hugging" policy is certainly far better than a no-touch policy, it still limits a very natural human expression. In addition, it could be very psychologically damaging for people to be told that they cannot hug others or be hugged. Harber and Hingsburger (1998) argue that other forms of affection such as holding hands and the sideways hug are okay, however, this

approach is still taking away a very natural and human form of expression. For a population that has been so widely rejected by society, to be further rejected in this small way, even when it is healthy, respectful, and both people are comfortable, by the people with whom they spend a large amount of time seems more damaging than positive, even if it does help to protect them. I argue that there is a more humane and respectful way to protect people with disabilities, which acknowledges their humanness and needs for touch. It is not to say that the way the L'Arche approach this issue is the only correct method, however, what I saw was empowering and respectful and led me to believe that there is another way to protect people with disabilities other than employing restrictive policies.

Hingsburger and Harber (1998) also discuss some other related issues, such as that of paid friends and that many people with disabilities have to depend on their caregivers for affection. However, until we change the nature of our care system and until society changes to be more accepting of people with disabilities so that they do not have to rely on caregivers for affection, the question remains: who is going to hug people with disabilities? The disability care system is undergoing a major transition after the deinstitutionalization movement, from a more medicalized approach to care to a more consumer directed model based on inclusion, human rights, advocacy, and community participation (Dunn, 2003). With this transition people with disabilities are no longer in institutions and are now cared for "in the community". However, our system of social services and society are still catching up to this more humane and progressive approach to supporting people with developmental disabilities, and many people do not have active contact with their families or a meaningful community in which to participate. Therefore, unless staff facilitate social connections and community outside of paid support workers, people with disabilities will spend most of their time with paid staff. Isolation remains a major issue for many people with disabilities (Dunn, 2003; Hingsburger, 1995; Vanier, 1998; White, 2005). Therefore,

Harber and Hingsburger are right, it is horrible that people with disabilities have become dependent on staff to provide what would normally come from a friend or family member. However, until we overhaul the entire system and society at the same time I am afraid that people will not receive the type of warmth and comfort that can be provided by a hug that is given respectfully and appropriately. L'Arche as an organization also takes a different approach to care-giving by encouraging staff to develop friendships with Core Members, which can be argued to be just another manifestation of "paid friends". However, in practice, becoming a L'Arche assistant is more of a lifestyle choice than a job, which could also weigh in to the appropriateness of such affectionate exchanges. Ultimately the concern about hugging is complicated and affected by many complex issues associated with the system of care-giving, social isolation, and the need to protect people with developmental disabilities. Even though Harber and Hingsburger (1998) obviously have good intentions, I argue that there is a more humane way to approach this issue that is not as generalized. We are talking about human beings and I do not think it is ethically appropriate to lump an entire group of people into a "no hugging" zone simply because their cognitive, physical, and relational needs are more complex. As a method of communication, touch is too powerful and complex to impose upon it simplistic rules (Field, 2001; Kertay & Reviere, 1998). This approach seems more like a band-aid solution to a very big issue, where people with disabilities are ultimately the ones who suffer the loss of touch while the root causes to the issue are not addressed. Again, this solution is more of an individual level approach to change versus a change that could address more systemic level issues.

While Harber and Hingsburger's (1998) work is widely known throughout the disability field, has successfully been adopted to some extent at the organizational level, and may have contributed to protecting people with developmental disabilities from the misuse of touch, it has prevented people with disabilities from receiving the important benefits of expressive touch. Based

on extensive field observations, I argue that an approach based on education, context, and relationship could adequately protect people but also honor their humanity, something that has been stripped away from people with disabilities for far too long. As discussed in the review of the literature, the over-regulating of touch can de-humanize a therapeutic and care-giving relationship by strictly controlling what is a very natural form of human communication (Field, 2001; Kertay & Reviere, 1998; Zur, 2005). Moreover, people will never learn about appropriate touch and affection if they themselves are never touched (Hingsburger, 1995).

Ethical contributions.

In addition to theoretical contributions of this research, there are also implications for feminist ethics theory. To begin, Prilleltensky et al. (1996) advocate for a process-oriented understanding of ethics, which considers that because “mental health treatment is inherently relational, greater sensitivity to harm and risks will be fostered by understanding actual relations between persons, their needs, preferences, values, and choices” (p. 289-290). It is more than clear from the data that this L’Arche community takes a process, relational and contextual approach to ethical decision making. For example, while the following example is very simple, I think it powerfully demonstrates this approach to ethical decision making. Recall the scenario when Joan and Bonnie discussed when Bonnie was requiring more help with her personal-care to wash her hair. Bonnie is a Core Member with more structured and firm boundaries around touch, therefore the assistants and Bonnie discussed her care options in several meetings, and what it might feel like for someone to help her with her hair and to touch her head. Through Bonnie’s participation and the assistants’ knowledge of her struggles they decided together that an assistant helping her with her hair would be the best course of action, and as Bonnie said in her interview, “it’s working fine now”.

In addition, with expressive and affectionate touch, the data revealed that only if both Core Member and assistant were comfortable, would various forms of appropriate expressive touch be okay within the relationship. This relational and contextual approach is in contrast to previous no-touch or restrictive policies (Field, 2001; Harber & Hingsburger, 1998; Hingsburger, 1995). It has been clearly established that the use of expressive touch in relationships with inherent power differentials, such as those found in care-giving, is an ethical issue. However, the fact that this issue was addressed relationally, in context and in discussion between all parties involved promotes, according to the feminist ethic of care, a more ethical method of negotiating this issue. For example, for some Core Members it was healthy and safe for them to be hugged, while for others it was very damaging. The ease with which assistants could discuss this reality and how they dealt with expressive touch on an *if* and *how* basis with Core Members, suggests that they have been socialized in their organizational environment to be respectful and compassionate to the Core Members' needs around touch and boundaries. Therefore, this L'Arche community's approach to ethical issues around touch serves as a tangible example that gives evidence to this process oriented, relational and contextual way of creating a more ethical environment. This community found a way to balance the importance of safety with the importance of touch.

In addition, the actual ethical approach to this research is a contribution to the literature on ethics and future research with people with developmental disabilities. The alternate consent forms for the Core Members were easy for them to understand and follow. These simplified consent forms engaged people in a way that was accessible, which increased the ethicality of the research.

Practical contributions.

There are several practical benefits of the research. First of all, this research documents a controversial and sensitive topic within the disabilities field. Talking about controversial topics in the open demystifies them, and helps people feel comfortable talking about such topics

(Hingsburger, 1995). By encouraging people to reflect on the way they use and receive touch, and what makes touch safe and respectful, this research can contribute to a broader knowledge base in academia and the disabilities field. In addition, documenting ways to include people with developmental disabilities in this research is a practical contribution to future research. As previously discussed, this population has been excluded from academic research in the past. However, by communicating to other academic researchers that this type of inclusion is possible, I hope that this study will affect change within academic processes of research. Publishing a study that involves people with disabilities in a participatory manner will not only show other researchers that it is possible and important to include people with disabilities in research, but also that people with disabilities can help direct and shape the research process. This relates to the disability movement slogan, “nothing about us without us”; people with developmental disabilities have the right to participate in research that affects them, and this is a valuable contribution of this research.

Recommendations for L’Arche and other care-giving settings.

Most practically, however, this study can contribute to organizational change within this L’Arche community, and other communities within L’Arche Ontario. Therefore, I will now address some specific recommendations for L’Arche as a practical way of maintaining safety and offsetting potential risks in their environment. These recommendations will also hopefully be transferrable to other care-giving settings and could be incorporated into a practice-based promotion approach to safe touch. To begin, client and staff education and skill development is imperative; it is necessary to teach people about their rights and how to advocate for themselves. Staff education and skill development means ensuring that people know how to do their jobs correctly and respectfully, which involves learning policies, protocols for emergencies and when to ask for further information from outside professionals. Both clients and staff also need adequate

information and training with regard to boundaries and how to identify what kind of touch is healthy and safe, generally speaking, and also individually. Learning about boundaries should help them know whether they are comfortable receiving or giving hugs, etc., and also about receiving or giving functional, procedural and therapeutic touch. In addition, as previously discussed in the findings section, boundaries must be taught with communication skills for staff and clients. These skills must include the ability to ask or inform the individual being touched and how to understand whether a non-verbal client is welcoming any kind of touch. The participants in this study told me that body language, such as smiling, nodding, turning away, and making a grumpy face were all indicators they used to understand whether non-verbal clients were okay with being touched. In addition, with communication comes the aspect of giving and receiving feedback in relation to standards and policies of the organization. Further, important communication skills to be taught to staff and clients include the ability to be honest and open about difficult feelings that might get in the way of being professional or respectful, and also open communication about when a staff person has used a protective restraining touch, which might have been rough or left a bruise on a client. All of these forms of capacity-building should also be able to be incorporated into agency policy and practice over time. A reorientation of organizational mission or attitude might be required if the agency is not already in a position that empowers both clients and staff. Gershon's (2007) empowerment model of change might be useful in these situations. This model gives concrete strategies on how organizations can be innovative and maintain a common vision and value system.

The next set of L'Arche strategies that could be incorporated into a practice-based promotion approach to safe touch are more specific to L'Arche philosophy and have to do with community. At L'Arche, assistants and Core Members develop long-term relationships that sometimes span more than 20 years. Participants in this research told me that these relationships

allowed assistants to get to know Core Members intimately. This knowledge then made the environment safer for people because assistants were able to adjust quickly between their approaches to supporting different people and also use their knowledge to support individuals appropriately and in a person-centred manner. This protective factor might not be as transferrable to other care settings where the nature of the relationships between staff and clients are shorter or less personal, which could be due to several reasons, such as a less intensive health condition of the client, high staff-turnover or organizational policy that discourages friendships between staff and clients. However, the extent to which staff and clients are able to develop long-term relationships, and manage the dual roles of these relationships in mature and responsible ways can act as a powerful protective factor that could be incorporated into other care settings. It was evident that through these long-term relationships Core Members were able to develop a sense of self-worth, which added to their ability to protect themselves when it came to the use of touch.

Moreover, employing mutuality in the care-giving relationship was also an important way to increase respect, as participants indicated that mutuality meant both people thinking about a relationship in the same way to prevent misunderstandings, and help both people know how to use touch appropriately with one another. From this research it is clear that using a relational approach of mutuality helped assistants to understand how to be respectful. However, I would recommend that L'Arche staff who train new assistants clarify the exact meaning of mutuality and the role that assistants have in putting the needs, limitations, and wishes of Core Members first. In addition, there is the need to provide more meaningful social and emotional support to international assistants, who make up a bulk of L'Arche staff.

Further, I would recommend that L'Arche maintain its strategy of working on a team to help assistants support one another in difficult situations. Many staff persons in other non-community focused residential agencies or group homes also work on a team. Therefore, learning

how to rely on your team of staff for support in difficult situations, such as helping an aggressive client, could increase the safety of a given situation. In many other situations however, one single support worker goes into an individual's home, provides the necessary care and then leaves for the day, and in these situations relying on a team will not be possible; therefore supporting other protective factors such as communication and boundaries would become more important.

I would also recommend that L'Arche continue its discussion on safe and healthy expressive touch. Even though it was clear that this community had found ways to include expressive touch between community members, several participants felt that the community had become 'too boundaried' and that there was even fear sometimes around expressing healthy forms of touch with Core Members. Because there is a large grey area with regard to expressive touch and also given the fact that the use of touch as a boundary crossing between people with power differentials is a clear ethical issue, I recommend that L'Arche create some clear guidelines and policies around expressive touch and what is appropriate. These guidelines would also include a timeline of when it is okay to start developing appropriate affectionate aspects of an assistant's relationship with a Core Member and guidelines such as asking first, consent and comfort level.

In conclusion, a valid contribution of this research is employing the strategies that were revealed to me in this L'Arche community as a practice-based promotion approach to safe and respectful touch. These strategies could be partially or fully adopted in other care settings as a way to increase the respectfulness and safety of a given environment most importantly for people with disabilities, but also for staff.

Limitations of this Study

As with any research project, there are limitations to this study. First, the time constraints of a Master's degree limited the breadth of my topic. In addition, the findings of this study are relatively limited to a specific demographic within the disabilities field, and will most easily be

applied within the L'Arche context. Because L'Arche is unique in its approach to care-giving the findings of this study may not be directly transferrable to other care-giving environments. Another issue is that I was only able to engage with one L'Arche community. While the data speaks for L'Arche as an organization, it does not represent the structure and practices of all communities; in fact, inconsistency amongst the communities is an issue that I have addressed. Further, because I had faith and worldviews in common with L'Arche philosophy, I did not go into the data collection with a classic "objective" lens. There are additional ethical issues associated with entering into a study as a completely objective researcher (Charmaz, 2006). I am aware that my status informed and probably strengthened how I did this research, and I did strive to maintain critical reflexivity through my daily journaling, as I discuss next.

Personal Reflections from the Fieldwork Experience

I would like to add some reflections from my personal experience throughout this six-week fieldwork experience. To begin, I remember upon beginning my fieldwork having a palpable feeling that my research had become much bigger than me. I felt deeply honored that this community welcomed me to do this work, and I was humbled by people's willingness to contribute and participate in the research process. Although it was difficult to be away from home and my husband for this length of time, I did come home every other weekend to visit. In addition, while I was in the L'Arche community it was difficult not to fall into my usual "L'Arche" role of being an assistant, and I found myself wanting to develop friendships with the people in my house. Even though I feel the research relationships that I did develop were authentic and meaningful, I challenged myself to keep a degree of distance from the day to day goings-on of the house. It was important to me not to cross any inappropriate boundaries or become too involved in the interpersonal dynamics of the house. For example, during weekly house meetings when house members would check in with each other about their week and any personal struggles or issues

they were having, I chose to withhold most of my personal feelings that I would normally share at a L'Arche house meeting. Instead I gave updates on the research process. I found it unnatural to not fully engage in the community to the degree that I was used to participating in L'Arche, and I got lonely sometimes. I journalled every day about my personal feelings to help me through these difficult moments, and spoke with my husband regularly via Skype, which is a computer program for verbal communication available for download on the internet. Even though I had a unique role in the community my house leader still managed to find a way for me to feel welcome and at home there. I did not think it was fair to the participants for me discuss personal issues or complain about how I was getting tired from my busy research schedule, when they had been so gracious to welcome me into their home to conduct my research.

In addition to the wonderful experience of the actual data collection and seeing the research take shape, my experience with the participatory approach was one of the highlights of the fieldwork. In the Advisory Group meetings I received valuable feedback, revisions were made to interview guides, and the research process that increased the ethicality and allowed the community to have meaningful control over the research. The participation of the Advisory Group also improved the validity of the research by obtaining the expertise of the community members who were more attuned to the important issues that I should have been addressing or questions I should have been asking. I remember leaving each Advisory Group meeting thinking that the quality of my research had just increased because these wonderful people were pouring their energy and knowledge into it, and were making it better in ways I never could have imagined. I am forever grateful for the participation of this group of committed people. This participatory methodology also helped me feel like I was bridging my activist and my academic selves, and pursuing social justice through the approach to my thesis.

On my last night in the community the members of my house had a going away party for me, which involved the L'Arche candle passing ritual. This ritual happens on birthdays, anniversaries or if someone is leaving the community, and involves each person holding the candle and saying something nice or what they appreciate about that person, and then passing the candle to the next person. This experience was powerful and I was struck by what some of the people at the table had to say to me. Even though I had tried to remain more removed and guarded throughout my time in the community, it was apparent that people had gotten to know me and appreciated my presence in the house. One Core Member said with tears in her eyes, "you are a good woman. I'm going to miss you". Her expression and words truly touched me.

One of the issues I struggled with when I was planning this research process was that I was only going to be living in the community for six weeks. People with disabilities have people come into and out of their lives so often, and even though I believed in the value of my research, I was challenged by the thought that I was just going to be another one of these people to come and go from their lives. Although I had consent from the community director, the ethics office had approved my research, and I was working with the community in a participatory fashion, I struggled with my increased responsibility as a researcher who had invited approximately 50 people to participate in my research, and how to take care that no one was harmed by my presence in the community. I could not foresee how my presence would harm people as I was taking care to be extremely respectful, but it was apparent in my last week in the community that some of the Core Members were having difficulty with the fact that I was leaving.

One morning in my last week in the community I left my bedroom and this same Core Member from the story above was standing in the hallway crying. I asked her what was wrong and she communicated to me that she was sad that I was leaving soon. I was deeply hurt that I had caused anyone in the community any grief whatsoever. An assistant from the house came over and

supported this Core Member through her difficult moment and she and I later debriefed the experience. However, on my last day in the community this Core Member ran away from home, which is something she does when she is very upset. In the end she had walked to another one of the L'Arche houses in the community, and returned home within several hours. However, during the time when she was gone my stomach was in knots thinking about what could have happened to her, if she was safe, and if my leaving had anything to do with her running away. When this Core Member returned home one of the assistants informed me that she did run away partly because of my leaving that day. In community psychology we often talk about unintended consequences, and this event was certainly a negative unintended consequence. Even though I could not have foreseen that she would have reacted in this way to my leaving, I could not help but wonder if the research process was too much for some of the Core Members. This experience has implications for future research with L'Arche and methodological approaches. I believe that this study was extremely valuable not only for this L'Arche community but also for other care-giving settings, and the observations made possible through the relational and ethnographic approach increased the validity of the findings. However, if future researchers are going to live in a L'Arche community for an extended period of time there should be more formal supports set up for any Core Members who might need help to understand and deal with difficult feelings they may experience from a researcher leaving a community. Leaving the community on this note was very difficult, and while I was grateful that this Core Member was safe, I felt awful about the incident happening at all. Aside from this very challenging experience, people continually throughout my fieldwork told me that they were glad I was doing this research.

Areas for Future Research

There are several related areas of research that could contribute to creating a safer and more respectful environment at L'Arche with regard to the use of touch. The first possible area of

research could examine sexuality at L'Arche and the extent to which sexually active relationships are supported between adults with disabilities, and how to help people be safe in such relationships. Second, while the community that I worked with had some very progressive policies, there were areas such as guidelines for expressive touch that could use more specified and concrete policies. A study evaluating the policies of L'Arche communities would be beneficial and would increase the safety of touch at L'Arche by ensuring that policies are informative and help staff know exactly how to handle situations involving grey areas around touch, such as expressive/affectionate kinds of touch. Third, it would be valuable to repeat my thesis research but to engage more than one L'Arche community to examine cross community differences and similarities. While I know from personal experience and the data from this study that there are inconsistencies between L'Arche communities, in order to most meaningfully comment and provide feedback to L'Arche about how to bridge these inconsistencies to create a cohesive approach to training, education, relationships, dual roles, etc., an inter-community study would be necessary.

Action and Dissemination Plan

In order for this research to create change I will carry out the following dissemination and action plan. First, I will meet with the leadership team of the L'Arche community in which I conducted this study. I will discuss with them the findings of the research and consider on how to implement potential organizational changes through policy and practice. I will also meet with leadership from L'Arche Ontario to discuss how to best implement the findings in all L'Arche communities, and I will follow up with L'Arche Ontario and provide support as it executes potential changes. Further, I will write and publish several articles about the various approaches, findings and contributions of this study so that this information is available to other professionals and academics in the disability field.

Conclusions

Through this ethnographic-case study with one L'Arche community in Ontario, I learned extensive amounts of information on the nature of touch at L'Arche, and how the approach of this community creates protective conditions or risk factors regarding the use of touch in care-giving for people with developmental disabilities. In regards to the first research question on the nature of touch, L'Arche employs a broad range of touches, such as functional and procedural, therapeutic, expressive and community. Participants said that touch was used gently, respectfully, and intentionally, but that it was complex, and sometimes uncomfortable or unnatural.

In regards to the second research question about risk and protective factors, the participants indicated to me that there were practices of this L'Arche community that worked to promote a safe and respectful environment when it came to the use of touch. Various kinds of capacity-building and education around several subjects, such as boundaries and communication, helped community members to be able to use touch safely and respectfully with one another. There were also inherent aspects of living in community, such as the long-term relationships that people with developmental disabilities and staff developed with one another, that contributed to feelings of self-worth and respect. The safety associated with working on a team and employing a relational approach of mutuality also helped people to feel that touch was used safely and respectfully. If these protective factors are enhanced and supported in a systematic and intentional manner, they could work to offset potential risks from affecting people with disabilities when it comes to the use of touch.

There were also risk factors within this L'Arche community that need to be addressed in order to make the environment safer, such as the occasional time when assistants did not ask or verbally inform Core Members before touching them. The inherent vulnerability associated with disability was also a risk. Moreover the vulnerability of new staff persons needs to be formally acknowledged in order to prevent inappropriate affectionate touch between themselves and clients.

There were risks in personal-care time, such as the fact that personal-care routines are done behind closed doors, which is inevitably the place where abuse would happen if it were to happen. In addition to inconsistencies between the communities, there were complex issues around power and dual roles between people with disabilities and staff, and how to negotiate these power differences in ways that did not create additional risks for the people with disabilities. Last, there were some discrepancies with the same-sex personal-care policy, in addition to concerns that the community had become too boundaried, which could be remedied by talking more about personal-care policy and safe expressive touch and how to help people feel comfortable in their individual needs for this form of touch.

Overall, however, I found this environment to be empowering and respectful. Assistants took great care in making sure that Core Members' needs were put first. One of my initial concerns in this research was around expressive touch and the way that mainstream organizations' approach to this form of touch had become reactionary and associated with very restricted or no touch at all. I was concerned about whether Core Members were receiving critical affective touch that research has indicated is so important (Field, 2001). I did indeed observe and learn through this study that this community has found a way to incorporate a safe and respectful approach to expressive touch between people with developmental disabilities and their caregivers. This approach has to do with guidelines around boundaries and relationships, but is very person-centred and influenced by each individual relationship. This L'Arche community did not immoralize expressive touch, as do many Western professional bodies with relationships characterized by power differences (Zur, 2007). Instead, through communication, education and long-term relationships, this L'Arche community found a way to include expressive touch in a manner that is healthy and respectful. This learning is of extreme importance, as it shows that care settings with relationships characterized by power differences do not always have to take rigid, reactive, rule-

driven, one-sided approaches to the use of expressive touch. Instead, this community replaced this oversimplified approach to human interaction with another version based on respect, justice and compassion, which has reclaimed the importance of relationships and incorporate expressive touch in a more humane manner. Recall that Gale and Hegarty (2000) stated that “expressive touch, used deliberately and professionally, as a therapeutic medium, should be incorporated into the provision of care” (p. 105). The L’Arche approach, based on a long-term family-style living arrangement, has not been, and most likely will not be, generalized to the broader system of care-giving. However, until society and the broader system of support services for people with disabilities realize the importance of community and relationships, L’Arche may serve as an exemplar of a particular way to keep the use of expressive touch safe and respectful in care-giving relationships.

In addition, this research meaningfully sought the participation of people with developmental disabilities, which has been a very controversial issue in the past. I chose to honor the disability movement phrase, “nothing about us without us”, and work toward a new form of accessibility and inclusion in my research. The study represented the voices of people with developmental disabilities at L’Arche on this very sensitive issue of touch, which to my knowledge, has never been done before. Illuminating the feelings and concerns of people with disabilities, and bringing their voices into the literature on issues that directly affect them, is an important contribution of this research.

In conclusion, the nature of touch in this L’Arche community was complex, and there were risks that need to be addressed by enhancing the protective aspects of this environment. Overall, I found these protective factors such as capacity-building and community to be very strong, and that they worked in a compensatory fashion to offset the risks, as suggested by the literature (Felner et al., 2000). This L’Arche community engaged in touch in way that was respectful and safe for

people with disabilities. And, as participant Jim explained, “we’ve got to respect each other, or else L’Arche isn’t L’Arche”.

Appendix A: L'Arche Identity and Mission Statements

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 recognize 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.

Appendix B: Observation Template

	F - Functional E - Expressive T - Therapeutic	A - Assistant C - Core Member	P - Positive N - Negative Ntrl - Neutral	e.g. gentle, professional, appropriate rough, forceful, etc. e.g. handshake, helping with a task, hug, etc.	Asking first? Boundaries respected? How?
1					
Description: Power Analysis:					
2					
Description: Power Analysis:					
3					
Description: Power Analysis:					
4					

Appendix C: Interview Guides

Core Member Interview Guide

Could you tell me about your life here at L'Arche?

How long have you lived here?

What do you like about living at L'Arche?

What makes you feel like you belong to this L'Arche community?

Do you feel like you belong to this community?

Do you do activities with people that make you feel like you belong?

What makes you feel like you included?

Meal times? Celebrations? Spending time with friends? When someone does something nice for you?

Do you ever feel excluded or left out? How/why?

How do you make your thoughts heard to other community members?

Do you feel like people listen to you? Why/why not?

Do you feel comfortable talking to people about things that are happening in the community?

Do you feel comfortable talking to people about things that might be difficult to talk about?

How would you describe your relationships at L'Arche?

Can you tell me about your friends in the community?

Are other Core Members your friends?

Are assistants your friends?

Do you feel equal to, or as good as, the assistants?

How do you know you are appreciated or valued in your community?

Do you feel like people see your gifts and strengths?

Do you feel respected by assistants?

Do you feel respected by other Core Members?

How do you feel comforted, supported, reassured or calmed by your friends in the community?

Do you feel that you can depend on or lean on people when you need some comforting?

How would you describe the way that touch is used at L'Arche?

How do assistants use touch with you?

Do assistants use touch to help you with tasks? How?

Bathing? Dressing? Eating?

Do assistants use touch to comfort you? How?

Hugging? Holding hands? Put an arm around your shoulder?

Do assistants use touch as a part of your friendship? How?

Hugging? Holding hands? Put an arm around your shoulder?

Do assistants use touch in a therapy kind of way? Like to give you a massage or to help you stretch?

Foot rub? Shoulder massage? Hand massage? etc.

What is comfortable touch to you?

How do you tell assistants whether or not you feel comfortable being touched?

- Do they give you choices?
- Do they ask whether they can touch you before they touch you?
- Do you say 'yes' if you are comfortable with someone using touch with you?
- Do you say 'no' if you are uncomfortable with someone using touch with you?

What makes touch uncomfortable for you?

- Are you unsure about the way assistants use touch with you?

- Is there anything that makes you feel uncomfortable or unsafe?
 What kinds of touch are bad touch?
 Is there anything about L'Arche that makes you feel unsafe?
 What makes you feel safe when people use touch with you?
 What kinds of touch are good or safe touch?
 Is there anything special about L'Arche that helps you feel safe?
 How do you feel about the way touch is used in your life?
 Do you have anything else to tell me about how touch is used in your life?

Thanks for talking to me about your life at L'Arche.

Assistant Interview Guide

Could you tell me about your life here at L'Arche?
 How long have you lived here?
 What do you like about living at L'Arche?
 What makes you feel like you belong to this L'Arche community?
 How do you know you belong to this community?
 How do you make your thoughts heard to other community members?
 Do you feel like people listen to you? Why/why not?
 How would describe your relationships in the community?
 - How would you describe your relationships with Core Members?
 How would you describe your relationships with other assistants?
 Can you tell me about your friendships in the community?
 How do you know you are appreciated in your community?
 Do you feel like people see your gifts?
 How do you show respect for the Core Members?
 Do you feel respected?
 How do you feel comforted and supported by the community?
 Do you feel that you can depend on people?
 How do the Core Members receive comfort or support?
 Touch & Boundaries
 How would you describe, in your words, the way that touch is used at L'Arche?
 How do you use touch with other assistants?
 How do you use touch with Core Members?
 Do you use touch to help Core Members with tasks? How?
 Do you use touch to comfort Core Members? How?
 Do you use touch as a part of your friendships with Core Members? How?
 Do you use touch therapeutically? E.g. giving a massage or helping someone to stretch?
 How did L'Arche prepare you to use touch with Core Members?
 Were you given any training about how to use touch with the Core Members?
 How do you understand whether or not Core Members feel comfortable being touched?
 Do you ask whether you can use touch before you do use touch?
 How can you tell whether a non-verbal Core Member feels safe when you use touch with them?
 Is there anything about L'Arche that makes touch unsafe, or puts Core Members at risk?
 What kinds of touch are inappropriate or abusive?
 Is there anything about L'Arche that makes touch safe, and protects Core Members?

What kinds of touch are safe and appropriate?
 How do you meet your own needs for physical touch while living at L'Arche?
 How do you feel about the way touch is used at L'Arche?
 Do you have anything else to tell me about how touch is used at L'Arche?

Thanks for talking to me about your life at L'Arche.

Key-informant Interview Guide

Could you tell me about your life here at L'Arche?
 How long have you lived here?
 What do you like about living at L'Arche?
 What makes you feel like you belong to this L'Arche community?
 How do you know others feel they belong to this community?
 How do you make your thoughts heard to other community members?
 Do you feel like people listen to you? Why/why not?
 Can you tell me about the relationships in this community? Describe them - what are they like?
 Are other assistants and Core Members your friends?
 What are friendships like at L'Arche?
 How do you people know they are appreciated in community?
 Do you feel like people see the personal gifts of others?
 Do people value the gifts of Core Members?
 How do assistants show respect for Core Members?
 How do you know when Core Members and assistants both feel respected?
 What is your sense of the level of interpersonal respect in the community?
 Do people generally feel respected?
 How do you think people feel about their self-worth?
 - Do Core Members and assistants have a sense of their self-worth in this community?
 How does the community provide comfort and support to Core Members?
 Do you think people feel that they can depend on others?
 How would you describe the way that touch is used at L'Arche?
 How do assistants use touch with Core Members?
 Do assistants use touch to help Core Members with tasks? How?
 Do assistants use touch to comfort Core Members? How?
 Do assistants use touch as a part of your friendship with Core Members? How?
 Do assistants use touch therapeutically? E.g. giving a massage or helping someone to stretch?
 How does L'Arche prepare assistants to use touch with Core Members?
 How are assistants taught about the use touch with the Core Members?
 How can you tell whether or not Core Members feel comfortable being touched?
 Are they asked first whether or not they feel comfortable?
 How can assistants tell whether a non-verbal Core Member feels safe when you use touch with them?
 Is there anything about L'Arche that makes touch unsafe, or puts Core Members at risk?
 What kinds of touch are inappropriate or abusive?
 Is there anything specific about L'Arche that makes touch safe, or protects Core Members?
 What kinds of touch are safe and appropriate?

How do assistants meet their own needs for physical touch while living at L'Arche?

How do you feel about the way touch is used at L'Arche?

Do you have anything else to tell me about how touch is used at L'Arche?

Thanks for talking to me about your life at L'Arche.

Appendix D: Focus-group Interview Guides

Core Member Focus-group Interview Guide

Could you describe your relationships here at L'Arche?

- Can you describe your friendships?
- Do you feel respected in the community?

How is touch used here at L'Arche?

How do assistants use touch with you?

Do assistants use touch to help you with tasks? How?

Bathing? Dressing? Eating?

Do assistants use touch to comfort you? How?

Hugging? Holding hands? Put an arm around your shoulder?

Do assistants use touch as a part of your friendship? How?

Hugging? Holding hands? Put an arm around your shoulder?

Do assistants use touch in a therapy kind of way? Like to give you a massage or to help you stretch?

Foot rub? Shoulder massage? Hand massage? etc.

Is there anything about L'Arche that you feel makes touch uncomfortable?

What kinds of touch are uncomfortable?

What makes touch unsafe?

Is there anything about L'Arche that you think makes touch safe?

What kinds of touch are good or safe?

What makes touch safe?

How do you feel about the way touch is used at L'Arche?

Thank you for sharing your thoughts and feelings with me today.

Assistant Focus-group Interview Guide

1) Could you describe your friendships here at L'Arche?

How is touch used at L'Arche?

How do assistants use touch with Core Members?

3) What can make touch unsafe at L'Arche?

What kinds of touch are bad or unsafe?

Is there anything about L'Arche that you think makes touch safe?

What kinds of touch are good or safe?

How do you feel about the way touch is used at L'Arche?

Thank you for sharing your thoughts and feelings with me today.

Appendix E: Interview Consent Form for Core Members

WILFRID LAURIER UNIVERSITY
 CONSENT STATEMENT FOR COREMEMBER INTERVIEW
 The Nature of Touch in Caregiving Relationships between People with and without
 Developmental Disabilities: L'Arche as a Case Study
 Lindsay Buckingham (Principal Researcher), Terry Mitchell (Supervisor)

Hi _____ (Name of participant). My name is Lindsay Buckingham, and I am a university student doing research with your L'Arche community.



Do you remember when someone spoke about a few weeks ago about the research project about touch?

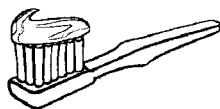


I'd like to talk to you more about this research project that is happening in your L'Arche community. In this project I am about learning how people who live in this community use touch with each other, and about how assistants use touch with coremembers.

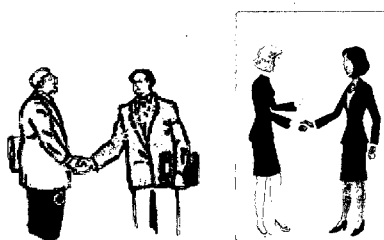


Do you remember the different kinds of touch?

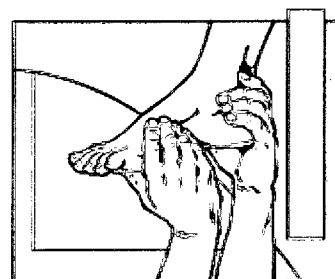
People can use touch to help someone with a task like tying up shoelaces or brushing teeth.



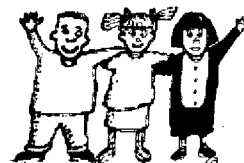
People can use touch to greet someone else with a handshake.



People can use touch to make a sore muscle feel better, like with a massage or a stretch.



People can use touch because they are friends or family, like a hug or holding hands.



Touch can be comfortable and safe.



But touch can also be unsafe or uncomfortable.



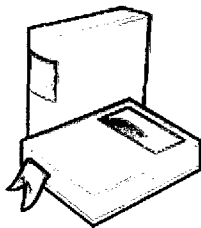
I want to make sure that people use touch safely and comfortably with each other in this community.



This research project is part of my work as a student.



Doing research means I am trying to learn more about something. I am trying to learn more about how people in this community use touch with one another. There are lots of ways that we can do research, like by reading books.



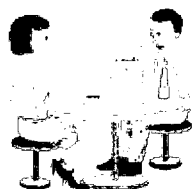
We can also do research about people by spending time with them, like by talking with them.



I would like to invite you to have a conversation with me about your life here at L'Arche.



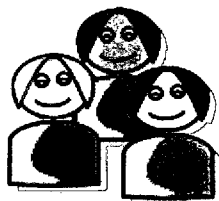
This conversation is called an in person interview.



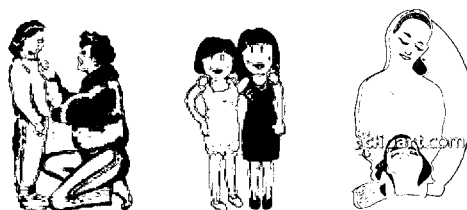
During the interview we will talk, and I will ask you some questions. These questions will be about your life at L'Arche.



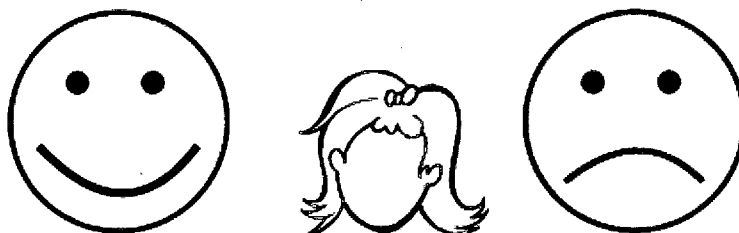
I will ask you questions about your friends.



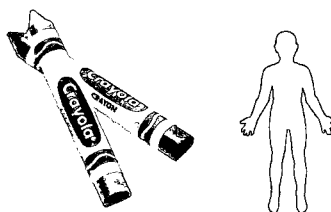
I will also ask you questions about touch, and how assistants use touch with you.



I will ask you how you feel about how assistants use touch with you.



I will also ask you to do a colouring exercise with me.



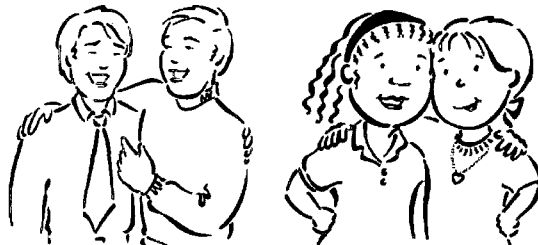
All the things that I learn from you in this interview will help me to understand how people use touch with each other at this L'Arche community.



If it is okay with you, I will use the stories you have shared with me in my school work to help me tell other people how to use touch safely with others.



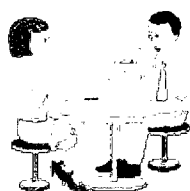
Also, I will ask if you would like to choose an assistant from your house to be your Safe Person. Your safe person can support you in your interview.



I will tell this person that you are doing an interview with me. You can choose how you would like your Safe Person to support you in this interview. You can choose whether you would like him or her to be with you during the interview.



You can also choose for your Safe Person to be in a different room during your interview, so it will just be me and you talking together.



After the interview is done your Safe Person can help you settle back into your day, and make sure you are feeling okay. If you don't want to choose a Safe Person, this is also okay. It is completely up to you.

It is okay if you do not want to have this conversation with me. It is also okay if you do not want to do the colouring exercise.



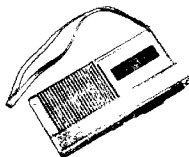
This is your choice, and I will not be upset if you do not want to talk with me or do the colouring. If you want to have this conversation with me, but there is a question that you don't want to answer, you do not have to answer it.



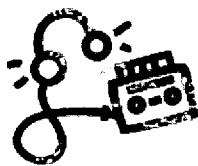
Even if you would like to have the conversation, when I ask you questions you can change your mind and we can stop the interview. This is okay. I will not be upset with you, and no one else will be upset with you either. I will not tell the other assistants and coremembers that you are taking part in the interview. But some people in the community will know that you are having this conversation with me.

These people are _____ (Community Director), _____ (House Leader), _____ (Parent/Guardian), and the members of the Community Advisory Group for this research project. Also, if you see a personal counsellor and you would like me to tell them that you are participating in an interview I can do this. This way your counselor can ask you if you would like to talk about the interview in your next session.

If it is okay with you, during the interview I will record our conversation on a small tape recorder.



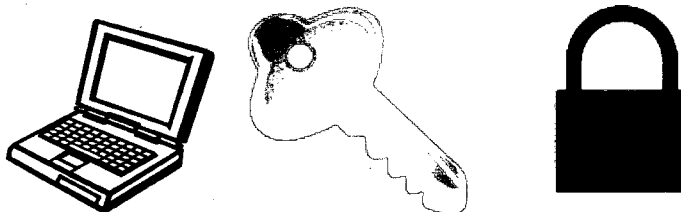
The tape recorder will remember our conversation. When the interview is over, I will listen to our conversation again on the tape recorder with head phones.



On a computer I will write out all the words that you and I said during our conversation.



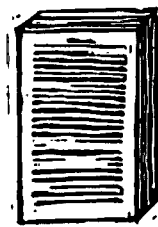
When I listen to our conversation on the tape recorder and write it out on the computer, I will make sure that no one will know that I am writing about you. I won't put your name in my computer. I will also keep my computer in my safe bedroom that is locked.



This is called keeping something private or confidential. The only reason why I would tell someone something private about a person is if they told me that they were being hurt by someone else. This means that if someone else was touching them in their very private areas and hurting them. If someone tells me that this is happening I have to tell someone.



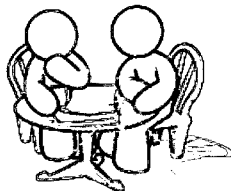
After I am done writing out our conversation, I will print out the conversation onto paper. This is called a transcript.



Then I will meet with you again to talk about our conversation. I will bring a copy of your interview transcript written out on paper.



This is so we can read it together.



I will do this so that you can tell me if there is something in the interview that you said that would like me to take out.



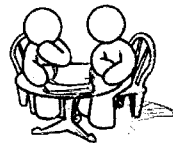
Do you remember how I said that I would keep information about you private? I will not use your name when I write about your interview in my school work. But even if I don't use your name, if someone from this community reads my schoolwork it might be harder to make sure they don't know I'm talking about you. This is because you could have a favorite word or sentence that you like to say.



Maybe other people in the community know that you like to say this word or sentence. If someone from the community is reading my school work, they might know that I am talking about you, even if I don't say your name.



So, when we read over your interview, you can tell me if there are any words or sentences that you would like me to take out.



You might feel a little nervous or sad when I am talking to you and asking you questions about touch.



If you feel nervous or sad during the interview and you do not want to talk any more you can tell me this. You won't get in trouble if you say that you do not want to talk anymore. Nobody will be upset with you. If you are feeling upset and want to talk to someone, and you have chosen a Safe Person, you can talk to _____ (Safe Person). If _____ is not here in the room with us, I will go and get _____. I will tell you and _____ of some people that you can talk to if you are sad because of our conversation. If you are feeling at all sad, please tell me and you can decide if you would like to stop the interview.



It is important that you feel safe and comfortable when you are talking to me.



If you are comfortable with talking to me about your life at L'Arche, and about how assistants use touch with you,



you will be helping me to learn about what makes touch comfortable and safe at L'Arche.



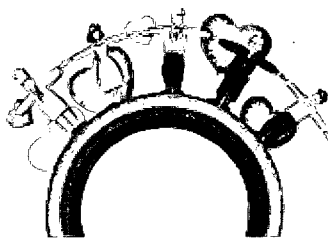
This will help your community to know more about using touch safely with one another.



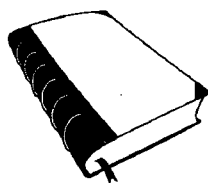
This will help people to feel good when they use touch with each other.



You have the right to join in this research, because it is about you and your community. You are an important part of your community.



After I have thought a lot about the stories you have shared with me, I will write your stories down in a book.



This will help me to share your stories with other people so that they can learn from this research.



Is it okay with you if I ask you some questions about your life here at L'Arche, and how assistants use touch with you?

YES _____ NO _____

If I remove your name, is it okay with you if I share your words with other people?

YES _____ NO _____

If I remove your name, is it okay if I show other people the picture you coloured?

YES _____ NO _____

Is it okay if I use a tape recorder to remember our conversation?

YES _____ NO _____

Would you like to choose a Safe Person?

YES _____ NO _____

If yes, who would you like your Safe Person to be?

Do you want _____ to be in the room with us while we do the interview? YES _____ NO _____

Do you want _____ to be in the same building as us but in a different room while we do the interview?

YES _____ NO _____

Do you want _____ to help you to help you to go back into your day?

YES _____ NO _____

If you see a counselor, do you want me to tell them that you are taking part in an interview? YES _____ NO _____

Participant's signature _____ Date _____

Researcher's signature _____ Date _____

Safe Person's signature _____ Date _____
(If applicable)

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