# REGULATION OF THE PROFESSIONAL RELATIONSHIP:
# A CASE STUDY

BY DEBORAH TOMLINSON, B.A., B.S.W.

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AUTHOR: Deborah Tomlinson, B.A., B.S.W. (McMaster University)

SUPERVISOR: Ann Fudge Schormans

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# Abstract

The social inclusion of adults with intellectual and developmental disabilities remains an elusive goal for many adults, their families, and allies. Many of the typical relational human interactions people without intellectual and developmental disabilities enjoy and take for granted, have been denied to adults with intellectual and developmental disabilities, largely because of harmful conceptualizations of what it means to live with a disability. These conceptualizations have not only influenced the development of public policy but they have also shaped the interactions and relationships between professionals and adults with intellectual and developmental disabilities. Equipped with the historical knowledge of how public policy was used to cultivate and maintain the mass institutionalization of adults living with intellectual and developmental disabilities – and then subsequently used to lead to it’s demise – this study set out investigate if and how public policy might influence the nature of professional relationships between service users with intellectual and developmental disabilities and service providers. Using qualitative methods guided by critical disability theory, this study looked specifically at how *Ontario Regulation 299/10* has already, and/or may in the future, change the interpersonal relationships that exist between adults living with intellectual and developmental disabilities and their care-givers at L'Arche Hamilton. Research methods included working with the policy document and also conducting face-to-face interviews with adults with intellectual and developmental disabilities and their caregivers. It was important for this study to include the voices of adults with intellectual and developmental disabilities and to examine the research question from their perspective because without their input it would not be possible to really understand the regulation's impact.

This study focused on the current experiences of three residents (core members) and three care-givers (assistants) at L'Arche. It was found that there exist genuine and caring relationships between the two; relationships shaped by the understanding of the assistants that adults with intellectual and developmental disabilities have something of value – a "gift" – to contribute to what they define as a mutual relationship. In addition, both core members and assistants point to the importance of human touch in care-giving interactions – touch that moves beyond the functional (e.g., assistance with personal care) to also include expressive touch (e.g., hugs) that conveys affection and love. However, the findings further suggest that *Ontario Regulation 299/10* threatens the ability of care-givers to engage in the intentional form of relationship which currently exists within the L'Arche service model. This form of relationship is understood to be restricted by the regulation under the guise of "protection" and as being "best practice". The legislation recognizes that people living with disabilities have

higher rates of abuse then those living without disabilities; in response to this reality the legislation attempts to reduce opportunity for such abuses to occur and, as a result, articulates clear boundaries around the type of relationships that are permissible. The assistants interviewed for this study also recognize these concerns but they also worry that these concerns overlook the reality of the limited opportunities for genuine relationships between adults with intellectual and developmental disabilities and those without. Further research, directed by adults with intellectual and developmental disabilities, is needed to unpack how this relationship is understood and experienced by both parties, and how each feels it should be maintained, especially in regards to the use of physical touch as an expression of relationship. Research which engages the core members in dialogue on what “safety” and “relationship” mean and looks like for them is needed in order to truly understand the potential impact limiting the professional relationship may have.

# Acknowledgements

First and foremost I would like to thank the core members and assistants of L’Arche Hamilton who welcomed me into their home and shared with me what it means to live in community and in relationship.

This thesis would not have been possible without the patient guidance, astute feedback and on-going support of my supervisor Anne Fudge Schormans – this study would not have been possible without her and for that I am grateful.

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## Introduction

Within social work practice the ability to develop and maintain rapport with service users are a fundamental practice skill. How this relationship manifests itself can differ for different practitioners based upon a multitude of factors. The social work code of ethics outlines several basic guiding stipulations for what this relationship should look like. For instance, the code instructs practitioners to "maintain the best interest of the client as the primary professional obligation" (Ontario College of Social Workers and Social Service Workers, 2008, p. iv). But what is the best interest of the client? And who gets to decide? These questions, as they percolated in my mind, drew me to explore the central research question of this thesis – how public policy affects practice. This question led to exploring how public policy sometimes attempts to regulate and set boundaries to the professional relationship. While in of themselves these limits, or, if you will, guidelines that are put forward by public policy are meant to protect the best interests of the clients, do they always?

Individuals with intellectual and developmental disabilities have lived through a dark history of institutionalization and maltreatment created, at least in part, by inadequate and oppressive – albeit generally well-intentioned - public policy that for many years was endorsed by the Canadian public (Simmons, 1982). Their history is a prime example of how best practice did not serve the best interest of the client but, instead, masked the ignorant fears of society behind the guise of protection and service. With the dismantling of institutions in favour of a community-based approach to service provision, the lives of adults with intellectual and developmental disabilities continues to be shaped and altered by public policy. The newest addition to the policy repertoire is *Ontario Regulation 299/10 (2010),* which seeks to promote the social inclusion of adults with intellectual and developmental disabilities in their communities and to promote abuse prevention by setting limits to the professional relationship. I wondered how community agencies and service-providers would interpret this new act and what it might mean to how they delivered service. In particular, I was interested in how one organization, L'Arche, might be impacted by this new legislation. From what I knew of L'Arche it does not understand, or confine the relationship between caregivers and adults with intellectual and developmental disabilities within a strictly defined professional model. However, under the newest legislation this relationship is defined in such a way that sets limits on the boundaries of a professional relationship.

In order to carefully explore how Ontario *Regulation 299/10* may affect the professional relationship, this thesis reports upon my research into how the regulation has affected life at L'Arche Hamilton. L'Arche is an international intentional community of group homes for adults with intellectual and developmental disabilities in which people with and without disabilities live together. L'Arche was the only group home identified by the Canadian Mortgage and Housing Corporation, in their 2006 report *Housing for Adults with Intellectual Disabilities*, as being best practice for adults with intellectual and developmental disabilities - because the staff function more as 'family' than 'paid staff' (Lenk, 2010). L'Arche homes foster a unique relationship between their staff and residents, one that differs from those typical of other residential services, but one that may be challenged by the introduction of *Ontario Regulation 299/10*. So, are these newly introduced regulations impacting the relationship between service users and service providers (and if so, how)? And, who gets to decide what serves the best interest of the residents with intellectual and developmental disabilities at L'Arche? This study set out to explore just that.

# Background Information

## Disability policy and deinstitutionalization

In order to discuss how contemporary social policy affects service provision, it is necessary to provide a brief, yet concise, history of disability policy in Ontario. There is a dense historical literature demonstrating how policies affecting the rights and wellbeing of those living with intellectual and developmental disabilities in this province have been shaped over the past century; for example, Harvey G. Simmons (1982), in his text *From Asylum to Welfare*, provides an in-depth look at this evolution. A significant phenomenon noted by Simmons was the common practice of housing those with many forms of disability in institutions. (For the purposes of this study I will focus on the experience of adults with intellectual and developmental disabilities.) This process is commonly referred to as institutionalization.

The Ontario ministry of Community and Social Services website also provides a comprehensive, albeit slightly biased[1], depiction of the process of

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[1] Despite substantial literature that documents the maltreatment of children and adults living with various forms of disabilities while institutionalized (for example, Simmons, 1982; Brown et al, 2007 and Fudge Schormans & Sobsey, 2007), the Ministry of Community and Social Services website presents the historical development of these institutions without acknowledging or accepting accountability for the horrendous abuses that occurred. Instead, these institutions are

institutionalization and its eventual demise (Ontario Government, 2009). When describing why such institutions existed the website states that, "doctors counselled parents to send their children to institutions...so they could be sheltered from the stresses of everyday life and the judgment of society" (Ontario Government, 2009). This is not to say that doctors were acting alone. Instead these doctors are but an expression of a larger societal belief that adults with intellectual and developmental disabilities were unable to function in society and could be/needed to be rehabilitated in institutions (Brown, Buell, Birkan, and Percy, 2007).

However, these institutions also served to separate individuals with intellectual and developmental disabilities from their families, to isolate them from their communities, and to exclude them from the types of lives and relationships that non-disabled citizens took for granted, but this version of how services for adults with intellectual and developmental disabilities operated cannot be found on the Ministry of Community and Social Services website. Instead, this particular historical narrative uncritically presents the practice of institutionalization as best practice and as a way of protecting adults with intellectual and developmental disabilities from the harsh realities of life. The need to protect those with disabilities is a common theme throughout literature

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presented as a necessary step in the evolution of providing care for children and adults living with disabilities.

and will be further unpacked, but first let me continue to unravel the history of disability policy in Ontario.

Beginning in the 1800s, asylums[2] housed those who could not work and were perceived to be a burden on society; the function of asylums, or institutions as they will be referred to from here on, was to segregate those who lived within their walls from the rest of society (Partingon, 2005). Conceptually, these institutions emerged from a humanitarian approach to supporting those in society who were seen as less fortunate and were organized around an educational model of service delivery. As a result, they began as places where residents could be treated, potentially rehabilitated, and learn necessary skills to be reintegrated into their communities (Woodill & Velche, 1995; Kyle, Sandys, & Touw, 2010; Brown et al, 2007).

At their inception it was not intended that participants would permanently reside in these institutions (Simmons, 1982). Brown reminds us that these institutions were originally created by “well-meaning”, even “progressive”, individuals in their time (p. viii, 2004). In Ontario, the first institution opened in 1876 outside of the city of Orillia and accommodated 2,300 people at it`s peak

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[2] Asylums were large institutions that housed people with various forms of mental, physical, intellectual and developmental disabilities (Simmons, 1982). They were simultaneously overcrowded, lacked funding, and overused medication (Brown, 2004) and often relied on a medical model of disability which will be discussed shortly.

(Kyle et al, 2010; Brown, 2004). As more and more people were placed into these institutions, while funding remained stagnant and community support and resources for re-integration dwindled, the education model was no longer deemed to be manageable. Coinciding with these increased service demands during the late 1870's was an ideological shift that no longer viewed adults with intellectual and developmental disabilities as needing protection but, instead, understood that "society was to be protected from them" (Simmons, 1982, p. 22). The humanitarian tradition that determined the asylum model overlapped with and was eventually replaced by a custodial model (Simmons, 1982) that was focused on social control rather than education (Woodill & Velche, 195).

Many factors were implicated in this shift. It was difficult to justify the permanent isolation of adults with intellectual and developmental disabilities as being 'for their own good'. There was also the emergence of what Simmons (1982) refers to as the myth of the feeble-minded. The term feeble-minded was coined when children, without observable physical or cognitive disabilities, who struggled to do well at school began to be identified in increasing numbers; these children were also referred to as being "simple" (Simmons, 1982, p. 65). The threat of the feeble-minded was their assumed connection to social problems of the time; specifically, unwed mothers, poverty, and crime (Simmons, 1982, see also Brown, 2004). Feeble-mindedness was thus perceived as a moral disease that was undesirable and needed to be controlled or eradicated (Simmons, 1982; Brown et al, 2007).

Under the legislation of the time, only those who were deemed "idiots" or "insane" [3] were legally able to be detained in asylums, but there was an active movement of social reform groups' intent on social control who were organized for the sole purpose of changing the legislation so that the feeble-minded could also be detained in institutions (Simmons, 1982). There was great debate about the feeble-minded who were seen as *"almost normal"*; a class of people separate from non-disabled people as well as from idiots or lunatics who were more easily identifiable either by physical impairment or cognitive limitations (Simmons, 1982, p. 65). However, those who were seen as being feeble-minded did not necessarily have any distinct physical characteristics that distinguished them from the general public and could often go unnoticed in a crowd of people; therefore it required the expertise of trained professionals to identity who was feeble-minded (Simmons, 1982).

As a form of social control, this process of being categorized as feeble-minded was vague and ambiguous but is representative of the rise of scientific,

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[3] The terms "insane" and "idiot", while often used interchangeably to refer to those who lived with mentally illness, a physically disability and/or an intellectual and developmental disability, actually refer to different things. Brown (2004) defines the historical use of "insane" as referring to individuals living with a psychiatric diagnosis and "idiot" as referring to individuals living with an intellectual disability.

medical, and professional expertise – an expertise that similarly came to rule the lives of those categorized as intellectually or developmentally disabled (Simmons, 1982). This was the emergence of the medical model of disability, which continues to play an important role in shaping how disability is conceptualized and will be further discussed shortly.

However, the ultimate form of social control for people with disabilities – including people with intellectual and developmental disabilities and the feeble-minded - was enacted through forced sterilization; a method by which it was believed that genetic deficiency – and thus moral degeneracy - could be eliminated (Simmons, 1982; Brown et al, 2007). The eugenics movement, concerned with controlling the assumed threat of feeble-mindedness and other disabilities, moved north from the United States to Canada; Alberta was the first Canadian providence to introduce sterilization in 1928 and from there it spread to other provinces - including Ontario (Simmons, 1982). The eugenics movement was a dramatic rejection and devaluation of difference. L'Arche's model of service stands in direct contrast to this rejection and devaluation by creating community with adults with intellectual and developmental disabilities.

Reviewing this history it is clear that during this time public policy was being debated around the questions of who should and should not be institutionalized, who should and should not be able to bear children. At the heart of the arguments was the creation of what was to come to be understood as “disability” and “disabled persons”. This conversation around the social construction of disability is an important concept to the research study and will be further explored throughout this study. While this study will focus on adults with intellectual and developmental disabilities, formally referred to as lunatics or idiots, the history of the myth of the feeble-minded was intentionally included in this historical review to connect how disability and the language used to describe disability has been shaped over time. It is also representative of how outsiders, those who are categorized as non-disabled, act upon the disability community through public policy. It is a historical marking of how our understanding of disability can shift over time and how the power of labelling also shapes our perception of disability.

Complicating this historical narrative of policy for people with intellectual and developmental disabilities even further was the emergence of industrialization. Notions of productivity, as defined by a changing economic landscape, complicated what it meant to be a contributing member of society. Many people with disabilities were not able to meet increasingly restrictive understandings of what qualified as ‘productive’. Also, as a direct result of industrialization, people were moving into smaller geographical regions and those who were perceived to be different (either because of physical presentation, social interaction, or cognitive ability) were that much more visible (Brown et al, 2007).

An interesting observation to consider regarding the institutionalization of adults with intellectual and developmental disabilities is that, before the introduction of capitalism, adults with developmental disability were often successfully integrated into the workforce, engaged to perform simpler or more repetitive tasks that did not require specialized training (Partington, 2005).

When the economic culture shifted and these jobs became harder to find, adults with intellectual and developmental disabilities were increasingly seen as burdens (Partington, 2005). As is evident in Simmons' description of the historical landscape of disability policy, individuals with disabilities were seen as a problem to be solved – a faulted individual – instead of exploring how environments could be impacting the human experience.

However, through all of this there were dissenting voices; in Ontario B. T. McGhie was one of them. In 1928, McGhie became the acting superintendent of the Orillia asylum (Simmons, 1982). During his time at Orillia, McGhie began voicing his support for the deinstitutionalization of both children and adults with intellectual and developmental disabilities and moving them into the community. He proposed the radically new idea that, "the main purpose of Orillia was to prepare mentally retarded children to return to the community" (Simmons, 1982, p. 123).

Preparing children for life in community was one of the original founding premises of institutions but was lost over time because of numerous ideological shifts, making it seem once again to be radical in McGhie's time. McGhie based his argument upon the idea that between disabled and non-disabled children "the points of resemblance of the groups are much greater then the differences" (Simmons, 1982, p. 122). McGhie valued both groups of children equally. While he recognized there were differences amongst the children, he also recognized a shared basic level of humanity. This was an essential shift in ideology because it no longer placed a person's value upon their cognitive or physical ability but, instead, assumed an inherent worth. This understanding of an inherent worth is integral to the L'Arche model and will be further explored when exploring what this model entails:

> The social problem, or in other words the problem of the community, would seem to be to provide for the necessary training and socializing of the retarded individual and, having made this provision to educate the so-called 'normal' members of the social group to adopt a helpful and understanding attitude which will enable the retarded members to take their place in society and be reasonably happy (Simmons, 1982, p. 124).

He believed that with the right supports and some societal restructuring, those with disabilities could be integrated back into the community. McGhie's and the counter-perspectives of others like him,[4] can been seen as the start of an

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[4] Dr. Clarence Hincks shared McGhie's understanding; one example can be found in a speech he gave on January 28th, 1925 that called into question many common practices, assumptions, and notions of the feeble-minded, however, his concerns were largely ignored (Simmons, 1982).

ideological shift that, in time, led to a social constructionist understanding of disability and to deinstitutionalization.

Moving forward in history to the introduction of the Rehabilitation Act in 1955, those living with an intellectual and developmental disability were, in time, able to access professional services which were previously not available to them (Kyle et al, 2010). Following World War II there were an increased number of veterans who faced physical disabilities as a result of the war and, as advances in rehabilitating veterans were made, these new technologies and interventions expanded to include other individuals living with various disabilities (Kyle et al, 2010). In 1958, the Smiths Falls Hospital School Welfare League, a group of parents of institutionalized children began advocating for improved services for their children and family members (Kyle et al, 2010). This was in stark contrast to the (publicly) unquestioning parent of earlier years; families were now speaking out and more often against institutions' claim of expertise. Parent groups across the province played a significant role in successfully moving forward the process of deinstitutionalization by advocating on behalf of their family members (Lemay, 2009).

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Hincks questioned the validity of confining to an institution a person with a low intelligence score who could be integrated into the community as a good worker if s/he had an appropriate education starting from a young age (Simmons, 1982). He spoke about social adaptability and the importance of establishing supports in the community that would enable those deemed feeble-minded to be integrated into community (Simmons, 1982).

By the 1960's, the Community Living movement was active in Ontario: it, too, was started mainly by family members who argued that individuals living with intellectual and developmental disabilities had always been (although in limited numbers), and should always be able to, live in their home communities (Kyle et al, 2010). They argued that in their home communities adults with intellectual and developmental disabilities could, once again, access the relationships, love, and care of their family and friends from whom they had been segregated. The institutional experience could provide only a limited number (if any) of meaningful relationships to people with intellectual and developmental disabilities. Supportive family relationships played a significant role in the successful reintegration of adults with intellectual and developmental disabilities into their home communities (Lemay, 2009).

With each passing year there appeared to be a growing momentum for deinstitutionalization. In 1974, when the *Developmental Services Act* passed, there were sixteen institutional facilities operating in Ontario and providing care to more then 10,000 residents with intellectual and developmental disabilities (Kyle et al, 2010). The *Developmental Service Act* introduced, for the first time, the concepts of autonomy and social inclusion to the services provided to those living with disabilities and how the services were to be provided (Kyle et al, 2010). The passing of this Act set the stage for the active process of deinstitutionalization.

Current conditions for people intellectual and developmental disabilities have evolved from segregation to a commitment, in 1987, by the Ontario government to focus on a community-based system of services instead of an institution-based system of care (Kyle et al, 2010). In that year, the Ontario government announced their intention to close all residential institutions in a document entitled *Challenges and Opportunities: Community Living for People with Developmental Handicaps* (Kyle et al, 2010). However, it took until 2009 for the final three institutions to close in Ontario (Kyle et al, 2010). It wasn't until 2008 that the *Social Inclusion of Persons with Developmental Disabilities Act* replaced the 1974 *Developmental Service Act* (Kyle et al, 2010). The introduction the 2008 act was an important evolution of disability policy because, until then, services and policy had been guided by a document that was created prior to deinstitutionalization. Frankly, the 1974 *Developmental Services Act* was out-dated and no longer represented the current ideological stance underpinning developmental services. While there is still much debate about the motivation for community care (as a matter of human rights or as being more of a fiscal or economic concern linked to a tightening of the provincial budget), it does also represent a significant practical shift around intellectual and developmental disability (Partington, 2005).

With this debate in mind it is important to highlight that, for good or ill, community care has shifted responsibility for care away from formal state-run institutions to informal caregivers, such as the family (Galvin, 2004). In Canada, it is estimated that 75 to 90 percent of all care provided to people with intellectual and developmental disabilities is informal (Galvin, 2004). This is an important number to consider when looking at the on-going development of public policy around disability.

As I have sifted through the dense and evolving landscape of disability policy it becomes apparent how ideology, political climate, and social norms affect disability. This historical account reminds me that policy has consistently shifted and been re-negotiated to determine who is and is not deserving of service and what constitutes “best practice’.

## Best practice and the role of protection

At the root of this discussion of best practice is the common element of protection. This was seen in the historical literature and continues to play a significant role in current policy development. In Canada, the United States, Australia, and Britain there are various forms of adult protection services and legislation for people with intellectual and developmental disabilities; these services emerged in the 1990’s as a result of increasing numbers of reported cases of abuses against vulnerable adult populations, including seniors, adults with developmental disabilities, and those accessing mental health services (Mansel et al, 2009; Gordon, 2001; Beadle-Brown et al, 2010).

Throughout the literature there is some debate that those living with a disability are at greater risk of abuse and maltreatment (Beadle-Brown et al, 2010; White, Hollad, Marsland, & Oakes, 2003; Bigby & Fyffe, 2006; Mansel et al, 2009). As a result of this mounting concern it seems justified and rational that the creation of relevant services or legislation - such as *Ontario Regulation 299/10* - has occurred. What is significant to note, however, is the approach that is taken by some of these measures to address abuse prevention. The existence of abuse prevention policies is a positive development. However, the issue at hand is much more complex and at times problematic then these policies might suggest as will become clear in a later section of this thesis.

Simmons cautions us with a reminder that this notion of protection, "against the vicissitudes and cruelties of the outside world goes back to the very beginning of mental retardation policy and was the central justification for the asylum model of care" (1982, p. 66). This will be important to keep in mind when considering the potential impacts of *Ontario Regulation 299/10* on life within L'Arche. It is this historical understanding that prompts the necessity of critical examination of how protective policies interact with service providers and users. Community organizer John McKnight cements critical examination as necessary by articulating that often, under the guise of protection, some of humanity's worst forms of victimization and abuse have occurred (Porter, 2005).

Looking at contemporary disability policy, as it exists in western countries, White et al (2003) comment that much of it is a reactive measure that attempts to safeguard against the abuse and mistreatment of those with disabilities once abuse and maltreatment have occurred. Protection, in and of itself, is a good thing however this approach to protection does not recognize the compounding factors that may cultivate environments in which abuse occurs. It is argued that current institutional policies which outline procedures for reporting and responding to abuse when it has occurred do not address any pro-active means of eliminating environments or situations that cultivate or possibly condone the abuse of adults with intellectual and developmental disabilities (White et al, 2003). As a prominent example of this, White et al (2003) provide and summarize the conceptualization of the *bad apple* in policy making. This conceptualization centres on the idea that maltreatment occurs because of a few *bad apples*; people who are deviant, the exception, and not the norm, and that, therefore, an organization requires only thorough staff-screening practices to weed out these bad apples and thus prevent abuse (White et al, 2003). Again it is important to recognize that this type of policy and procedure can be a valuable asset, however, they do not often include pro-active initiatives to stop abuse before it occurs.

In addition to the bad apple model, there is a body of literature addressing why abuse occurs in the context of caregiving relationships between adults with intellectual and developmental disabilities and their caregivers. Some research has suggested the competence of managers and their relationship with staff is an important factor in the protection against abuse of residents (White et al, 2003; Cambridge, 1999; Foster, 2007). Other research has suggested inadequate or insufficient training of staff persons can lead to abuse during interactions between staff and adults with intellectual and developmental disabilities in which the disabled adults are engaging in, for example, what are perceived to be difficult behaviours (Chung & Harding, 2009; White et al, 2003).

Emerging from the research literature, what is most interesting for this study is the importance and significance being placed upon 'staff culture'. There is an increasing emphasis in the research into the abuse of adults with intellectual and developmental disabilities on an understanding of how stress factors into the caregiver relationship (Chung & Harding, 2009; White et al, 2003). However, stress faced by staff as a result of often being overworked and underpaid (Kittay, 1999) is but one component; staff culture – which impacts both attitudes and behaviour – is also shaped by the staff training, organizational climate, working conditions and staff support (White et al, 2003). Each of these components contributes to healthy, or unhealthy, working environments and play significant roles in shaping how relationships with adults with intellectual and developmental disabilities grow. It will be difficult in an unhealthy staff culture, one in which the staff persons are is overworked, bitter and resentful, for staff persons to develop meaningful relationships with people with intellectual and developmental disabilities.

Part of the staff culture is the way in which disability is constructed. Individuals living with physical disabilities have provided countless stories of being talked to differently than their non-disabled peers; sometimes they are talked to more loudly or more slowly (Liesner & Mills, 1999). There appears to be a perceived understanding of, and a connection made between, the individual's physical capacity and dependence upon others to assumptions regarding their intellectual capacity that leads to infantilizing interactions (Liesner & Mills, 1999; Robey et al, 2006; Cushing & Lewis, 2002). Unfortunately, it does not require a great deal of imagination to see how this infantilization of individuals with physical disabilities might also translate onto the interactions between adults with intellectual and developmental disabilities and their non-disabled caregivers and peers. This notion of a staff culture will be an important concept when exploring the L'Arche model in light of *Ontario Regulation 299/10*.

## Ontario Regulation 299/10

*Ontario Regulation 299/10* was introduced in the summer of 2010 and was designed to accompany the *Services and supports to promote the Social Inclusion of Persons with Developmental Disabilities Act*[5] which came into affect in 2008;

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[5] http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_08s14_e.htm

the regulations captured by *Regulation 299/10* did not come into effect until January 1, 2011 (Ontario Regulation 299/10, 2010). All service agencies that provide supports or services to adults with intellectual and developmental disabilities are required to adhere to *Regulation 299/10* (2010). All staff persons at these organizations were also required to attend training sessions in the fall of 2010. At this training, staff persons were informed that these regulations were created as a result of concerns expressed by self-advocacy groups of people with intellectual and disabilities (Quality Assurance Measures, 2010). No indication was given of who the self-advocacy groups were or what their concerns were – just that they existed.

There are two core components of *Ontario Regulation 299/10*; they are the ‘protection’ and ‘social inclusion’ of those with intellectual and developmental disabilities (2010). These are concepts that commonly emerge when discussing deinstitutionalization and will be important when considering if *Ontario Regulation 299/10* has or will affect L’Arche’s service model. *Regulation 299/10* was created to provide directives for facilitating social inclusion; creating individual support plans; promoting health; abuse prevention & reporting; confidentiality and general safety of service users (Quality Assurance Measures, 2010). There are also eighteen additional Quality Assurance Measures for residential facilities, which include directives on everything from recreation to the physical structure of the residence (Quality Assurance Measures, 2010). While each of these directives is important, in this research it is the Quality Assurance Measures that pertain to protection and social inclusion that are of particular interest.

As part of the training around *Regulation 299/10*, staff persons were instructed on the types of training workshops that organizations can, and should, provide to residents with intellectual and developmental disabilities to educate them around this new regulation. One evident benefit of this training is the potential for on-going dialogue between families, residents, and service providers regarding the policies and procedures regarding abuse prevention. Additionally, adults with intellectual and developmental disabilities will be required to participate in annual workshops on abuse prevention (Quality Assurance Measures, 2010). This appears to be one small step in shifting agency responses from reactive to proactive. *Ontario Regulation 299/10* defines abuse as, "action or behaviour that causes or is likely to cause physical injury or psychological harm or both to a person with a developmental disability, or results or is likely to result in significant loss or destruction of their property, and includes neglect" (2010, p. 2).

On the handouts provided to staff there were several key components that adults with developmental disability should be taught in order to safeguard against abuse (Quality Assurance Measures, 2010). The first skill listed is boundary training. The training material informs staff that:

> It is easy for the offender to prepare the person with a developmental disability for abuse by using for example, close up hugs, or resting hands on thighs when talking. These are actions that paid care givers should never do (Quality Assurance Measures, 2010).

The training materials also make the distinction – a distinction that service providers must then make clear to residents and family members - that staff persons are not 'friends' or 'family' (Quality Assurance Measures, 2010). As will be addressed more fully in the next section of this paper, this distinction of the type of relationship that can and cannot exist between staff and resident may not sit well within the L'Arche model.

Another potentially positive action introduced by *Regulation 299/1*0 is the requirement that all agencies have a posted bill of rights for adults with intellectual and developmental disabilities (Quality Assurance Measures, 2010). Similar to the training provided around boundaries, the bill of rights is to be explained to residents and staff through a workshop-style presentation. It is recognized that unless residents are aware of their rights and how to access them a bill of rights is, in and of itself, useless. This bill of rights is understood not only to be about abuse protection, but also to be part of a service provider's requirement for agency-specific policy addressing social inclusion, but the regulation does not define or set out any parameters of what is meant by "social inclusion" (Quality Assurance Measures, 2010). As will be discussed shortly social inclusion is an elusive term that is used as an ideal goal but without much concrete substance to measure this against.

## L'Arche

The following is a brief introduction to L'Arche drawn from the work of Kathryn Spink in her book, *Jean Vanier and L'Arche: a communion of love* (1991). L'Arche is an international Christian community made up of community-based homes where adults with intellectual and developmental disabilities and non-disabled volunteers live together. These communities grew out of what may at first seem to have been a haphazard invitation by Jean Vanier to a group of people with intellectual and developmental disabilities to live life together. Vanier founded L'Arche after a visit to a local institution for adults with intellectual and developmental disabilities in France where he found the conditions to be, in his words, "repulsive" (p. 39). Vanier envisioned something different; he had a "desire to create homes – not institutions" (p.2). At the time he was living in a small village in France, Trosley-Breuil and, after his visit to the institution, he invited three men from the institution to come live with him in his home for a period of one month. Being a reasonable man he arranged for this trial period up-front to see if what he envisioned for living with these men was manageable. On the first day that the three men went to live with Vanier, after a celebratory lunch and once all the guests had left, “he found himself alone with this three new companions” (Spink, 1991, p. 39) and proclaimed himself “completely lost” (Spink, 1991, p. 39). Vanier then surrounded himself with people, from his own personal support network and eventually professionals, who were able to provide him with guidance.

There followed, for Vanier, a steep learning curve in communal living and also on how to live with marginalized people. The early days were tough but if you ask Jean Vanier why he extended this invitation he typically responded that it was because it was what “Jesus wanted” (p.1). A strong commitment to the Christian faith is at the core of L’Arche communities and of Vanier’s commitment to pursuing his vision of what Jesus wanted him to do. Shortly after inviting the men to stay with him he was asked to take on the directorship of a local institution (after its director left without much warning). Vanier was reluctant to do so, as the institution’s high number of residents would alter the small home environment he had envisioned for L’Arche, but with no one else available, Vanier accepted the role. Due to the insufficiency of staffing and Vanier’s inexperience the institution soon erupted into chaos as he tried to reconcile the conditions with his vision of human dignity and the realities of the residents’ needs. Eventually, volunteers and local professionals began to assist Vanier to understand the struggles and daily challenges of those living with intellectual and developmental disabilities. Vanier’s recognition of requiring the assistance of others would eventually evolve into a model of support that would come to characterize the L’Arche model of care. These humble and, at times, chaotic beginnings gave forth to a movement. Also, at this time French legislation was encouraging the creation of smaller, community-based homes for adults with disabilities through the financial incentive of twenty-one francs per resident per day. In France, this shift in legislation coincided with the beginning of the larger global movement (evident also in Ontario) of deinstitutionalization.

As of February 2005, there were twenty-six L’Arche communities and two hundred L’Arche homes operating on a global scale (Porter, 2005). L’Arche has grown from Vanier’s invitation to three men to include thousands of people with intellectual and developmental disabilities worldwide. While each home is unique, each follows a similar model. The adults with intellectual and developmental disabilities are typically referred to as the “core members” of the community, and those non-disabled or differently disabled people who come to live with or assist the core members are referred to as “assistants” (Reimer, 2009). Assistants are, as Reimer, describes them, “people who have for one reason or another come to be with them” (Reimer, 2009, p. vii). This is an indication of the philosophy of mutuality that is at the centre of the L’Arche model and will be discussed shortly. Interesting to note is that assistants, at one time, were volunteers who were not paid salaries but were, instead, given small honorariums in addition to room and board (Spink, 1991). Salaries were not paid because, “the absence of a regular salary would help them [assistants] to deepen and clarify their motivation" (Spink, 1991, p. 58). Currently, assistants are paid small salaries in addition to room and board (Kelly, 2010). Together the core members and assistants share in and make decisions about daily life (Spink, 1991).

At the core of L'Arche is relationship; Vanier started L'Arche on the simple idea of acceptance of others despite circumstance or ability (Porter, 2005: Cushing & Lewis, 2002). L'Arche is not modeled upon a traditional professional staff/client relationship but, instead, attempts to build relationships in which both participants contribute equally in their own way. However, these relationships are not without their struggles. The relationships between core members and assistants are always instrumental as well because assistants assist (Cushing, 2003). Many of the ways assistants assists is with tasks that adults with intellectual and developmental disabilities cannot do on their own; Kittay (1999) passionately writes of how these tasks – which her own daughter requires much assistance with (for example bathing, eating, dressing) – create opportunities to abuse the trust placed in caregivers and creates an imbalance in power distribution. How this imbalance in relationships plays out is widely debated (Cushing, 2003) and accounts for some of the scepticism around whether truly mutual relationships can exist between adults with intellectual and developmental disabilities and their caregivers. However, L'Arche is not focused on idealistic notions of equality as it is typically understood, but with giving and receiving from one's ability (Cushing, 2003). Vanier believes that for both those with and without intellectual and developmental disabilities "the learning which needs to occur in adults will take place as the relationship develops" (Foster et al, 2007, p. 40).

L'Arche provides a concrete example of what has been defined as a transformational learning process; the core members and assistants engage in this process of transformation by coming together to better understand and meet each others needs (Foster et al, 2007; Cushing & Lewis, 2002). This model recognizes that both core members and assistants receive benefits from living at L'Arche and the relationships that develop there. To summarize, the L'Arche model challenges the "basic human definition" (Reimer, 2004, p. 6) of what it means to live with a disability, to provide care, and to be in relationship with adults with intellectual and developmental disabilities as a caregiver. This is not a denial of impairment; instead it is creating adaptive spaces for multitudes of abilities (Delvin & Pothier, 2006). The culture within each L'Arche home is geared to meet the needs of everyone who lives there and is argued to be an example of what is possible when barriers fall away (Porter, 2005). L'Arche is about people choosing to live together and to fully integrate their lives together.

Vanier was sure of two things when he started this journey, "one was that what he was doing was irreversible; the other was a somewhat ambivalent feeling about possible growth...there was a model of community which consciously or unconsciously he was following" (Spink, 1991, p. 42). Within this is "an approach which is more about being with and less about doing for the individual with disabilities" (Foster, 2007, p. 44). While this model is revolutionary it would be naive to ignore the many struggles within these intimate communities. There are many personal narratives of both core members and assistants that highlight the challenges of adapting to this way of life (Reimer, 2009; Spink 1991; Cushing & Lewis, 2002). Most of these narratives are grounded in relational conflicts or of experiences of culture shock – adjusting to living in an intentional community (Spink, 1991). Life at Larche, like life everywhere, is messy. However, coming out of this learning curve the larger Canadian L'Arche community has created best practice guidelines for working and living with adults with intellectual and developmental disabilities entitled *More Than Consult* (Porter, 2005). (Direct comparisons of *Regulation 299/10* and *More than Consult* will be woven throughout this paper.) Beth Porter (2005) compiled contributions and knowledge from many different residential settings across Canada and from the individuals with intellectual and developmental disabilities and the assistants who live there. The focus of this document is the social inclusion that occurs within the walls of L'Arche - but also within the larger community – and on how other service agencies might implement these practices to improve services and supports for the people with intellectual and developmental disabilities who use them (Porter, 2005). Porter summarizes the document by stating:

> Our hope is that this little book will stir individuals in the general public and social service agencies, friends and family members and also government policy makers to imagine new ways of seeing and welcoming the potential contribution of people with developmental disabilities. A society needs all its citizens to contribute if it is to be healthy. Ironically, it is the very people whom our society so readily excludes whose humanizing gifts are most needed today. It will be through meaningful relationships – relationships of mutuality – that lasting changes will come about in the perspective and practice of individuals and eventually of society as a whole. And when the wider society grasps the benefits it receives from including all its citizens, the work of pleading for inclusion will no longer be necessary (2005, p. 10).

## More than inclusion: L'Arche's approach

In stark contrast to how *Ontario Regulation 299/10* addresses relationships between caregivers and service users, the community of L'Arche (as outlined in the *More Than Inclusion* document) centres relationship as the main means of achieving social inclusion (Porter, 2005). While there are many definitions of what social inclusion means, it is my understanding that social inclusion is ensuring that adults with intellectual and developmental disabilities "have full and fair access to activities, social roles and relationships directly alongside non-disabled citizens (Bates & Davis, 2004, p.197). Social inclusion is not merely being physically present in a community and was not automatically achieved with the closing of institutional care. This notion has been widely and soundly critiqued in the literature as it misrepresents the experiences of those living with disabilities (Cummins & Lau, 2003; Partington, 2005; Reynolds, 2008). However, the concepts of 'community' and 'social inclusion' are often still used and understood to be interchangeable when discussing and developing disability policy. Community can be used to mean one of three things; a geographical region; a common identity; or to refer to issue-based communities (Craig, 2007). L'Arche's community is defined by a common identity. While there is, arguably, some overlap between the two concepts – community and social inclusion – failing to recognize the particularities of each construct can be a problem. The separation of the two concepts serves also as a rejection of this notion of physical presence and social inclusion being one and the same.

The question that remains is "Why does meaningful social inclusion of adults with intellectual and developmental disabilities still appear to be an unattained goal?" Much of the research that attempts to answer this question articulates that adults with intellectual and developmental disabilities continue to experience isolation because their inclusion in communities may require the non-disabled members of those communities to rethink how they have structured the community and the lives of the members in it (Partington, 2005). L'Arche acknowledges that by focusing on intentional relationships they "challenge some of the boundaries between caregiver and friend" (Porter, 2005, p. 78), but they also willingly and actively rethink how they have structured their community to include adults with intellectual and developmental disabilities. Within an intentional, identity-based community like L'Arche, one which comes together around a common mission or philosophical worldview, this restructuring and the ongoing and reflective process of being socially inclusive may be easier than for a geographical region in which members may not feel the need or motivation to consider engaging with the process of change that may be necessary to achieve the social inclusion of all of it's members. Social inclusion requires the members of the larger community to shift their way of life – a shift which may be resisted; "the cry of the person in need inconveniences those who are comfortable and satisfied with themselves and their lot" (Spink, 1991, p.2).

L'Arche further recognizes that some have articulated that "professional distance" is needed because of unequal power distributions inherent to care-giver/service user relationships, however, L'Arche also highlights that adults with intellectual and developmental disabilities have been socially excluded and it seems "illogical to prohibit friendships with caregivers" (Porter, 2005, p. 79). The reality is that adults with disabilities tend to have very small social networks in which staff or family members are often the only non-disabled members (Cummins & Lau, 2003). As I learned more about L'Arche and *Ontario Regulation 299/10* the tension resulting out of the contrasting views of the boundaries of professional relationships became evident. Both Cushing & Lewis (2002) and Pottie et al (2004), in their research on L'Arche, also highlight how these friendships can sometimes manifest themselves through physical touch; again another practice advised against by *Ontario Regulation 299/10.*

### Human touch in care-giving relationships

There was limited research literature available on the use of human touch in care-giving relationships with individuals with intellectual and developmental disabilities; much of the literature that did exist was confined to the profession of nursing in which touch has been categorized as a “fundamental human need” (Bush, 2001, p. 256). Giasson and Bouchard (1998) and Bush (2001), through their own studies, highlight the potential benefits of the use of therapeutic touch on an individual’s sense of well-being. However, these studies also note that there is limited research literature on the benefits of therapeutic touch and that more research is needed.

Gale and Hegarty (2000), in their work on the use of touch with adults with intellectual and developmental disabilities in the field of nursing distinguish three types of human touch which will be important to consider in relation to core member/assistant relationships within L’Arche; expressive, functional, and therapeutic. Functional touch occurs when a physical caring task occurs – this type of touch is a result of a caregiver’s role and nonverbally communicates a requirement for the touch to occur. Expressive touch nonverbally expresses a desire or willingness to engage in physical contact with another person. Gale and Hegarty (2000), provide the example of “holding a person’s hand to convey empathy” (p. 99). Therapeutic touch is used for the physical or psychological benefit of someone. Gale and Hegarty (2000) further distinguish that functional touch is a routine part of a care-giver’s role, but that expressive or therapeutic touch are used at the discretion of caregivers. Within the field of nursing, their research suggests that “expressive touch, used deliberately and professionally, as a therapeutic medium, should be incorporated into the provision of care” (Gale & Hegarty, 2000, p.105). In light of the blatant stance against the use of physical touch within the care-giving relationship explicit in *Ontario Regulation 299/10,* and the anecdotal examples of how touch is woven throughout the L’Arche experience between core members and assistants, I am interested in exploring how this tension manifests in the daily practices of L’Arche.

# Conceptual and theoretical framework

It is evident from the historical review that the way disability has been conceptualized has shifted overtime and this has shaped the development of public policies and practices in the support and services for adults with intellectual and developmental disabilities. Traditionally disability has been approached from a medical model; this was briefly seen in the literature summarized earlier and will be demonstrated through references to the history of policy and practice outlined above. However, more recently there has been an ideological shift to a social model of disability. Both of these models will be briefly described in order to introduce my own theoretical positioning within a critical disability theoretical lens.

## Medical Model of Disability

Through the lens of a medical model, disability is perceived as a biological or medical problem, one that requires diagnosis and specialized intervention by professionals (Foster et al, 2007; Hosking, 2008). Through these interventions, the goal is to fix the problem and return the person with the problem to a socially accepted – or 'normal' - level of functioning (Foster et al, 2007). Therefore, the medical model of disability places the problem of disability on the individual (Reinders, 2008), instead of questioning larger social, political and attitudinal factors that may be at play (a questioning which would eventually lead to the emergence of a social model of disability that will be discussed shortly). Important to note from this is that the medical model relies on the maintenance and preservation of 'normalcy' (Reynolds, 2008). This socially constructed notion of normalcy often serves as a site of oppression for individuals living with a disability (Llewellyn & Hogan, 2000), because it requires individuals to strive for arbitrary notions of what is considered to be normal based upon an able-bodied bias. As a result, the medical model focuses on the physical or cognitive limitations and differences of the individual and thus contributes to the social perception that individuals living with disabilities are different and are therefore to be pitied, marginalized, and oppressed because they are lacking the ability to function normally (Barnes & Mercer, 2010).

### Social model of disability

Alternatively, in a social model of disability it is emphasised that disability is socially constructed and is maintained by inaccessible structures (political, attitudinal, economic, material social and linguistic) in society (Foster et al, 2007; Hosking, 2008; Tregaskis, 2004). Each of these structures is maintained and upheld as inaccessible by the oppressive attitudes of the people who collectively make up the system. Therefore, whether or not a person is perceived to be disabled is dependant upon the structure of their community (Delvin & Pothier, 2006). Beginning to view disability through a social model of disability rather than a medical model, it begins to be possible to view how societal structures and notions of normalcy discriminate against individuals living with disabilities (Tregaskis, 2004). This model of disability puts the responsibility for how disability is understood and responded to onto the collective consciousness instead of on the individual who has been labeled as having a disability (Llewellyn & Hogan, 2000; Tregaskis, 2004). This is in direct contrast to a medical model that aims to correct the impairment – to fix the individual - rather than change the larger society by creating structures that are adaptable to individual ability.

### Limitations of the social model

However, there have been critiques of the social model of disability. Arguments are made to the effect that it de-emphasizes the effects of impairment, the physical or cognitive realities individuals live with (Mansell, 2006; Meekosha & Shuttleworth, 2009) and, thus, is not always inclusive of people with intellectual and developmental disabilities. Denying or minimizing that some adults with intellectual and developmental disabilities will always require assistance, service provision is shaped in very specific ways. For example, it has generated services that assist people to learn skills that are designed to minimize the effects of impairments, thereby making invisible the reality that that some individuals will always need supports (Mansell, 2006; Reynolds, 2008; Bollard, 2009; Clements & Read, 2008). The social model “cannot adequately address the reality of all impairments and therefore, should not be perceived as speaking with one voice" (Foster et al, 2007, p. 37).

Reynolds (2008) stresses that the medical model should be supplemented by the social model of disability and not simply replaced by it because he finds value in the many medical interventions that have provided assistance to individuals living with various forms of physical and developmental disabilities. The model should "be expanded to account for the bodily reality represented by impairments" (Foster, 2007, p. 38). Using the example of a diagnosis on the autistic spectrum as his prime example, Reynolds (2008) further argues that some lived experiences are not products of how society is structured but instead are inherent to the experience of living with specific impairments.

## Critical Disability Theory

Critical disability theory (CDT) is an emerging school of thought that developed out of a significant analysis of disability discourse (Meekosha & Shuttleworth, 2009; Delvin & Pothier, 2006). There is no one singular definition of what is theoretically encompassed by CDT (Delvin & Pothier, 2006); however at the core of CDT is – like the social model of disability - the problematizing of the understanding and/or perception that the able-body is the norm and the most desirable form (Hosking, 2008; Llewellyn & Hogan, 2000). As was previously discussed, this idealization of the able-body emerges from a medical model of viewing the body and disability. Where CDT differs from the social model of disability, and where much critique is found in the social model, is the lack of research and analytic support for the social model’s premise that the barriers an individual with an impairment faces and the supports they then require could be eliminated if society is changed (Rioux & Valentine, 2006). Instead, CDT recognizes that “it is too simple to distinguish disability as either a physical or social problem” (Bollard, 2009, p. 6), because it does not account for the reality that even in a utopian world some individuals will still require some forms of supports. CDT however, emphasizes that it is the devaluing of the individual who requires such supports that is the problem, not that the individual requires supports (Rioux & Valentine, 2006). CDT still highlights the body as important unit of analysis because ignoring it makes the physical realities invisible. As a result of CDT’s recognition of the presence of physical or cognitive limitations, without devaluing the person, what emerges are conversations centred on equality not of sameness (Rioux & Valentine, 2006; Delvin & Pothier, 2006). CDT frankly suggests that there is another way of understanding and valuing the disabled experience that is not dependant upon oppressive notions of normalcy.

Devlin and Pothier remind us that, “historically, we have tended to adopt a binary conception of disability: there are the disabled (them-us) and the able-bodied (us-them)” (2006, p. 5, see also Goodley & Tregaskis, 2005). CDT challenges this binary and understands disability discourse as being political by questioning “what-qualifies-as-a disability” (Delvin & Pothier, 2006 P. 4). As a researcher, CDT encouraged me to consider and unpack questions of:

> Access and participation, exclusion and inclusion, rights and obligations, legitimate governance and democracy, liberty and equity, public and private, marginalization and belonging, social recognition and redistribution of resources, structure and agency, identity and personhood, and self and other (Devlin & Pothier, 2006, p. 2).

Similarly, Kitchin (2000) – who is also working from a critical disability perspective - views the use of research as a political tool to challenge the oppression and discrimination of individual with disabilities. These questions were relevant not only to the methods I would use in this research project, they were also questions that drove my interest in the topic under study here, and which informed the how, why, where and when of my project. Engaging with these questions was then also a process of un-learning and re-learning what is meant by, and communicated through, my own understandings ideologies of disability.

### Language

The first step in this process was an interrogation of language and how it is used to communicate about disability. CDT examines the words that are used to define “disability” and to describe and label people with disabilities because it recognizes that language holds great power in shaping both what is understood to be a disability and who does and does not count as a person with a disability

(Hosking, 2008). One example of the power of language surrounds two terms central to any CDT (and social model) discussion - “impairment’ and “disability”. The use of either of these words can convey significantly different messages depending on which theoretical framework you are situated in. As critical disability studies continues to grow and expand its knowledge base, there is continued debate even on the definitions of these two terms (and the distinction between them) however, I will provide a common manner in which the two terms are currently understood.

“Impairment” is typically understood as the presence of a physical or cognitive limitation experienced by an individual, such as not being able to hear (Delvin & Pothier, 2006; Llewellyn & Hogan, 2000). In other words, impairment is understood as something that is naturally occurring in the human experience (Delvin & Potheir, 2006). Using this example of deafness and the physical function of being able to hear, critically disability theory would identify the impairment as the inability to hear but would not see the individual who cannot hear as lacking but, instead, as having a different experience. In this way it is understood that impairment can have certain effects on an individual’s life and, in response to critiques of the social model, understands that not all of these effects can be eliminated by social or structural change. In addition, the meaning of these effects is left to the individual with the impairment to determine – they are not evaluated by (non-disabled) society more generally.

A “disability” is understood to be the result of the structures around a person with an impairment that are disabling (Delvin & Pothier, 2006; Llewellyn & Hogan, 2000). This means that it is not because of an individual’s impairment that they are disabled but, instead, it is because of their community’s response to and interaction with their impairment that makes it disabling (Delvin & Potheir, 2006). The way in which modern societies have been organized physically, politically, socially and economically means that they operate as sites of discrimination and oppression for individuals with impairments because society fails to recognize and adapt to a full range of human experience (Barnes & Mercer, 2010; Delvin & Potheir, 2006). From a CDT framework, living with an impairment is “different from (rather than inferior to) being non-disabled” (Clements & Read, 2008 p. 4). This distinction of what is meant when using each term is important to the framework of CDT.

Similarly, CDT explores the language used to refer to or address individuals and/or groups of persons living with disabilities. Both Devlin and Potheir (2006) and Titchkosky (2001) highlight some of the debate surrounding the discussion of language. To summarize, there are two distinct schools of thought on how to name disability. The first is the use of the language “disabled person” (Titchkosky, 2001; Devlin & Pothier, 2006). Titchkosky (2001) argues the use of this language represents the acknowledgement that a person is disabled by forces outside of themselves and not by their impairment. It is thus a political use of language that keeps the focus on these disabling forces outside of the person. However, Delvin and Pothier (2006) argue that this use of language inappropriately insinuates that the whole person is disabled because of their impairment making this the most important aspect of their experience and identity – something which many people living with impairments have trouble with.

The second terminology, which is currently favoured in Canada among people with intellectual and developmental disabilities, is the intentional use of "people with disability" which is seen as an example of "people first" language (Titchkosky, 2001). People first language intentionally puts the person first before describing impairment. The use of this language is thought to reduce the objectification of those living with disability by recognition of the personhood of the individual (Titchkosky, 2001; Devlin & Potheir, 2006). Devlin and Pothier (2006) opt to use persons living with disabilities because they find "it is the least worst option" (2006, p. 4). They do not offer their use of person first language without critique, adding for consideration that, "we do not speak of persons with a gender or persons with a race" (2006, p. 3). So why do we speak of persons with disabilities? Because - like 'disabled people' language – it, too, is political. Difference matters and, as a researcher, I must remain vigilant to questions of language and critically reflect on the language that is used – by myself and others - to define and describe "disability" and "people with disabilities": "Is it empowering?" Or, "Does it continue to construct a pathology of disability?"

For this study I have chosen to use the term individual(s) living with intellectual and developmental disabilities instead of intellectually and developmentally disabled because, at this point in my own journey of understanding disability, it is the term that sits best with me. In contrast to Titchkosky (2001), I feel the people-first term expresses an active political stance recognising that you are an individual first who happens to live with a disability, whereas the disabled people term, for me, feels as if the individual has been immobilized by their impairment. In her work in cancer care, Christina Sinding recognizes "how common it is...to deny that difference matters" (2009, p. 167). The language we use can either be empowering or disempowering and Meekosha and Shuttleworth (2009) stress that language within a critical context must be empowering for those to whom it makes reference.

## Moving forward connecting L'Arche with Critical Disability Theory

L'Arche has been described as an example of what is possible when barriers fall away (Porter, 2005). The L'Arche model of service provision is unique and, as part of my learning for my research project, I wanted to examine how they have created communities that are supportive of all members.  A foundational belief within L'Arche is creating communities and practices that engage in active dialogue and learning around how to create these types of inclusive spaces (Foster et al, 2007; Porter, 2005): creating a collective consciousness of how we engage or disengage members of a society, while simultaneously working to "change our patterns of social organization, so too might we have to change our understanding of what and who qualifies as disabled" (Devlin & Pothier, 2006, p. 6). Essentially, critical disability asks us to analyze how we have structured our society, our communities, and our lives to either enable or disable individuals based upon their physical or cognitive abilities. It wonders, too, "If we rethought how we structured society, would disability exist?" It is not asking would 'impairment' still exist in this new societal arrangement, it is asking if 'disability' would.

# Methods

## Purpose of the study

The purpose of this study is to examine how public policy affects the provision of social services for adults with intellectual and developmental disabilities. More specifically, this study focused on the research question "How does a particular public policy (*Ontario Regulation 299/10*) attempt to regulate the therapeutic relationship between adults with intellectual and developmental disabilities and their caregivers in the context of L'Arche?"

When I began conceptualizing this study I knew that I wanted to include the voices of the core members in examining the therapeutic relationship with their caregivers. I knew, too, that I wanted to look at policy and its impact on service provision but I was not, initially, sure of how to do so – whether to look at the effects of policy more broadly, or to choose a particular policy and, if so, how to determine which one. It wasn't, however, until I approached the board of directors at L'Arche to learn about their process of approving research projects that I had even heard of *Ontario Regulation 299/10*. Being newly introduced in Ontario during the summer of 2010, L'Arche was, and still is, reflecting on what this new policy means for their organization. By focusing my study on *Ontario Regulation 299/10* it not only allows me – as a researcher – to explore an emerging policy and its effects, but also allows me to explore and potentially answer questions that the organization may be working through itself. It was important to me to do research that the community might benefit from.

### Study Design

I completed a qualitative case study at L'Arche Hamilton. I chose L'Arche Hamilton as a single-case design because it allowed me to focus my efforts on one setting while exploring all the complexities of the relationships between *Ontario Regulation 299/10* and the L'Arche community within its own context (Stake, 1995l; Flybjerg, 2006; Darke et al, 1998; Yin, 1981; Kreuger & Neuman, 2006). Case studies are often used to answer questions of 'how' or 'why' (Yin[2], 1994): this study will attempt to shed light on how *Ontario regulation 299/10* may impact life at L'Arche. Case studies are also conducted when looking at organizational decision making, communities, histories, economic development or housing structures (Yin, 1981), making it well suited for this study as L'Arche reacts to and continues to develop in the shadow of institutionalization. I believe it is important that disability policy be mindful of the history of institutionalization and learn from its mistakes in order to not merely recreate these errors. As has been previously mentioned, institutional policies were well intentioned but morphed into oppressive practice overtime.

In its design, a case study allows for multiple perspectives on the same phenomenon, thus capturing a fuller understanding (Flybjerg, 2006) which, for the purpose of this study, is important because I not only want to hear from the assistants but, more importantly, from the core members as well. This practice is also consistent with CDT, which seeks to include the voices of those living with disabilities in all forms of knowledge creation (Delvin & Potheir, 2006). Hosking (2008) reminds researchers that:

> Able-bodied people think about disability from their able perspective...it is only by listening to and valuing the perspectives of those who are living disabled lives that the able bodied can begin to understand that even severe disability does not have to prevent a joyful and desired life (p. 13).

Related to this principle I relied upon the L'Arche best practices document, *More Than Inclusion* (Porter, 2005) – a joint effort between core members and assistants across Canada – as a source of information as well. So, while case studies often rely heavily on interviews, they also allow the flexibility to draw from several other sources, including organizational materials (Darke et al, 1998; Yin, 1981; Yin$^2$ 1994). In light of the emphasis by disability activists and researchers placed on constructing a research project that is centred on the knowledge held and produced by adults with intellectual and developmental disabilities, I not only interviewed core members, and utilized a document that significantly incorporates their perspectives, but also spent significant time in the Hamilton L'Arche community to develop a more personal, and hopefully more accurate, knowledge of life at L'Arche.

### Ethical considerations

During the planning and preparation stage of this study two significant ethical considerations arose for me as a researcher; concerns that required intentional effort on my part to work through their potential implications for this study. The first of these considerations emerged while beginning to construct the study design; it also serves as the largest limitation of this study. Disability advocates, allies and researchers have made it abundantly clear in the research literature that any attempt at the creation of knowledge about disability requires the full and active participation of individuals who live with disability during the creation, implementation and data analysis of a study (Bollard, 2009; Kitchin, 2000;Clear, 1999; Goodley & Tregaskis, 2005; Devlin & Pothier, 2006). As a researcher I wholeheartedly believe this is true but, because of the limited time frame of this study (just shy of six months), it was not possible to design a study with this level of intentional participation. In addition, as a researcher without an identified disability, I struggled with whether I could engage in a master's level research project without actively involving the core members in all stages of my study.

In the end, after much reflection and dialogue with peers and mentors, I decided to proceed cautiously with this research study, accepting that time would not allow me to conduct the type of research I would ideally like to do, and recognizing that my positioning as an able-bodied researcher would influence how I interpret and represent the data. What I did decide to do was to involve core members as much as possible (this will be elaborated upon in my description of the research methods). I believe that research is political and, by proceeding with the study, I hope it will begin a dialogue around the effects of this bill and facilitate ongoing research that is able to incorporate the voices of the core members in a larger way.

The second ethical concern relates to the type of data being sought. Due to the personal nature of discussing with the core members their experiences of living within an intentional community I was mindful that many of the core members may also have lived within institutions and that these conversations could potentially raise for them memories of possibly traumatic pasts. With this in mind, the questions that would be asked of the core members were created to reflect the themes that are captured by *Ontario Regulation 299/10* (i.e., social inclusion and protection) without venturing too closely to the topics of abuse prevention, physical touch or safety. For example *Ontario Regulation 299/10* addresses abuse prevention but I did not ask core members specific questions about abuse prevention but, instead, asked about what it is like to live at L'Arche or if they felt they belonged at L'Arche (with prompting questions to explore their relationship with assistants and how they did or did not feel cared for) (See appendix A). Each of the questions also focused on the present and was designed to allow the core members the space to answer in a way that was comfortable for them without purposefully leading them to divulge their past experiences.

Again, because of the delicate nature of the topic and the limited scope of my relationship with the core members, there were times during our conversations when I wanted to ask more but restricted myself because of the potential risk of emotional harm. As will be discussed further in a later section of this thesis, the limitations imposed by the time frame left me with many thoughts of how this study could be expanded to include not only more active participation of individuals with intellectual and developmental disabilities, but also more discussion with the core members as to their own thoughts on abuse prevention, safety and physical touch.

## Recruitment

After receiving ethics clearance from McMaster University Research Ethics Board, I distributed fliers (see Appendix A) to each of the four L'Arche homes in Hamilton. These fliers provided a brief description of the study and also informed core members and assistants that I would be attending a L'Arche community barbeque and would be available to discuss the study and recruit participants for this study. In an attempt to introduce myself to the assistants and core members before attending the barbeque, I had hand-delivered the fliers and provided verbal descriptions of the study to the assistants and core members who answered the doors. In addition to attending the community barbeque, I also attended an evening worship service where, after the service, a core member whom I had already interviewed took it upon herself to assist me in my recruitment efforts by openly sharing her involvement with the other members of the L'Arche community. As a direct result I was able to secure the final core member interview I was seeking.

As part of the recruitment process each potential participant was given a letter of information and consent (see Appendix B and C) which provided potential participants with the parameters of the study and with information about risks and benefits, and their rights around not answering questions and/or withdrawing from the study at any time. The letter of information and consent was also verbally explained to each of the potential participants by me and time was provided to answer any questions about the study. Usually, there were more questions asked about me personally (e.g., how old I was; was I married; did I live in Hamilton) than there were about the research project itself. This was a clear indication to me of the importance building rapport played in this community.

## Participants

In total three core member and three assistants were interviewed for this study. Each of the core members I interviewed has been living at L'Arche for at least fifteen years and has lived at two different homes. None of the assistants I interviewed currently "lives-in", meaning they do not reside, at present in one of the community homes, but each continues to be employed by L'Arche in other roles. Each of the six participants was given a pseudonym that would be used to refer to them in the discussions and findings section of this paper. I chose to use names as pseudonyms instead of an acronym (e.g. CM 1) because the use of an acronym felt dehumanizing. For the core members the pseudonyms Lauren, Liane and Ben were used; for the assistants the pseudonyms Gillian, Oliver and Cait were used. As a result of the intimate size of L'Arche and the close-knit nature of the community I am not providing any descriptive information about the participants in an additional effort to maintain their confidentiality.

### Data collection

Data was collected for this study through semi-structured individual interviews with core member and assistants of L'Arche Hamilton. An interview guide (see Appendix D & E) was used with several prompts after each question which expanded upon the themes captured by each question. Core members and assistants were asked differently worded questions that addressed the same content; social inclusion, care, participation, and life at L'Arche. The questions were worded differently to reflect the different roles core members and assistants fulfil in the L'Arche community.

The interview locations were arranged with the core members and assistants at times and locations that were convenient for them. After discussing with the core members and assistants the issue of confidentiality and the potential for more limited confidentiality if interviews took place within L'Arche group homes, two core members chose to complete the interview within the community and one at their home while two assistants chose to interview at the L'Arche main office and one chose to be interviewed in the community. Five of the six interviews were tape-recorded with permission, one core member requested I not tape the interview and extensive notes were taken by hand instead. Audio files were identified by the participants' pseudonyms and password protected on my personal computer. Any paper documentation was stored in a locked drawer at my home office to which only I had access.

## Analysis

After personally transcribing each of the interviews, analysis of the data was conducted using the open coding method (Strauss & Corbin, 1998). During this process conceptual themes that emerged from participants' responses were labelled; this process of labelling concepts was influenced by concepts important to my theoretical perspective as well as those revealed by the literature that I had explored for this study (Strauss & Corbin, 1998; Yin[2], 1994). After the initial process of conceptualizing many of the themes that emerged from the data, some of these were then grouped together with similar concepts and a larger thematic category was created[6] (Strauss & Corbin, 1998). This stage of the analysis established the categories and sub-categories of the data – the different thematic ideas that helped me to make meaning of the data and which will be taken up in the discussion portion of this study. After completing the analysis and discussion portion of my thesis I contacted the core members (and assistants) a second time to show them how their data had been interpreted into the thesis and allow them to

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[6] For example the concept of family and touch were categorized under the concept relationship

direct any changes they felt were needed if I had misrepresented their experiences and thoughts.

## Limitations

As previously mentioned, a significant limitation of this study is that it did not include the participation of adults with intellectual and developmental disabilities during the design, implementation or analysis phases of this study (outside of member checking). Additionally, due to the size and time restrictions of this study, there was a small sample size of only three core members and three assistants. As a result, I was unable to include as many of the core members voices as I had desired and had more limited data with which to work. Also, not working directly with adults with intellectual and developmental disabilities during the data analysis, I had to be mindful of how my own biases and assumptions might impact my analysis and conclusions about what was represented in the data. I was also limited in the questions I could ask of the core members as a result of the potential of re-traumatization from questions that might have triggered memories of living in other group homes or institutions. Often during our conversations there were glimpses of this past but I was careful not to ask them to expand on these.

# Findings and Discussion

While each of the conversations I had with the core members and assistants was unique and represented the distinctive life journey that brought them to life at L'Arche, there were clear themes that were woven throughout and which united their stories. The following section will focus on the two major themes of "relationship" and "valued contribution". Associated with the theme of relationships at L'Arche, the sub-themes of "family" and "touch" will also be explored. In order to unpack these themes I will use quotations from the participants as the basis of my discussion and will incorporate linkages from my theoretical framework and from the literature when appropriate.

## Relationship

The reality reflected in the literature is that woven throughout the L'Arche experience is the common thread of relationship (Porter, 2005; Pottie et al, 2004; Cushing & Lewis, 2002; Foster et al, 2007; Cushing, 2003; Reinders, 2008). This was also supported by my conversations with core members and assistants. I heard firsthand from both core members and assistants about the value and importance placed upon relationships within L'Arche. Cait, an assistant, when asked about the strength of the L'Arche model shared that:

> The focus on community, the focus on relationships, I think is really at the heart of L'Arche.

She went on to describe the relationship as "a beautiful family," a common sub-theme that emerged when core members described their relationships at L'Arche (this will be discussed shortly). Another common word was "friend". When I asked the core members who their friends were at L'Arche, each of them stated several names; some of these names were of other core members and some were of assistants. When I asked Lauren she exclaimed, "I've got lots!" During our conversations often both words, "friend" and "family", were used interchangeably but, most importantly, the choice of either word reflects a relationship that is not bound by a strict professional border but, instead, is experienced by both caregivers and adults with intellectual and developmental disability mutually.

This type of relationship is in stark contrast to the relationship outlined in *Ontario Regulation 299/10* (2010) which outlines rigid boundaries for separation between family, friend, and professional relationship. The legislation mandates professional distance while it was apparent from my conversations that L'Arche however intentionally attempts to foster intimate relationships. It was important for me to hear from both the core members and the assistants that friendships, or relationships, exist between core members and assistants because it cemented for me that this wasn't just an idealized practice found on paper but one that was being lived out in practice.

### L’Arche as family

For me, the most powerful word used to describe life at L’Arche was “family”. Each of the core members interviewed identified L’Arche as being like a “family”, as did each of the assistants. For each of the core members this was the primary word chosen to describe what it was like living at L’Arche. As will be shown shortly *Ontario Regulation 299/10* does not encourage this form of relationship instead they assert that caregivers are not family or friend (Quality assurance measures, 2010). It was significant to me because of the societal importance and norms placed around the family unit and how it represented their relationships within L’Arche as being a primary relationship for them. This is not to say that the core members or assistants have replaced or forgotten their birth families or other families that may live outside the L’Arche community (as most did make references to outside family); it is, instead, a significant reminder of the intimate and bonding relationships that form within L’Arche. But don’t take my word for it; listen to the voices and experiences of the core members because they said it so beautifully. Ben, a core member, identified that L’Arche was especially, “a good place for you if your parents have passed away”.

When I asked another core member, Liane, to describe what she meant by L’Arche being like a family she shared, “like when you have a brother or a sister but they’re all from different homes and you do things together”. Through this seemingly simple statement she has articulated the coming together of the eclectic mix of people who find themselves living at L'Arche – a mix that is articulated in the literature and one which I observed throughout this project. However, this is not said to idealize that everyone who comes to L'Arche comes together perfectly; this community – this family – like any other has its fair share of problems and challenges. However, returning to the use of the term family to describe L'Arche, Lauren, another core member stated that "We tell people at L'Arche that we love them like a family".

Lauren goes on to share what family looks like to her by sharing:

> It's been like a family because we've been back and forth to different houses...we're so close to the other houses, within walking distance...when there's birthdays we make a card and we go to the other houses and we celebrate them with cake.

Descriptions like Lauren's are examples of how the relationship between friend, family and/or caregiver is blurred within L'Arche. It seems that this blurring of boundaries is exactly what the regulations are attempting to curb.

While some may contest the use of this word, "family" (Levine, 1990), and its implications, it is important not to let this distract from what this word alludes to – relationship. Levine (1990), picking up on the challenge of defining family, problematizes its traditional boundaries and asserts that:

> Family members are individuals who by birth, adoption, marriage, or declared commitment share deep, personal connections and are mutually entitled to receive and obligated to provide support of various kinds to the extent possible, especially in times of need (p. 36).

It is clear from my conversations with the participants that L’Arche is rooted in this type of relationship. What is of great importance to note is the significance that these core members place upon L’Arche as a primary and genuine relationship. In the conversations I shared with the participants I heard a commitment by assistants and core members of L’Arche to care and provide support for each other.

It is also important that we not forget that this role of “family” is one of the main reasons that the Canadian Mortgage and Housing Corporation named L’Arche as the only best practice model of group home in their 2006 report, *Housing for Adults with Intellectual Disabilities (*Lenk, 2010*).* It is this exchange of mutual relationship, which will be unpacked further shortly, that provides the basis of what it means to be a member of the L’Arche community. Oliver, an assistant, provided a detailed example of a relationship he shares with a core member that highlighted many of the themes of this thesis and will be referred to throughout. To start the dialogue Oliver begins by sharing:

> I’m really good friends with the core members in my house...and I do think that if and when I move on that I will still consider them friends.

Oliver articulates two important realities within L’Arche: first, that friendships exist but, second, even though assistants often leave L’Arche, these friendships frequently continue. The reality that these friendships continue between core members and assistants was also captured and highlighted in the stories told in

*More than Inclusion* (Porter, 2005). Cait, an assistant interviewed for this study light-heartily shares:

> I will say this, when assistants come back to our community they don't come to see [the directors] they come to see the core members because it's with them that they have the relationship and many assistants do stay in touch and that's pretty cool.

Liane, a core member in this study, shares that she tries to keep to keep in touch with assistants but "it's hard because they move away". She also shares that sometimes assistants who have moved away will "call the office and tell people how they are." This is a reality of the L'Arche model – that some assistants are not there long-term and they do eventually leave the community. This leads me to wonder if this is part of why the makers of the regulation want to limit the interaction and potential for friendship between care-givers and adults with intellectual disabilities, to protect them from the potential of emotional harm when assistants leave.

Lauren, a core member, reflecting on assistants leaving shares, "when assistants leave L'Arche we go around and we put hands on their head and we give them a candle and say "thanks for being here". During the worship service that I attended, I had the privilege of witnessing one of these goodbyes. A young man was seated in a chair and every member of the L'Arche Hamilton community stood around him with their hands either on his arms and shoulders or wrapped around the person beside them. A few words were said about him and then a parting song was sung. I was surprised however, that the tone of the evening was not one of sadness but, instead, like a graduation it felt more like a rite of passage; he had spent his time in the community and now he was moving on.

### L'Arche as family: language of inclusion

Assistants leaving L'Arche is a reality that core members live with but is also reflected in the philosophy and language used at L'Arche. Gillian shares:

> The lingo at L'Arche, I think it's unique. Intentionally referring to, being careful and mindful of your language, and how it affects how you perceive other people.

As was reflected upon earlier, the language we use in society to name and label disability is important. Current debates with critical disability theory are important conversations to have and should continue to be had. Cait said:

> The word "core member" tells you that the people with intellectual disabilities are at the centre of the organization. They were members before I was and the assistants – they're it. It's not like we're the organization helping them. So just by the name it raises the social status of the core member within the organization. We gather around them.

Another way the relationship between the core members and assistants has been described is that the adults with intellectual and developmental disabilities are the hosts and the assistants are the guests (Webb-Mitchell, 2010). This distinction is a reflection not only of the positioning of people with intellectual and developmental disabilities as the "core" of the organization, but also of the reality that once they have moved in, many core members choose to stay long term

(Porter, 2005). It reflects, too, the organization's awareness of the phenomenon that assistants sometimes leave.

### How relationships affect assisting

Oliver offers his own explanation for the phenomenon of assistants coming and going:

> People are going to come and it's going to be great when they're there but they probably won't stick around for too long because it's a lot of work.

It is important to remember the functional role that assistants play in the lives of core members when discussing the relationship between core members and assistants because it became evident in my conversations that these relationships are what keep many assistants at L'Arche for as long as they are. Oliver articulates that relationship is what makes the sometimes difficult work of providing care for another human being possible:

> There were days living-in that I would just go to bed completely drained and to wake up in the morning and know that you've got to do it all again but...just even seeing this guy, just seeing his face, you kind of forget it all and it's like... you're just helping a friend. He just happens to need some help in these areas and when there's a relationship that's so much easier to do.

It is because of this recognition of the work – the labour – of providing care that prompts some to take issue with the possibility of genuine relationships existing between core members and assistants, because of the seemingly unequal footing the core members and assistants come to the relationship with (Kittay, 2001). It is this very focus on the type of relationship, the possibility of real friendships between core members and assistants that involve the provision of care, which is at greatest odds with *Ontario Regulation 299/10*. The regulation encourages the maintenance of professional boundaries between caregivers and adults with intellectual and developmental disabilities. However, within L'Arche it seems that in regard to the challenges the assistants face (the labour of care) or that the organization faces (assistants leaving), the impact of each is minimized by the presence of relationship. The legislation would seem to suggest that such a relationship is neither possible nor desirable. Nevertheless, in light of the isolation and segregation that many adults with intellectual and developmental disabilities faced living in institutionalized care, I wonder how we can deny core members and assistants the opportunity to engage in meaningful relationships with each other. It appears to be the way these relationships might play out (i.e., the risk for abuse) that creates tension between the new regulation and life at L'Arche.

### Touch – Healthy or dangerous?

One of the resounding elements of this relationship that the core members stressed was the importance that exchanges of physical (i.e., hugs) and verbal affection (i.e., statements such as "I love you") play in their interactions, not only with other core members but between the assistants as well. Lauren described that when she is feeling upset about a personal life event that assistants often give her hugs to help her feel better. She went on to describe one of her relationships with a long-time assistant (whom she did not name) and stated that not only does the assistant gives Lauren hugs but that “I give her hugs” too.

These exchanges of affection are believed to play an important role in the well-being of core members and are an expression of the relationship that exists between the two adults. Assistants also told stories of how physical affection plays out in celebrations or in daily life. Oliver, when describing a close relationship with one of the core members, shared:

> I just really like the guy a lot and we give each other big bear hugs each time we see each other. It’s really fun.

Throughout the conversations, the types of physical touch that were described were not functional (task) touch but expressive touch (Gale & Hegarty, 2000). In light of the dark history of isolation and rejection of adults with developmental and intellectual disabilities, having non-disabled people choosing to be in close proximity to labelled people and vice versa is a strong rejection of this history of being considered untouchable or repulsive. Cait, an assistant, beautifully asks:

> Why should we be denying people physical touch when physical touch is so important to humanity?

This question prompts the important discussion of why are we denying or placing limits on the role of physical touch in the relationships between core members and assistants. The restrictions on the use of touch posed by the incoming regulation were also noted by the assistants. Reflecting on the incorporation of the new regulations into life at L’Arche Gillian shares:

> It’s challenging for us. We’ve talked about physical touch for example –. That’s a big one.

From my conversations with assistants I have come to see that L’Arche is still trying to make sense of how to incorporate the regulations without dramatically impacting or changing their service mode. If you read through the regulation it may not immediately jump out at you as to how or where the regulation speaks against this type of interaction – it didn’t for me either. However, all L’Arche staff had to attend a training session in the fall of 2010 on the new regulations and this prohibition against physical touch was included in the hand-outs made available to attendees. To state it plainly, physical touch and relationships are being discouraged in the regulation as a means of abuse prevention.

### Ontario Regulation 299/10 – A threat to relationship?

Also emerging from these conversations is the possibility of these relationships as characterizing a form of social inclusion. When asked, all three core members answered - without hesitation - that they felt that they belonged at L’Arche. As has been discussed, there is overlap and ambiguity about what is meant by “community” and “social inclusion” but it is evident that in L’Arche to be in community and to be socially included is found in relationships with other people. Throughout, all my conversations were sprinklings of celebrations, anniversaries, shared meals, social gatherings and even gatherings to say goodbye, but these memories spoke of spending time together, of “sharing home together.” Ben identifies simple daily tasks, such as eating dinner together, as one of the many reasons he likes living at L'Arche. As a researcher and ally, I struggle with *Ontario Regulation 299/10*, not because of its desire to promote social inclusion or to highlight the reality that abuse can occur in such intimate exchanges – these are important. However, while reading the regulation and the training materials, I struggled with the threat that it serves to the relationship – the family – that is L'Arche.

Similar concern was found throughout my conversations with the assistants. As previously mentioned, Cait asked why touch is being restricted. She went on to say:

> It would be really sad if someone came in and said you can't do this, you can't hug anybody. I don't know what we'd do.

So where does this concern arise from? Ironically it arises from one of the greatest strengths I found in the regulation – abuse prevention. The legislation requires that organizations provide annual workshops on abuse prevention, not only to their staff, but also to core members. This requirement was discussed with L'Arche members at the mandatory *Ontario Regulations 299/10* training in the fall of 2010. The hand-out provided to the assistants at the training included a framework for replicating a workshop within their own organizations on educating core members about abuse prevention. The material provided was created by David Hinsburger, a well-known disability activist and author. The material was created to follow the six required skills outlined by the regulation. It is within these training materials that the boundaries on the care-giving relationship are explicitly drawn and which clearly puts the L'Arche model outside that of "acceptable" service. The proposed educational material on the first skill, boundary training, states the following:

> People with developmental disabilities often have difficulty understanding boundaries...it is easy for offenders to prepare the person with developmental disability for abuse by using for example close up hugs or resting hands on thighs when talking. These are actions that paid care givers should never do! **Learning that staff are only staff and not friends or family can be painful learning but imperative if we are to establish that staff have a different set of boundaries than those with whom they have real intimacy** [*emphasis added*]...training individuals with developmental disabilities in the knowledge that paid care providers only touch you in a limited way, is the first step to recognizing when someone crosses the line (Quality Assurance Measures, 2010).

It is evident from the discussion in this study that L'Arche does not agree that core members and assistants cannot be friends. However, both Gillian and Cait identified the general idea of a workshop initiative on abuse prevention for core members as a positive addition to L'Arche practices – if done without including its rejection of relationship. This is exactly the type of proactive approach to abuse prevention that the research literature has been calling for (White et al, 2003); however, the struggle here for L'Arche, and for Cait in particular, is how to negotiate the need to recognize and educate about the reality of the potential risk without limiting the expressions of affection. Oliver similarly struggles with this:

> Some people think that that friendship or whatever shouldn't be there because you're paid to be there and they should be friends with people who aren't paid to be there. I understand that but it doesn't, I understand but I've experienced the other side. I've been there and I've been paid to be there but it doesn't take away from the realness of it. It would be hard for me to believe someone would, I don't know, experience that and say that against it.

This type of training threatens the relationship or, if you will, the model of care that L'Arche provides to adults with intellectual and developmental disability by devaluing the uniqueness of L'Arche. Cait reflects on David Hinsburger (the author of the training materials) stating that, in her opinion:

> He has a love hate relationship with L'Arche because he doesn't think that any service provider should hug anybody. Well we hug people all the time! And we touch. We consider ourselves family so there's a real tension there.

L'Arche, as expressed by Cait, is not naive to the fact that by permitting physical touch there is the potential risk for exploitation of that touch:

> There are boundaries issues and we know that, and there are issues that we do have to keep reminding ourselves of. We have a lot of assistants that go in and out and some assistants, they come for a field placement, so they're only really here for four months. How often does one of our core members, who need support in bathing, and all of a sudden there's someone new touching them intimately? We have to keep making ourselves aware that this is sacred ground that we're on here. I think we do a reasonably good job of that but it is something that you have to keep reminding yourself of...that sacred trust that we have with our core members.

It is doubtful that an argument could be made that no guiding principles should be established for what constitutes crossing the appropriate physical boundaries for caregivers of adults with intellectual or developmental disabilities. Cait shares that they are "already doing most" of what the regulation suggests and requires of them however:

> There are some things they don't suggest you do that we do do but we'll struggle with that balance. We're not doing anything illegal but it does challenge us, especially around touch and relationships.

This is a serious and important conversation to have, but the concern, as articulated by Cait, is that we now have to deny all forms of physical touch that are not functional. She wonders what this articulates to the core members. Due to the sensitive nature of discussing physical touch and abuse prevention, this study did not have the means to safely broach this topic with the core members, and this is a question that lingers for me still. It would be interesting to hear from the core members their perspective on safety and physical touch. At the heart of this conversation is the safety of the core members but it is not clear to me from reading the literature on the regulation, or the literature on non-functional physical touch by staff, whether anyone has asked them what they think. If not, I wonder if this is just another infantilizing example of policy making.

### Valued contribution

While the intentional relationship between members of the L'Arche community was at the centre of all the conversations that took place for this study and emerged as the central component threatened by *Ontario Regulation 299/10,* there was also something else being woven throughout these dialogues that, at first, I couldn't quite put my finger on. As an outsider, I struggled to name it but it was present when re-listening to the interviews and reading the transcripts – but what was it? Gillian shed some light on it when she described the relationships with core members as being “life giving” for the assistants who come to live and work at L’Arche. She further went on to describe that it is a relationship of “mutual respect, mutual learning, mutual growth”, and there it was – valued contribution.

In a mutual relationship both parties give and take; in the context of L’Arche the acknowledgement that core members have something unique to bring to a relationship is important. This concept of mutuality, giving and taking by both assistants and core members in their relationships, is key to understanding how L’Arche understands disability and community. Remember that during the era of institutionalization adults with intellectual and developmental disabilities were not only segregated under a guise of protection but also because they were seen as non-contributing members in a rapidly changing economic revolution. L’Arche directly challenges these notions of productivity by instead seeking out each member’s “gift” (Reinders, 2010, p. 4). Cait explains it like this:

> We see ourselves as supporting the core members to fulfill a mission; it’s their mission to the world that they have a gift to offer and through our support they can offer that gift... It’s about mutuality; we’re not helping the core members as so much as we’re helping each other. So it’s that model of mutuality, but also that the core members have a very special gift to give.

This idea of core members having a 'gift' and of helping each other seems to be dependant upon the presence of a relationship existing between core members and assistants. Oliver expands upon this idea of the importance of relationship:

> We've had some assistants who come and are just kind of there and aren't really embracing it and who have been there [but just] go through the motions, and I think the core members can sense that.

Assistants are not just providing functional support for daily living tasks (such as bathing) but supporting the important task of altering how intellectual and developmental disabilities is perceived by larger society. From a rigid medical, able-bodied bias it might be difficult for some to conceptualize what this "gift" may look like. Cait understands it like this:

> We're people with over-developed minds living with people with over-developed hearts, and we need each other because we're not as comfortable with our hearts as the core members are. They live from the heart all the time.

Oliver shares this sentiment when discussing his close relationship with one of the core members:

> I've never met anyone who, like, views life the way he does. He takes so much; he gets so much joy out of the simple things. Like this cup of coffee - he would be elated to have a cup of coffee and it's not, like, and I'm enjoying this cup of coffee but he understands… I feel like I've become a bit more calloused in all the things that I can have, you know? It's almost like he's blessed to not understand a lot of the things that we can understand and then go after, striving to achieve a lot of those things lets us down but he like lives in this, with this simplicity and this thankfulness for the small things that he has.

Both Oliver and Cait have been challenged and grown as individuals in unique ways because of their relationships with core members. *Ontario Regulation 299/10* may serve to protect adults with intellectual and developmental disabilities from the potential of abuse by focussing attention on the subject matter of potential abuse (which, in of itself, isn't negative) but by doing so it also may serve to limit the full scope of human relationship that is possible between care-giver and adults with intellectual disabilities. Will assistants still look for the gifts core members have to offer them if the relationship is weakened?

When considering how the L'Arche model is different than other models, one assistant reflects upon several experiences of observing an adult with an intellectual and developmental disability interact with their caregiver from another residential facility. She shares that there are:

> Differences in how his assistants interact with him and how they don't really know him – it's a striking difference.

*Ontario Regulation 299/10* presents a singular model of care which L'Arche does not fit into. In the above description we are offered a small but significant example of how without the emphasis on relationship the interactions between caregivers and adults with intellectual and developmental disabilities may change. The regulations threatens to alter the manner in which core members and assistants interact and, by doing so, may hinder the opportunity for assistants, or caregivers, to recognize the valuable contributions adults with intellectual and developmental disabilities can make to their lives. If strict professional boundaries are upheld, if the assistants were to only view themselves as staff and no longer as friends, will assistants still appreciate core members in the same way?

Cait recognizes that:

> There's a tension between being an agency and being a community that we live with and we try to balance.

*Ontario Regulation 299/10* magnifies that tension. The regulation stands to limit the possibility of caregivers learning and growing as a result of their relationship with adults with intellectual and developmental disabilities. Current western culture does not value the contributions of adults with intellectual and developmental disabilities (Clements & Read, 2008) but hearing the way in which assistants spoke about core members it was evident to me that the L'Arche staff culture cultivated a deep respect and appreciation for the core members, so I wonder why we would place legislative limits on this. Gillian shares:

> I think a lot of assistants come into L'Arche thinking "I'm going to come here and make someone's life that much better", "I'm gonna serve", but I think a lot of people are surprised for the fact that they learn and grow a lot as an individual, they learn a lot from the core members things that they would never have expected.

For some, it may be a paradigm shift from understanding core members as dependant because of their disability, to questioning if they are disabled instead because of our approach. This comes back to an individual's perception of "disability" and is shaped by the relationship assistants have with core members. As assistants come to L'Arche, are challenged in their thinking and, hopefully, come to learn to value difference: do we not want them to take that with them to the rest of society and continue the process of shifting an oppressive paradigm? Currently, L'Arche stands as a dissenting voice on the possibilities for relationships between core members and assistants.

### Is Ontario Regulation 299/10 needed?

"Relationship" – as understood by core members and assistants at L'Arche – is not written in the new regulation, and neither is recognizing the valuable contribution of adults with intellectual and developmental disabilities. Nonetheless, none of the assistants I spoke with spoke negatively about the whole of *Ontario Regulation 299/10* but, instead, all could recognize the need and value for a document of this type. Having said this, it is evident from my conversations and from the literature on the model of care that L'Arche provides, that *Ontario Regulation 299/10* threatens the type of relationship that currently exists within L'Arche. Gillian honestly shares:

> My faith and what drives me as a person – I feel more accountable to that than to the legislation... L'Arche is a home and that overpowers any sort of hesitancy or worry about, you know, crossing your "Ts" and dotting your "Is": that's a lot stronger. It's really woven deeply in the humanity, the way that people approach their roles at L'Arche.

She is quick to add:

> Those values are, in a lot of ways, very similar to what the mindset the legislation is coming from, you know, respecting the inherent dignity of all people. I'm not out there to break laws. (laughs)

Oliver reflected that many of the regulations are things that L'Arche already had in place but realizes that *Ontario Regulation 299/10* was created because not all service agencies may have had similar standards and approaches to care. Oliver also knows:

> What we've got going is a pretty good thing and it'd be a shame if it got changed too much.

I asked the core members if there was anything they would change about L'Arche if they could: Ben wanted to pray more; Liane thought it was "okay the way it is now." When I tried to explore further what she meant by this she told me, "I love that place". And Lauren? At first she thought there wasn't anything she would change, she liked everything the way it was, but then she changed her mind and said she would change the waiting list:

> I know that a lot of people would want to get in if there wasn't a waiting list. I'm lucky. There wasn't a waiting list when I came to L'Arche.

I asked her why she thought so many people would want to live at L'Arche. She told me:

> Because they, well we're worldwide known and they hear us talk about the family aspect. And between you and me, most group homes are not a family organization.

This was the closest we came to talking about the reality that before coming to L'Arche, many of the core members lived elsewhere, whether it was with family, in community, or possibly in large institutions. The core members at L'Arche stated that they like things the way they are, so I wonder why are policy makers rocking the boat? Did they even ask the core members what they wanted? While, for now, life at L'Arche will continue as it has (with some minor tune-ups), the reality of *Ontario Regulation 299/10*, and others like it that may loom around the corner, is not lost on the L'Arche assistants.

# Conclusion and Implications for Social Work Practice

This study has only begun to scratch the surface of understanding the complex relationships that exist between adults with intellectual and developmental disabilities and their caregivers. These relationships are compounded by the historical maltreatment and abuse of this vulnerable population, as well as by a history of isolation and segregation. Policy makers and practitioners are faced with the dilemma of responding to the desire – and need – for meaningful social inclusion and balancing this with the need for adult protection. L'Arche's response to this dilemma and to the dark history of treatment of labeled persons, has been to engage in intentional and mutual relationships through which the core members (adults with intellectual and developmental disabilities) are valued and are central to their community. L'Arche intentionally challenges the dominant and harmful discourse that views adults with intellectual and developmental disabilities as dependant and lesser and, instead, values the inherent worth of each member of the L'Arche community. *Ontario Regulation 299/10* may well be a threat to this relationship because it seeks to limit the professional relationship, to set boundaries, on how caregivers and adults with intellectual and developmental disabilities interact with each other. It became apparent in my conversations with the participants in this study that L'Arche and supporters of *Ontario Regulation 299/10* have some opposing understandings and approaches to this delicate relationship, but for many involved with L'Arche it is the caring and valuing and personal nature of these very relationships that keep them at L'Arche.

It was not until I began my conversations with the core members and assistants that I truly realized the potential extent of the impact this newly implemented regulation could have on the experience of L'Arche. At the core of both the regulation and L'Arche's philosophy and practice is the negotiation of what it means to provide care to, and be in relationship with, adults with intellectual and developmental disabilities: the tension between the two arises when examining the boundaries of this caregiving relationship. More research is needed to unpack how this relationship is understood and experienced by L'Arche and how the legislation intends it to be understood and practiced. It is important to examine how L'Arche's version of relationship – given its centrality to their philosophy and practice – is to be maintained (or adapted?) to adhere to this regulation, especially in regards to the use of physical touch as an expression of relationship. This is an opportunity for L'Arche, led by the core members, to expand the research literature on the use of touch in caregiving relationships. The use of human touch in professional caregiving relationships is controversial (as is evident in the literature and by the tension that exists between this regulation and L'Arche philosophy). However, more research that specifically asks adults with intellectual and developmental disabilities about their perceptions and insights into the use of human touch in these caregiving relationships is needed. Projects similar to that of '*More than Inclusion*' are one way L'Arche may consider addressing this topic.

While L'Arche has the opportunity to take the lead in this area, it is important that other service providers also seek out the perceptions of adults with intellectual and developmental disabilities and that they, too, re-consider this regulation in light of the responses they are given. These types of decisions cannot, and should not, occur without direct consultation with those whom they will affect the most. Intentional conversations and collaborative research, which explore the types of relationships with professional caregivers that people with intellectual and developmental disabilities want is critical. But it is also necessary to explore the potential benefits and also risk factors of integrating "touch" (and what types of "touch") into these relationships and common practice when providing care for adults with intellectual and developmental disabilities.

As was evident in my conversations with core members, both relationship and touch are an important factor in creating a sense of belonging and home. Core members and assistants view themselves as a family and within these relationships exchanges of physical and verbal affection are exchanged. Further dialogue and research is needed on how to blend the continued use of physical and verbal affection within the professional caregiver relationships with adults with intellectual and developmental disabilities because, too often, their primary circles of support are comprised only of these professional (paid) caregivers and it seems unfair and even abusive to deny them this important form of care.

The L'Arche model of service provision encourages both core members and assistants to approach their relationship as mutual. Realistically, in most social work settings, it is not probable that we will live with service users in such an intimate way. However, as practitioners it is important to consider how we approach our professional relationship with service users. Do we understand them to be on equal footing with ourselves? Do we see the valuable contribution they have to offer? These are areas in which L'Arche has an area of expertise and a unique service model from which others agencies could learn. This is not to suggest that it is possible or ethical for all relationships to be grounded in this model and to incorporate physical touch and expressions of relationship in the same way but, instead, to suggest that we consider how often when working with marginalized populations do our actions make invisible the contributions of these populations? What can we learn and take away from our interactions with service users? If we learn nothing else from critical disability theory let it be how important it is for practitioners to be aware of how we conceptualize those we work with. Are we aware of the valuable contribution of each of the service users we interact with? Or have we so focussed on their assumed failures and deficits that we can't see them? By acknowledging that each person we work with has something valuable to contribute this can create a more empowering experience for service users. And we might also consider revisiting the notion of expressive touch in social work practice – should we use it? If so, how and under what circumstances? What do service users (not just those with disabilities) think about touch in the social work relationship?

L'Arche champions a discourse that values adults with intellectual and developmental disabilities and creates a staff culture that may serve as a protective factor. As a result, it demonstrates some of the limitations of the regulation. However, some of these strengths may be diminished because of the language in which L'Arche expresses the discourse. I wonder if L'Arche were able to articulate their model within a framework of a professional relationship, instead of using words like ’family’ or ‘friend’, would it be received as a more creditable model? The rhetoric of family does not always convey images of protection, care, and relationship. For some the construct of family conjures places of secrecy where abuse has thrived. However, it is clear from my conversations that the members of L’Arche use this language of family to express how important and strong the relationships within their community are but is this what others hear? Is it possible that because *Ontario Regulation 299/10* is so strongly tied to abuse prevention that using this language of family works to L’Arche disadvantage? It would be this study’s recommendation to engage in dialogue within L’Arche to explore how the organization can reframe their discourse, not to change it but to assist others to recognize the value of their model and how *Ontario Regulation 299/10* may threaten this. Because it would be a shame if this model were to be disregarded and diluted as a result of semantics.

As *Ontario Regulation 299/10* continues to mature and take hold in the lives of core members and assistants, further research documenting if and how the relationship between core members and assistants changes is warranted. Adults with intellectual and developmental disabilities should not be expected to choose between genuine relationships with their caregivers or protection from maltreatment – they have a right to both. Further work is needed to successfully blend these two. It will always be important to critically reflect upon best practice and examine if it truly moves towards the wellbeing and social inclusion of adults with intellectual and developmental disabilities because, as is evident in the history of institutionalization, just being physically present in a geographical community is not enough to achieve social inclusion. If we care about and value someone – if we are able to see their humanity – we are less likely to be exclusive and/or abusive and instead engage in relationship (Fudge Schormans, 2011). Genuine – and safe – relationships and friendships between people with and without intellectual and developmental disabilities are one clear way of marking progress towards the elusive goal of social inclusion.

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# Appendix A – Recruitment flier

McMaster University

## PARTICIPANTS NEEDED FOR RESEARCH ON LIFE AT L'ARCHE

***

We are looking for volunteers to take part in a study on what it is like to live at L'Arche. For example you may be asked to answer a question about how house decisions are made or what you like about living at L'Arche. If a question makes you uncomfortable you don't have to answer it.

Your participation would involve **one** interview session of 20-60 minutes

In appreciation for your time you will receive
*light snacks during your interview.*

***

For **more information** about this study or to **volunteer** for this study, please contact *Deborah Tomlinson at:*

*Phone: 905-912-9132*

*or*

Email: *tomlind@mcmaster.ca*

I will also be at the L'Arche BBQ on May 23rd
at 78 Sherman Ave. South to discuss this project with you.

***

# Appendix B – Core member letter of information and consent

**CORE MEMBER LETTER OF INFORMATION / CONSENT**

**A Study About Life at L'Arche:**

Regulation of the therapeutic relationship

| | |
|---|---|
| **Faculty Supervisor**: | **Student Investigator:** |
| Ann Fudge Schormans | Deborah Tomlinson |
| Department of Social Work | Department of Social Work |
| McMaster University | McMaster University |
| Hamilton, Ontario, Canada | Hamilton, Ontario, Canada |
| 905 525 9140 ext. 23790 | **(905) 912-9132** |
| fschorm@mcmaster.ca | tomlind@mcmaster.ca |

**Purpose of the Study**

You are invited to be in a study about life at L'Arche. I am doing this research for my master of Social Work thesis. I will be writing a paper I will submit to my university. I would like to do one-on-one interviews with core members, assistants and staff. I want to learn about your life at L'Arche and about how you all live here together. I will ask you some questions about what you like about living at L'Arche and what you would change about living at L'Arche. Through this research project I hope to better understand how policies affect how organizations operate.

**What will happen during the study?**

I will ask you to answer a few questions about your life at L'Arche. I have attached theses questions to this package. We will meet somewhere we choose that is quiet and comfortable. Our conversation will be about 20-60 minutes long, depending on how much you want to share. I will take hand written notes and, with your permission, I will use a tape reorder to record the interview. By recording our conversation I will be able to listen to it again later and make sure I didn't miss anything you said.

**Are there any risks to doing study?**

The risks involved in participating in this study are minimal. You may feel uncomfortable with the questions I ask. If any question makes you feel uncomfortable you do not have to answer them. You may also worry about how others will react to what you say - this is why I take your privacy very seriously and will not use your name in my paper. I will tell you more about the steps I will take to protect your privacy below. Also you can stop the interview at any time without having to explain why.

**Are there any benefits to doing this study?**

The research will not benefit you directly. This study will not change how L'Arche runs. I hope to learn more about life at L'Arche and its service model -- not change it. I hope that what is learned as a result of this study will help us to better understand the ways in which policy affects how organizations operate. This could help improve the design of future policy.

**Confidentiality**

All records of our conversation will be kept private. The only people who will read them are me and a transcriber (who will type out the voice recording). The transcriber will also be required to sign an oath of confidentiality; this means they cannot tell anyone about what they hear. No one else will know you participated unless you choose to tell them. However, sine your community is small, others may be able to identify you on the basis of what you say. Please keep this in mind when deciding what to tell me. You will have the opportunity to look at my notes from our conversation and to edit or change anything you may have said before it is used. You will also have a second opportunity to look at how what you have said will be used in the final paper. All records will be kept in a safe and secure place. No one will be identified by name in this study but instead by a code (eg. Resident 1, Assistant 2).

The information you provide will be kept in a locked cabinet where only I will have access to it. Any information kept on a computer will be protected by a password. Once the study has been completed, the data will be erased.

**What if I change my mind about being in the study?**

If you decide to be part of the study and then change your mind, you can decide to stop at any time, even after signing the consent form or part-way through our conversation. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you have provided will be destroyed unless you tell me otherwise. If you do not want to answer some of the questions you do not have to, but you can still be in the study.

**Information about the Study Results**

I expect to have this study completed by September*, 2011.* When the study is done you will have the opportunity to either have a brief summary of the results mailed to you. If you like, you could also sit down with me and have them described to you.

**Questions about the Study**

If you have questions or need more information about the study itself, please contact me at:

tomlind@mcmaster.ca

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance.

If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat

Telephone: (905) 525-9140 ext. 23142

c/o Research Office for Administrative Development and Support

E-mail: ethicsoffice@mcmaster.ca

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**CONSENT**

I have read the information presented in the information letter about a study being conducted by Deborah Tomlinson, of McMaster University.

I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.

I understand that if I agree to participate in this study, I may withdraw from the study at any time. I have been given a copy of this form. I agree to participate in the study.

Signature: ________________________________________

Core Member [ ] Assistant [ ] Staff [ ]

Name of Participant (Printed) _____________________________________

*1. I agree that the interview can be audio recorded.*

*… Yes.*

*… No.*

*2. …Yes, I would like to receive a summary of the study's results.*

*Please send them to this email address* _____________________________________________

*or to this mailing address:* ___________________________________________________

*… No, I do not want to receive a summary of the study's results.*

# Appendix C – Staff letter of information and consent

## STAFF LETTER OF INFORMATION / CONSENT

### A Study About Life at L'Arche:

Regulation of the therapeutic relationship

**Faculty Supervisor**:
Ann Fudge Schormans
Department of Social Work
McMaster University
Hamilton, Ontario, Canada
905 525 9140 ext. 23790
fschorm@mcmaster.ca

**Student Investigator:**
Deborah Tomlinson
Department of Social Work
McMaster University
Hamilton, Ontario, Canada
**(905) 912-9132**
tomlind@mcmaster.ca

### Purpose of the Study

You are invited to be in a study about life at L'Arche. I am doing this research for my master of Social Work thesis. I will be writing a paper I will submit to my university. I would like to do one-on-one interviews with core members, assistants and staff.  I want to learn about your life at L'Arche and about how you all live here together. I may also ask you some questions about Ontario Regulation 299/10, and if you think it will affect L'Arche and you. Ontario Regulation 299/10 was created by the provisional government and it sets out guidelines for operating developmental services. Through this research project I hope to better understand how policies affect how organizations operate.

### What will happen during the study?

I will ask you to answer a few questions about your life at L'Arche. I have attached theses questions to this package. We will meet somewhere we choose that is quiet and comfortable. Our conversation will be about 20-60 minutes long, depending on how much you want to share. I will take hand written notes and, with your permission, I will use a tape reorder to record the interview. By recording our conversation I will be able to listen to it again later and make sure I didn't miss anything you said.

**Are there any risks to doing study?**

The risks involved in participating in this study are minimal. You may feel uncomfortable with the questions I ask. If any question makes you feel uncomfortable you do not have to answer them. You may also worry about how others will react to what you say - this is why I take your privacy very seriously and will not use your name in my paper. I will tell you more about the steps I will take to protect your privacy below. Also you can stop the interview at any time without having to explain why.

**Are there any benefits to doing this study?**

The research will not benefit you directly. This study will not change how L'Arche runs. I hope to learn more about life at L'Arche and its service model -- not change it. I hope that what is learned as a result of this study will help us to better understand the ways in which policy affects how organizations operate. This could help improve the design of future policy.

**Confidentiality**

All records of our conversation will be kept private. The only people who will read them are me and a transcriber (who will type out the voice recording). The transcriber will also be required to sign an oath of confidentiality; this means they cannot tell anyone about what they hear. No one else will know you participated unless you choose to tell them. However, sine your community is small, others may be able to identify you on the basis of what you say. Please keep this in mind when deciding what to tell me. You will have the opportunity to look at my notes from our conversation and to edit or change anything you may have said before it is used. You will also have a second opportunity to look at how what you have said will be used in the final paper. All records will be kept in a safe and secure place. No one will be identified by name in this study but instead by a code (eg. Resident 1, Assistant 2).

The information you provide will be kept in a locked cabinet where only I will have access to it. Any information kept on a computer will be protected by a password. Once the study has been completed, the data will be erased.

**What if I change my mind about being in the study?**

If you decide to be part of the study and then change your mind, you can decide to stop at any time, even after signing the consent form or part-way through our conversation. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you have provided will be destroyed unless you tell me otherwise. If you do not want to answer some of the questions you do not have to, but you can still be in the study.

**Information about the Study Results**

I expect to have this study completed by September*, 2011.* When the study is done you will have the opportunity to either have a brief summary of the results mailed to you. If you like, you could also sit down with me and have them described to you.

**Questions about the Study**

If you have questions or need more information about the study itself, please contact me at:

tomlind@mcmaster.ca

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance.

If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat

Telephone: (905) 525-9140 ext. 23142

c/o Research Office for Administrative Development and Support

E-mail: ethicsoffice@mcmaster.ca

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**CONSENT**

I have read the information presented in the information letter about a study being conducted by Deborah Tomlinson, of McMaster University.

I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.

I understand that if I agree to participate in this study, I may withdraw from the study at any time. I have been given a copy of this form. I agree to participate in the study.

Signature: ________________________________________

Core Member [ ] Assistant [ ] Staff [ ]

Name of Participant (Printed) _____________________________________

*1. I agree that the interview can be audio recorded.*

*… Yes.*

*… No.*

*2. …Yes, I would like to receive a summary of the study's results.*

*Please send them to this email address* ____________________________________________

*or to this mailing address:* ___________________________________________________

___________________________________________________

*… No, I do not want to receive a summary of the study's results.*

# Appendix D – Core member interview guide

## Core Member Interview Questions

## Regulation of the therapeutic relationship: A Case Study

Deborah Tomlinson, Master of Social Work Student
Department of Social Work – McMaster University

**Information about these interview questions**: This gives you an idea what I would like to learn about life at L'Arche. Interviews will be one-to-one and will be open-ended (not just "yes or no" answers). Because of this, the exact wording may change a little. Sometimes I will use other short questions to make sure I understand what you told me or if I need more information when we are talking. For example, I might ask you "*So, you are saying that …?* or "*Please tell me more?", to get more information.* I might also ask "*Why do you think that is…?"*to learn what you think or feel about something*).*

**1) What is it like living at L'Arche?**

*Probes:*
*What do you like about living here?*
*What does your day look like?*
*What are your responsibilities?*
*Are there rules?*

**2) What would you change about living here?**

*Probes:*
*What don't you like about living here?*
*What do you think might make it better to live here?*

**3) Do you feel like you belong here? [ ] Yes [ ] No**

**Please tell me why.**
*Probes:*
*Can you explain what it is that makes you feel like you do or don't belong?*
*Who are your friends here?*
*Do you feel cared for here?*
*Do you like living here?*

**4) Is there something important we forgot? Is there anything else you think I need to know about life at L'Arche?**

**END**

# Appendix E – Staff interview guide

Staff Interview Questions

## Regulation of the therapeutic relationship: A Case Study

Deborah Tomlinson, Master of Social Work Student
Department of Social Work – McMaster University

**Information about these interview questions**: This gives you an idea what I would like to learn about life at L'Arche. Interviews will be one-to-one and will be open-ended (not just "yes or no" answers). Because of this, the exact wording may change a little. Sometimes I will use other short questions to make sure I understand what you told me or if I need more information when we are talking. For example, I might ask you "*So, you are saying that …?* or "*Please tell me more?", to get more information.* I might also ask "*Why do you think that is…?"* to learn what you think or feel about something*).*

**1) What brought you to L'Arche?**

*Probes:*
*How did you learn about L'Arche?*
*Why do you choose to live at L'Arche?*

**2) In your opinion what makes L'Arche different from other housing providers for adults with developmental disabilities?**

*Probes:*
*What are some strengths of the model?*
*What would you change?*

**3) What does it mean within the L'Arche community to provide care?**

*Probes:*
*What is the service model?*
*Do you think Regulation 299/10 will change this?*

**4) Can you describe the relationship between core members and assistants?**

*Probes:*
*Is it different from other service models?*

**5) What does social inclusion look/feel like at L'Arche?**

*Probes:*
*What does it mean to belong at L'Arche?*
*Do you think Regulation 299/10 will change this?*

**6) How are decisions made in L'Arche homes?**

*Probes:*
*Are their regular house meetings?*
*How are core members incorporated into this process?*

**7) How do you think Regulation 299/10 will change life at L'Arche? Yes [ ] No [ ]**

*Probes:*
*Do you have concerns?*
*What positives do you think might come out of this?*

**8) Is there something important we forgot? Is there anything else you think I need to know about life at L'Arche?**

**END**