Self-Determination and Community Life in Persons with Intellectual Disabilities

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DISSERTATION

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Dedicated to my community

"Community is a place of belonging, a place where people are earthed and find their identity.

[…] True community is liberating."

(Vanier, 1989, p. 13-16)

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LIST OF ABBREVIATIONS

DS	Disability Studies
ID	Intellectual Disabilities
IRB	Institutional Review Board
PI	Principal Investigator

SUMMARY

Self-determination of persons with intellectual disabilities (ID) has been understood as "acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference" (Wehmeyer, 1996, p. 24). Residential settings for persons with ID can support or hinder the empowerment of residents' self-determination (Finlay, Walton, & Antaki, 2008).

This ethnographic study examined the relationship between self-determination and community life in adults with ID (core members) living together with persons/staff without ID at a L'Arche community. L'Arche is a movement of communities in which persons with and without ID share life in a spirit of belonging (L'Arche USA, n.d.a).

The study found that core members reported making their own choices in community with pride, and observation showed that these choices were often influenced by external factors, including staff influences, community practices and environment/space. These choices included wanting to be in community, how to live in community, and life outside community. Different decision-making elements emerged from community life, including option availability (core members generally had options to choose from and staff generally sought to support this availability) and finding compromise.

The study also contextualized self-determination within a theoretical and communal framework, suggesting the importance of taking into account different elements of self, community and decision-making: unconscious motives/expression in choice-making, acceptance of interdependence, a relational understanding of the autonomous self, and a recognition of power differences within mutuality community discourse. It is hoped this study expands the current understanding of self-determination and informs action in the field.

I. INTRODUCTION

Self-determination of persons with intellectual disabilities (ID) has been defined as "acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference" (Wehmeyer, 1996, p. 24). Loman, Vatland, Strickland-Cohen, Horner and Walker (2010) highlight it as a psychological construct that refers to self-caused (vs. other-caused) volitional (conscious) action.

Self-determination has been presented as the result of a constant interaction between the individual and the different variables in his/her environment; residential settings for persons with ID outside the family home can present both supports and barriers to the empowerment of residents' self-determination (Finlay, Walton, & Antaki, 2008).

In response to dissatisfaction with often oppressive existing living conditions in group residential settings, various individuals and groups have tried creating more empowering alternative settings for support and service delivery for persons with ID (Dalton, Elias, & Wandersman, 2001). L'Arche communities, in which persons with and without ID strive to live together in a spirit of respect and friendship, are an example of this and can provide an example where the challenge between group living and issues of empowerment and self-determination can be present (McDonald & Keys, 2005).

There is a lack of research in self-determination of persons with ID within a community (and not merely a group) context, especially regarding L'Arche. This research, a grounded ethnographic study on the relationship between self-determination and community life at Serenity House in L'Arche Southown, seeks to address that gap.

II. RESEARCH QUESTION

The overall central research question was: What is the relationship between self-determination and community life for persons with ID living in community?

This question pinpointed to the larger themes of self-determination and community living; I was thus open to different sub questions throughout the research process. Indeed, in qualitative methodology, the researcher usually poses a central question as a broad or general question that asks for exploration without limiting further inquiry (Creswell, 1998). A sub-question that emerged as relevant was that of the relationship between assistants' support and persons with ID's self-determination.

The site employed to study these questions was Serenity House, in the L'Arche Southown community, where people with and without ID (core members and assistants) share life together.

III. LITERATURE REVIEW

This study is a grounded ethnography (see Battersby, 1981) on self-determination of persons with ID and community. As such it brings together ethnography, understood as the study of the culture of a site primarily through interviews and observations, and grounded theory, understood as theory development "from the ground up."

As I present a detailed literature review on relevant research topics, it must be noted that the place of the literature review in grounded theory studies has been the subject of debate, with some believing its place should solely be at the end of a study (so as not to influence emerging theory) and others advocating for a middle ground approach, allowing for previous literature review while ensuring the research site is entered with openness without prejudging research results (Dunne, 2011). This middle ground, which I employed, is aware that researchers often enter the field with some previous knowledge anyways but calls for not imposing a specific theoretical framework on the study at the outset. Henwood and Pidgeon (2006) call this "theoretical agnosticism." It is the role of the data to eventually approve, disprove, or broaden previous theoretical findings.

I will thus present here a literature review focusing on self-determination and community, particularly as related to L'Arche. My writing style is narrative. As I will present my research findings using the voices of informants (research participants) in the next chapters, I present here previous research findings using the voices of researchers and of people with ID. I sought to enter the research field with a certain detachment from these findings, without subscribing to them as necessarily true, thus allowing the data to eventually speak for itself.

A. **Self-determination**

Self-determination has been defined as "acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference" (Wehmeyer, 1996, p. 24). This is produced by the constant interaction between the individual and the multiple variables in his/her environment.

The term itself takes us to the philosophical root of *determinism*, which implies that events (like human behavior) are effects of preceding causes. In the case of self-determination, though, it would be simplistic to speak of a person's behavior being solely determined (rather than influenced) by a variety of factors, as his/her free will and decisional ability must be taken into account as well. Loman et al. (2010) highlight self-determination as a psychological construct that refers to self-caused (vs. other-caused) volitional (conscious) action.

Deci and Ryan, in their Self-Determination Theory, have emphasized that there are three psychological needs or domains that motivate the self to initiate behavior: competence, namely the need to learn and master appropriately challenging tasks; autonomy, which is the need to determine and organize one's own behavior and goals so that they are in harmony with one's own interests and values; and relatedness, understood as the need to feel attached to others and experience a sense of belonging, security and intimacy (2002).

Self-determination is often understood through different models or frameworks: a *functional model* that focuses on behaviors and the effects actions have for a person, thus emphasizing whether the person's actions enable him/her to act independently and/or improve his/her quality of life (Wehmeyer et al., 2011); an *ecological model* that emphasizes the role of the environment on the person (Walker et al., 2011); and a *self-regulation model* that sees the process of matching personal capacity with opportunities that are available to the person

(Wehmeyer & Bolding, 2001). These frameworks are not mutually exclusive but may be seen as interdependent, shedding light on different aspects of self-determination.

Self-determined behavior has been related to actions exhibiting four essential characteristics: "1) the person acted autonomously; 2) the behavior(s) is (are) self-regulated; 3) the person initiated and responded to the event(s) in a psychologically empowered manner; and 4) the person acted in a self-realizing manner" (Wehmeyer & Bolding, 2001, p. 373). Three main factors have been recognized as impacting self-determination: 1) individual capacity, affected by development and learning; 2) opportunity, affected by experiences/environments; and 3) supports and accommodations available to the person (Wehmeyer & Bolding, 2001).

Promoting and enhancing the self-determination of people with ID has become more of a focus of disability services in recent years. There are different ways of understanding and framing disability. A widely accepted definition of ID is that it is characterized by significant limitations in adaptive behavior and intellectual functioning, with consequences on social, conceptual and practical adaptive skills (Wehmeyer et al., 2008). The *Diagnostic and Statistical Manual of Mental Disorders* of the American Psychiatric Association (1994) sees "mental retardation" (an old term for ID) as defined by an IQ score below 70. A social model of disability (often emphasized by the Disability Studies discipline), instead, doesn't frame disability as solely inherent within the person, but as a social construct created by oppressive structures and systems (economic, environmental, cultural, medical, political, etc.). It thus differentiates between individual impairment and disabling social oppression (Shakespeare & Watson, 2002). The social model has helped people with disabilities move beyond negative self-images and encouraged them to advocate for their rights and challenge structural oppression. After being accorded little to no say over their lives (Dybwad & Bersani, 1996), this change of vision has

been empowering to many persons with disabilities, encouraging them to gain mastery over their affairs, which is how Rappaport (1987) has defined empowerment.

Research shows that albeit adults with ID place high value on self-determination (Schalock et al., 2005) in general people with ID are not very self - determined, albeit the cause of this is less clear. Across the disability spectrum, people with greater intellectual impairments show less self-determination than peers with mild ID or than people with developmental disabilities that don't have ID (Wehmeyer & Garner, 2003).

Shogren and Broussard (2011) have researched persons with ID's perceptions of self-determination and found that they described self-determination as being able to make choices and be in control of one's life and setting, as well as being able to work toward goals and engage in advocacy. Their social context, though, not always shared that value. Some participants mentioned their parents as being over-protective and not understanding that although they might always need support, they could also be more independent.

Self-determination does not necessarily mean total control at all times. Self-determination can happen in small or larger ways, even if a person needs supports. It generally refers to enabling people to make things happen in their lives, even if in small ways and step-by-step depending on the person (Wehmeyer, 2005). Hence, people with severe disabilities who might be able to do very little by themselves behavior-wise and thus might need various kinds of special support, can still be casual agents that cause things to happen in such a way as to retain meaningful control over their lives.

In his study, Crichton (1998) is critical of a direct care approach focusing so much on personal choice for persons with ID that the result is carelessness and neglect. He notes that with the move from institutional living to community living the relationship between staff and

residents has seen a shift in power relationships, towards relatively more “egalitarian,” or at least less oppressive, relations. This is usually done with good intentions, but sometimes the over-control of the “old days” has been replaced with under-control, leading to a certain type of neglect of some residents with ID. The example of a 50-year-old man with severe ID needing support for his basic needs and who moved from living in an institution for over 20 years into a group home, shows how problematic the line between restriction and respect for one’s choices can be. In his new less-restrictive group home, in fact, if the man did not eat well it was considered by staff members to be his choice and, following the same principle, he was often left in bed for many hours in the morning with his beard unkempt (Crichton, 1998).

In regards to quality of residential contexts for persons with disabilities, O'Brien (1984) highlights “five service accomplishments”. Having the opportunity to make daily choices and life choices is amongst these accomplishments. According to Wehmeyer and Garner (2003) in residential homes (and beyond) two primary contributors should be examined to understand the degree to which a resident is self-determined.

First, is the capacity of the resident to act in a self-determined manner. This causal agency capacity of the person can be gathered from the skills the person has to make decisions, to set goals and to solve problems, as well as the person’s ability to advocate for him/herself.

A second contributor to residents’ self-determination is how much the environments in which they live, play, learn or work provide them with occasions to practice control in their lives and make choices. This, of course, also includes the degree to which other people around the person enable him/her to do so (Wehmeyer & Garner, 2003).

A common misconception is that due to the presence of an intellectual impairment people with ID cannot become self-determined, an assumption that consequently limits their

opportunities to receive self-determination skills instruction (Wehmeyer & Garner, 2003). Using the 72-item self-report Arc's Self-Determination Scale (measuring autonomy, self-regulation, psychological empowerment and self-realization) as well as the 78-item Autonomous Functioning Checklist (measuring self and family care, management, recreational activity, and social and vocational activity), Wehmeyer and Garner (2003) found that the correlation between self-determination and IQ is somewhat low, with the distribution of self-determination scores being both broad and with a small skew towards higher self-determination. Discriminant functional analysis showed that for individuals with ID it was primarily their *perceptions of choice* rather than IQ score that predicted membership in the high self-determination group and autonomous functioning. Generally, people living or working in more restrictive settings have been found to have lower self-determination, showing how environment too, rather than mere IQ, can affect self-determining behavior. In summary, IQ level can predict the settings where people live/work but only in part in predicting their degree of self-determination, which is influenced instead mostly by their awareness of choice opportunities and by their environment.

What then does research identify as barriers to self-determination? In their work studying residential services for people with ID, Finlay, Walton, and Antaki (2008) describe empowerment as promoting choice and control (thus as promoting key elements of self-determination). Under this lens the two main barriers to the promotion of choice and control in support services are: support not being fitted to the individual (rather expecting the individual to fit into what is already in existence) and services tending to focus on inability, with the consequence of creating dependency from the part of the residents (Prime Minister's Strategy Unit, 2005). Within such a reality, subtle inter-relational power dynamics between staff and

residents might end up preventing the residents from growing in their personal choice and control abilities. The authors divide these disempowering dynamics into four types:

- *The presence of conflicting agendas and of inspection regimes*. This dynamic can be present, for example, during service user meetings where staff members direct who can speak, when and what topics should be talked about, possibly even asking for quick decisions from residents that might need more time to decide; this dynamic can also be present when staff have to decide which service objectives to prioritize in case they seem in conflict, for example whether to prioritize concern over respecting food hygiene regulations in case of impending inspections or having a number of people in the house, primarily residents, involved directly in the cooking and cleaning.
- *Over-focusing on the "big things."* When discussing choice and control there might be a danger of focusing on bigger decisions (e.g., where to live or where to go on vacation) rather than small day-to-day life actions (e.g., pouring one's preferred amount of coffee to drink). Beyond discussion and into action, though, the opposite seems to be happening. Heller, Miller, and Factor (1999), in fact, found that generally persons with ID are more likely to have control over "smaller" aspects of their lives (for example, in their selection of clothing or of leisure activities) and less control over bigger decisions (like consenting to medical procedures or choosing a home or a roommate). This is in agreement with the study by Hatton et al. (2004) that concluded that, at least in smaller sized community-based residential settings, people with ID tend to experience more choice than those in larger settings, but that this choice rarely extends to major life choices.
- *Communication difficulties.* When understanding is uncertain and verbal communication limited, it is not always easy to ascertain to what extent persons with ID decide for

themselves. The use of accessible language, symbols and objects to better understand what persons with limited communication might want to choose is of great importance indeed, but it is also important to keep power relations in check. Staff members can often "help too much" in residents' daily affairs and not help them enough to grow in their choice-making capacity. At a practical level, for example, if staff suspects that residents might habitually choose the last option offered to them in a question or would agree to suggestions without understanding them, staff needs to be aware of such dynamics and not take advantage by coercing residents with ID to make choices they do not really want to make.

- *Pervasiveness of teaching.* If on one hand services' staff members are often encouraged to be person-centered (i.e., catering services to the preferences and needs of individual residents) they might also be encouraged to help/teach residents how to develop decisional capacity. They thus become "teachers" of self-determination. This is not necessarily bad per se', but the danger must be recognized of putting residents who fall short on "capacity" in the position of constantly being "students" that always have something to learn from the staff. It must therefore be recognized that residents' empowerment in self-determination can be encouraged by staff members, but it cannot be given to residents, who can grow in it without needing to acquire it as if it was a commodity (Kieffer, 1984). On the other hand, empowerment is also about being informed, becoming aware of possibilities and developing skills.

If these are the barriers to self-determination, research also emphasizes five areas within residential settings that play an important role in residents' self-determination. From the manner and consistency by which staff supports residents to the actual built environment and structures,

together with the socio-cultural context residences are situated in, research highlights the role of the environment on the person.

- *The role of staff.* Direct care staff has a primary role within residential contexts for persons with ID. Their practical support in the daily lives of residents, as well as that which may be deemed their "moral support" in the empowerment (or lack thereof) of the residents, cannot be underestimated. Felce (1998) found that staff organization and working methods (e.g., staff working practices, agency policies, and household routines) can be more important for residents' personal control than staff ratio or staff members' personal characteristics (individual attitudes, skills, etc.). McConkey and Collins (2010) found support staff played a significant contribution in residents' achievement of their self-selected social inclusion goals, particularly when staff sought information about community participation options and offered practical support for taking advantage of them. The role of staff for residents, though, often extends beyond that of a professional inclusion facilitator, to that of being a friend (Flynn, 1989).
- *Staff Consistency.* Research also suggests how important staff consistency is in supporting self-determination. Abery, Scholin, Paris, and Smith (2009) show that when person-centered approaches to service planning and consumer-directed community supports are not followed through in a consistent fashion, consumers' self-determination is unlikely to increase. Indeed, research has shown how consumer-directed support does not consistently enhance self- determination, but often inhibits it due to conflict that can exist between persons with ID, desiring to control their supports, and staff attitudes, preferring to determine what, how and when to carry out their work tasks (for example, Finlay, Walton, & Antaki, 2008). It is therefore important for staff members to be more

consistent and have an ongoing commitment to self-determination values. Lastly, staff members need to be critically aware of their role and the subtle power dynamics they might engage in, since, "staff usually have the advantage when they interact with people with learning disabilities: the extra bit of knowledge, the privileged access to the organization and its priorities, the suspicions about other views which might be brought to bear on the issue, the vocabulary and verbal fluency, and, as a result, it is hard not to dominate" (Finlay, Walton, & Antaki, 2008, p. 358). Albeit this has not been researched as of yet, personal self-awareness and training in a social model of disability that frames disability in a socio-cultural context of power dynamics could potentially be helpful to staff members to keep power dynamics in check in an effort to support residents' growth in self-determination.

- *Residential placement size.* Many agencies still use a continuum approach in the residential service provisions to persons with ID. Within this approach, a person's IQ is the primary, and often sole, predictor of whether the person will live in an integrated or restricted setting; restricted settings, of course, carry with themselves low social expectations and lack of resources to provide individualized and inclusive supports, let alone self-advocacy empowerment. Wehmeyer and Bolding (2001) found that residents with ID after moving from a "living environment that was more restrictive to one which was community-based and less restrictive […] showed gains in self-determination and autonomous functioning, and reported that they had more choice opportunities" (p. 378-379). Regarding the size of the residential setting, the smaller the better. In fact, large congregate settings have been found to be significant barriers to the development and expression of self-determination (Heller, Miller, Hsieh, & Sterns, 2000). This is evident

even in residential facilities where person-centered approaches are practiced (Stancliffe, 2001). Tossebro (1995) found that self-determination has a positive significant relationship with unit sizes of residences that have one to five residents, and a negative one with those that have six to 16 residents. Indeed, residing semi-independently and in smaller home-like living units, with support staff not always present, seems to be related to enhanced self-determination, even when controlling for the person's cognitive capacity (Stancliffe, 2001; Wehmeyer & Bolding, 2001). While important, however, size and structure of residential homes are not the sole determinants of self-determination in those settings. It is also important to study the impact of other environmental features: whether the living arrangement is of mutual agreement, characteristics of the people that live together, power relations amongst staff and also amongst residents themselves, how supports are provided and to what degree do the interactions in the residence encourage autonomy, residents' preferences and their choice-making abilities (Wehmeyer & Bolding, 2001).

- *Built environment.* The physical environment residents with ID find themselves living in, particularly if they have a physical disability as well, can influence activity choice and involvement by facilitating certain ones and/or limiting others. From height of counters to placement of reading materials it is important to take note of the built environment and how it can influence the residents' ability to perform determinate activities he/she may choose to do (Wehmeyer & Bolding, 2001).
- *Culture.* Supporting self-determination in residents of different cultures implies realizing that self-determination behaviors express themselves differently across different cultures. Hall (1981) identifies low-context cultures as those emphasizing independence,

individuality and future-time orientation, while high-context cultures as those valuing interdependence, relationships and a present-time orientation. The latter generally understand self in relationship with others and set goals positioning the individual within a social circle. Many self-determination programs have been developed in low-context cultures, thus emphasizing individual independence. It is therefore critical to have culturally relevant approaches to self-determination for residents that might come from various cultures and might have different emphases in their understanding of self and group, and therefore of what they value in individual choice-making itself.

Other social and cultural factors that might be relevant for self-determination are the resident's social network of peers, since there is evidence that residents in community settings with greater degrees of peer contact are more likely to demonstrate independence in self-care skills (Heller & Berkson, 1982) and are more likely to transfer to less restrictive settings (Romer & Heller, 1983); the residents' gender, albeit more research needs to be done in this area as findings so far are limited and mixed; the residents' age, which is important for designing appropriate self-determination interventions; personal religious beliefs, which often appear to influence people's perception of disability; and residents' past experiences of oppression (Wehmeyer et al., 2011).

These five self-determination support areas highlighted in research are not static, but changeable. They pinpoint to supporting self-determination as a constant and active process.

Research shows different practical ways in which self-determination in residential settings can be supported, which take into account the residents, the staff that supports them and the environment they live in. Wehmeyer and Bolding (2001), for example, emphasize the importance of residents matching their capacities (the self-assessment of existing self-resources

like individual motivation and skills) with the opportunities that are available to them to achieve their goals. Indeed, there often exists a discrepancy between what residents want and reality. Regarding this dynamic, Mithaug (1996) mentions optimal prospects as those "just-right matches" in which individuals are able to correctly match their capacity with existing opportunities.

Encouraging, when needed, group discussion amongst residents on different topics pertinent to home life decisions (and beyond) can result in mature social decision-making. Heller (1978) conducted a study in which residents with ID met in small groups to make decisions about the administration of their group home. The 12-questions interview (given as a pre-test and post-test) ranged from asking "What should be done if someone has a seizure?" to "What kinds of decisions should you be allowed to make in the home?" As a whole, group discussion resulted in subsequent individual decisions that had a higher degree of social maturity than individual decisions made before group discussion. This study demonstrates that, at least on a short-term basis, peer-group discussion and decision-making of day-to-day administrative issues in the home could certainly be a beneficial learning experience to residents. For the sake of the present study, then, the concept of the individual and that of his/her group/community need not be total opposites when dealing with self-determination.

In regards to staff, training staff in residents' self-determination has been tested using the Abery et al. (2008) self-determination curricula, which resulted in residents exercising greater self-determination than persons their age in similar settings with staff that didn't receive the training; though the impact of the original training did decrease over time, it led to the addition of active coaching and follow-up components to strengthen the intervention.

Lastly, regarding the environmental context, putting in place environmental interventions and assistive technologies where and when needed has been shown to have positive results on function and on participation in desired activities for people with ID (Hammel, Lai, & Heller, 2002).

Albeit these findings highlight important elements, barriers and supports to individual self-determination, there is a lack of research on what self-determination looks like in the context of an intentional community, where the interplay between individual decision-making and group decisions can possibly present both challenges and/or supports to self-determination of persons with disabilities.

B. **L'Arche Communities**

There are various intentional communities across the globe, often planned from their inception to gather committed people who share a specific focus on specific values or lifestyles. They can be secular or religious-inspired. In the domain of ID there are some communities in which persons with and without ID live together. Two main ones are the Camphill Movement and L'Arche (Randell & Cumella, 2009). Albeit intentional communities have been criticized as a return to the segregation of persons with ID and a denial of the principles of normalization (Jackson, 1999), they have been found to provide a higher quality of life, more equalitarian staff-residents relations, a greater sense of community and less institutional regimes than other types of supported accommodations (Emerson et al., 1999; Randell & Cumella, 2009).

L'Arche is an international federation and movement of communities in which people with and without intellectual disabilities share life together. With roots in France and in the Catholic Christian faith tradition, L'Arche has become international and inter-faith through the years. There currently are more than 146 L'Arche communities in 35 countries, each community

being independent yet sharing a common identity and mission, expressed in the official Charter of L'Arche.

L'Arche identifies as a shared life movement grounded on mutual relationships and trust in God, celebrating the unique value of every person and recognizing people's mutual need of each other. Its mission is threefold: affirming the gifts of people with developmental disabilities, made manifest through reciprocally transformative relationships; fostering a community environment that caters to the changing needs of its members, while not forgetting the essential values of the founding story; and engaging/working together in different cultures for a more human society (L'Arche USA, n.d.a).

L'Arche began in 1964 in Trosly-Breuil, a French village north of Paris, after Canadian philosopher and ex-naval officer Jean Vanier visited his spiritual mentor, Dominican priest Thomas Philippe, chaplain of a small institution for men with intellectual disabilities. Vanier (2012a) was deeply touched by his meeting with persons with disabilities there, finding in their gestures and words a desire for love and friendship: "I met Raphael and Philippe in an asylum near Paris where they were locked up behind enormous walls (….) and (I) invited them to come and live with me. (….) Above all, they needed to escape from a sense of isolation, to belong to a community of friends and form bonds of love and communion" (p. 28-29).

Encouraged to "do something" by what he described as a call from Jesus, Vanier bought a small house in Trosly and invited two persons with disabilities that were isolated in an asylum, Raphaël Simi and Philippe Seux, to live with him in a spirit of friendship and communion. This house was called L'Arche, French for "the ark," as in Noah's ark, a biblical symbol of covenant and salvation (Spink, 2006). In L'Arche Jean, Raphaël, and Philippe prepared and shared meals, prayed together, performed chores and "wanted to learn to love each other and create a warm,

open and welcoming home" (Vanier, 2012b, p.29). Vanier (2012b) would gradually realize that the needs of Raphaël and Philippe "were exactly the same as mine: to be loved and to love, to make choices and to develop their abilities" (p. 29).

L'Arche began with strong ties to Catholicism, its founder being a celibate Catholic man, and its vision strongly influenced by a Christian worldview (Spink, 2006). Vanier did not have plans to start a movement or establish other L'Arche communities, but through lectures and retreats he gave beyond Europe, new people got to know L'Arche and some visited Trosly to experience it. A number of those visitors eventually started L'Arche communities in their own countries. The first community that sprung outside of France was L'Arche Daybreak in Richmond Hill, Canada (1969), which had an ecumenical character. The third community was Asha Niketan in Bangalore, India (1970), which welcomed people from different religions. Growth in other cultures, faith traditions and economic settings was not without its challenges. L'Arche communities in North America generally began either out of retreats Vanier gave or thanks to people sent from Daybreak (Vanier, 2012a). The first community in the United States started in 1972 in Erie, Pensylvania; there currently are 18 communities across the US.

The writings and vision of Vanier have informed the development of L'Arche and have helped make it known in the North American continent. Vanier's vision brings together Christian and humanist elements highlighting how persons with intellectual disabilities can lead others to a "way of love" in which one may encounter personal inner vulnerability and poverty, realizing his/her need for others, and being invited to enter into friendship and communion with others in a spirit of belonging, growing in one's humanity.

L'Arche has also been made popular in North America by the writings of Henri Nouwen (1932-1996), a Dutch-born Catholic priest who became a chaplain at L'Arche Daybreak

(Canada) after teaching at Yale and Harvard. Nouwen wrote more than 40 books that offered spiritual and psychological insights into the dynamics of the inner life. He often wrote on L'Arche and the life lessons learned there (for example, Nouwen, 1997).

At the center of L'Arche communities is the relationship between persons with disabilities and assistants. In the US the former are called "core members" (coming from the Latin *cor*, as in the *heart* of the community) and can potentially live their whole life in community, while the latter are generally asked to make a one-year commitment, which can be extended for a longer time. Core members and live-in assistants live together in the same house, generally a family-style house integrated in the neighborhood, and at times work together (some communities have their own work programs, ranging from candle-making to farm/garden work).

In L'Arche homes core members and assistants live daily life together – with its joys and challenges, with supports as needed. The shared evening meal and prayer times are of particular importance in the homes' life. Periodically, communities provide formation to their members, celebrate birthdays, community anniversaries and other special events, and invite visitors and new connections.

Considering L'Arche started in the 1960s, its communities may be considered part of a wider movement centered on affirming the dignity of persons with ID. Vanier mentions how people with ID are one of the most oppressed and excluded people in the world (Vanier, 1998). A brief look at history pinpoints to this. In ancient times, in both Greek and Roman societies, which have greatly influenced Western culture, infanticide was advocated for children with perceived imperfections. Some saw disability as a punishment inflicted by angry gods. Judaism and Christianity both prohibited infanticide, and people with disabilities tended to be seen as the "less fortunate" needing care (Barnes, 1997). During the Middle Ages, people with disabilities

have been objects of entertainment for the rich class and of public ridicule, for example, by being put on display at village fairs as objects of amusement. In the 17th century people with disabilities were confined in old leprosy houses together with other people deemed "strange," as Cartesian rationalism spread emphasizing the value of reason over unreason. From the 18th century on the scientific medical "gaze" gave birth to clinical diagnostics and treatments of "abnormality" (Foucault, 1965), while industrialization excluded people *un*able to work in factory settings.

Before the 1950s, many people with mental disabilities and illnesses were continuously segregated from society in large, remote institutions. In the following years, however, people became aware of the inhumane conditions people in these institutions lived in, and the deinstitutionalization movement grew in different parts of the world, including Europe and the United States (Bacharach, 1976). In the United States, for example, this was coupled with an emerging disability rights movement. A highlight of this was the passing of the American with Disabilities Act, passed by Congress in 1990, the first comprehensive civil rights law centered on the needs of persons with disabilities that advocated against their discrimination (Scotch, 2000). In 1999 a United States Court decision (Olmsted) held that people with disabilities have a right to receive services in the most integrated community setting as appropriate to their needs (Butler, 2000). The development of L'Arche homes, smaller in size and integrated in neighborhoods, may be seen as having been a part of this wider social change and movement.

In the United States (and beyond) L'Arche has had to bring together its faith community aspect and its state-funded agency aspect, with the specific requirements the latter might imply (assistants, for example, receive state training as support persons). L'Arche homes (generally 3 to

5 homes per community) vary in size and style. Often they might have about 3 to 5 core members living in them together with live-in assistants; some core members have more individualized apartments depending on need (a L'Arche in North America, for example, has a complex in which the first floor apartment is reserved for a married couple with disabilities and the third floor is a single apartment for a core member who needs occasional support). From an agency standpoint, L'Arche homes may generally be considered as small group homes. In fact, community residential contexts for persons with ID may be divided in at least five types (McConkey, 2007): *dispersed supported living*, in which a person is a tenant of an ordinary residential place, often within a community, on an individual or shared (generally no more than two persons) basis, with support staff visiting regularly as needed; *clustered supported living*, consisting of groupings of houses on one site with about 15 tenants in the same cluster and shared staffing across the houses; small *group homes* with about six persons per house, usually owned by a service provider and mostly located among ordinary housing; *residential homes*, which are specially built/adapted houses with an average of 19 residents; and *campus-style housing* settings consisting of groups of houses on the same site, accommodating about six/eight people per house, with up to 100 persons total on the site. The small group home model seems to be closest to the reality of L'Arche, with the understanding that also the assistants are its residents besides persons with disabilities.

L'Arche differs from other forms of group living settings in at least three ways: it is faith centered, with spirituality informing daily rhythms and traditions; it avoids the traditional staff-resident divide, with core members and assistants sharing and creating home together; and its communities share an internationally ratified charter that emphasizes the spirit of life sharing (McDonald & Keys, 2005).

My experience in L'Arche has led me to contextualize disability in the realm of community, which I define as an interpersonal network of belonging formed by friendships (between two or more people). It is hard to define friendship, a form of love, which is at the basis of belonging in a community, but certain words might convey a sense of it: presence, trust, vulnerability, sharing, interdependence, care, affirmation, reciprocity, equality, value, understanding, accepting weaknesses and strengths, and encouragement.

The community journey is identified by Vanier as one of forgiveness and celebration. Wary or definitions, he uses various words and images to describe community: belonging, openness, caring, forgiveness, healing, growth, mutual trust, sharing of weakness, using one's gifts, and coming together for a purpose (Vanier, 1989).

According the philosophy of L'Arche, community based on friendship is a way to grow as a person and to grow with others in unity in the midst of difference (Vanier, 1989). In living community together people with and without ID help each other realize their humanity by being drawn out of their individual worlds (Goldingay, 1997), their temporal and culturally-bound labels, into a shared life in a network of accepting and affirming relationships.

In L'Arche, friendship and the creation of community can happen through very simple gestures: going out together for a drink on a weekend, watching a movie together, talking about each others' lives, introducing new friends in the relationship, and other ordinary actions. There is a mutuality in friendship: each has something to give and to receive. If we look at our own experience of friendships we might find that a sense of belonging and interconnectedness with the other person or group of persons emerged in very simple moments. Somehow, though, these relationships might have given us a sense of being valued, appreciated, and encouraged to simply

be ourselves, even in our ups and downs. Mosteller spoke of L'Arche, as a book of hers is entitled, as "a place to hold my shaky heart" (1998).

Friendship and community, then, help frame the question of self identity - who am I? - into an interpersonal context question - whose am I? Where do I belong? (Gaventa, 2010). Lindemann (2010), in describing relationships of care towards people with dementia, uses the beautiful image of holding the other person and holding his/her identity. This image pinpoints to how community should not be controlling or coercive, but should be welcoming and individual-affirming. Indeed, Vanier (1989) notes that community must never take precedence over individual people but it is rather for them and their growth.

There are various ways of defining community, within different disciplines. As Gaventa (2005) mentioned regarding community spirit, "It is hard to define. We know it when we see it and feel it, and we also know and feel its absence" (p. 49). From a human ecology theory perspective, for example, a diverse group of theorists have focused on community in its spatial arrangements and characteristics (Hawley, 1986; Hutchison & Lee, 2011). From a public health perspective, "a definition of community emerged as a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings" (MacQueen et al., 2001, p.1929). Within sociology, Hillery's 1955 review of the sociological literature found 94 distinct definitions of community. Three elements, however, were shared by about three fourths of those definitions: geographic area, common interaction and social ties (Hillery, 1955). In more recent times, two different sociological meanings of community have developed: community as a geographic/territorial concept and community as a relational concept (Gusfield, 1975).

L’Arche may be said to blend the two sociological meanings of community - geographical and relational - together. People are bound by relational ties generally within a shared geographical area, usually surrounding the L’Arche residential homes where core members and assistants live. The geographical ties might be imagined in broad circles - live-in residents living within the closest geographical proximity from each other, followed by live-out community friends. Within the relational context, community ties do not necessarily follow the same dynamic as the geographical ones. In fact, long-time live-out community friends might have deeper relational ties to certain core members than live-in assistants who might only remain involved with the community for a year or so.

Within social psychology, McMillan, and Chavis (1986) have described four specific dimensions that in some way “make up” community: membership (feeling that one is invested in community and belongs to it); influence (a “force” exerted by an individual on the group and viceversa); fulfillment of mutual needs (the shared values, the exchanged resources and the satisfaction of needs amongst members); and shared emotional connection (emotional links between members of a group). According to McDonald and Keys (2005), if seen through these four lenses, L'Arche practices these values specifically when it asks core members if they want to stay in community year to year and celebrates their community anniversaries; when in transforms houses into homes and thus membership into belonging; when it has bidirectional influence as members adopt community principles but also influence its practices (for example, when new members can share their spiritual traditions with the rest of the home); when mutual needs are catered to through interdependent relationships where each gives and each receives; and when emotional links are forged through daily living and larger life events being shared together.

Thus, potentially, in L'Arche a certain equality can be formed and power imbalances can be more leveled through community. The division between staff and client common in other service settings is less prominent in L'Arche in favor of more egalitarian interpersonal connections. In this context the focus is not merely on problem solving but on a gentle, continuous presence in side-by-side relationships. This mutual respect can help persons with ID recognize their own self-worth and affirm that they can be agents that can take, as much as possible, positive control of their lives.

There are challenges to empowering the individual in L'Arche as well, though. McDonald and Keys (2005) describe them: group decisions can often trump individual desires; there is a struggle to renegotiate external power dynamics from larger civil and religious contexts that inform the community (for example, dealing with state trainings or religious understandings that might not always support the empowerment of persons with disabilities); relationships can take hierarchical forms in which assistants have power over core members (e.g., while core members usually engage in external work, assistants stay in the home where they often implement decisions in the absence of core members); there is a higher level of commitment towards building a sense of community as compared to increasing empowerment. Hence, even if L'Arche has not necessarily focused on empowerment per se as understood today, "many of its principles and practices suggest that empowerment may nonetheless occupy a valued position within the community" (McDonald & Keys, 2005, p. 15). There is a lack of research, though, on the particular relationship between self-determination and community living in L'Arche, which is what this study sought to address.

IV. METHODS

A. Research Aim

Adults with ID place high value on self-determination (Schalock et al., 2005). In general, however, people with ID are not very self-determined, albeit the cause of this is less clear. Residential settings for persons with ID can present supports and barriers to their self-determination (Walton & Antaki, 2008). There is a lack of research, however, examining the relationship between self-determination and community living settings, rather than mere group settings.

This grounded ethnographic research analyzes the relationship between self-determination and community in adults with ID living at Serenity House, a residence of the L'Arche Southown community. In this living context people with and without ID are invited to share life together. I, the researcher and Principal Investigator (PI), have been involved in this community for some years and work in it.

As it is a grounded study, it is hoped that insights from this research can hopefully expand the theoretical understanding of self-determination and community, as well as provide insight potentially leading to critical awareness/conscientization – a step for individual and social transformation (Taylor, 1993) in regard to self-determination and community.

On a practical level, I am aware of the benefit a greater understanding of the relationship between self-determination and community life could have in the structuring of the program, the tailoring/delivering of the services and in supporting the life of the community, for both L'Arche Southown but also for L'Arche across the globe.

Beyond L'Arche, I hope this research can inform community supported living environments and any residential/relational settings where the dichotomy individual/community

might present itself, as well as any community settings where individual self-determination and community life have to meet, with the exciting and the challenging dynamics that entails.

B. **Ethnography**

This study used a qualitative methodology. Qualitative research aims to gather, generally through interviews and group conversation, an in-depth understanding of human behavior and the reasons that influence and affect it. Qualitative data emphasizes subjectivity, thus starting from research participants' perspectives and experiences.

In this study, such a person-centered approach helped the "self" in "self-determination" take center stage and speak from his/her experience, adding different perspectives to the self-determination construct. After all, qualitative research is not merely subjective, too easily opposed to objectivity, but is rather perspectival (Maykut & Morehouse, 1994). The choices one wants to make, the group decisions one is willing to accept, and the way personal decisions interplay with communal decisions, are all elements that have to do with the perspectives of the persons involved and how their selfhoods are located within group dynamics.

Qualitative research epistemology springs from a phenomenological approach that observes and seeks to learn from hearing research participants' individual voices, observing their interactions and contextualizing them in a specific environment. This helps gain a deeper understanding of the meaning of everyday experience (Patton, 2002), which is precisely where self-determination is or is not exercised. Wehmeyer and Garner (2003) and Heller et al. (2011) emphasize how self-determination does not exist in a context-free reality, but is rather the product of multiple realities interacting with each other.

Lastly, whereas quantitative research tends to generalize, qualitative research seeks specificity and depth. The aim of this study is not so much to provide generalizable findings

(broad results), but is rather to examine the multi-layered dynamics of a specific people in a specific place at a specific time (deep insight).

There are various ways of doing qualitative research; for this study I employed ethnography. Ethnography literally means "portrait of a people," a written description of a particular culture (customs, beliefs and behaviors of a specific group of people) based on information connected through fieldwork (Harris & Johnson, 2000; Van, 2011). Ethnography examines the relationship between culture and behavior, analyzing what people do and interpreting why they do it (Ary, Jacobs, & Razavieh, 1996).

Most ethnographic research is case study research, focusing on a particular group, community, workplace, setting or event. It studies "sites" as living cases rather than just individuals, seeking a holistic depth of understanding of their complexity, with an ability from the part of the researcher to explore inter-connections, varying the focus (zooming-in and zooming-out) on people, places and events, so as to enter the way each group of people actually views the world (Hammersley, 1992).

Ethnography is about immersing oneself within a culture of investigation to observe behavior, and going beyond it to inquire about the meaning of behavior (Spradley, 1979). In ethnographic studies, observation and interviews are part of data collection (Ary et al., 1996). The ethnographic method also relies heavily on up-close personal experience and possible participation on the researcher's part in the natural reality being studied, making it a personalized method (Sangasubana, 2009).

For this research, an ethnography framework was chosen because realities such as "self-determination" and "community" are constructs that require a multi-layered understanding of personal meanings and understandings that are given by the informants themselves and because

these needed to take into account the setting and context informants found themselves in for a deeper understanding and analysis of the dynamics under study.

In L'Arche core members' choice-making is enacted within a relational network of interactions with fellow housemates (both with and without disabilities) and happens in the context of both a community and of an agency structure. All these elements interplaying with each other needed to be taken into account.

1. **Ethnographic theoretical and epistemological underpinnings**

The three theoretical underpinnings of ethnographic research as described by Genzuk (2003) are:

- *Naturalism.* Social research should capture human behaviors via first-hand contact with them where they actually happen, and not primarily via artificial experiment settings or in set-apart interviews. Social events must be explained within the relationship to the context they occur in. Ethnographers thus conduct their research in "natural" settings that exist independently of the research.
- *Understanding.* Human actions do not simply consist in mechanistic responses to stimuli, which is typical of physical phenomena, but they involve an interpretation of stimuli and the construction of responses. Therefore, to understand human actions effectively the researcher needs to understand the cultural context these happen in but also individual distinctive ways of thinking and acting in the world. Of course, people's thought processes and reasons for acting are not always clear (even to the thinking/acting person him/herself) but the ethnographer can at least seek to explore these for a greater understanding of the phenomena studied.

- *Discovery.* Rather than testing explicit hypotheses, the ethnographic research process is inductive or discovery-based. In other words, the focus of the research can be narrowed or possibly even changed as the research takes place, since the phenomena observed in some way leads the researcher, who should not force his/her assumptions on the it.

Whitehead (2005) presented various ways in which ethnography differs from more positivist approaches. Firstly, in ethnography the investigator/researcher is immersed in the host community, making it difficult to have investigator control, a hallmark of the dominant positivist paradigm. This lack of control allows for the spontaneous discovery of unexpected meaningful cultural phenomena that could have been missed by a more "controlled" approach.

Secondly, Whitehead (2005) continues, positivist approaches to social research can lack attention to the multi-layered meaning systems constructed by human beings. These systems express themselves differently in specific situations (context) and undergo change (process) – hence, ethnographic study does not begin with the idea of proving or disproving predetermined hypotheses as objective social facts, but seeks to learn as much as possible about those realities it studies as understood from the persons researched and from their own particular systems of meanings. Ethnography, therefore, is a highly flexible, open-ended and creative emergent learning process and not a "set in stone" rigid investigator controlled experiment (Whitehead, 2005).

Specific to Disability Studies (DS), ethnographic studies can provide rich contexts on which to base thorough critical reflections on disability matters, by helping investigate the interplay of agency, culture and structure (material and social) within people's daily lives (Davis, 2000). Some have criticized how DS has typically privileged emancipatory research and the social model of disability. This criticism is based on the awareness that the social model

understanding of disability might not be the research participant's own understanding of disability in the first place (Priestley, 1997; Stone & Priestly, 1996) and on the basis that such emphasis on a specific model can restrict the intellectual freedom and interpretative capacity of the researcher (Davis, 2000; Shakespeare, 1997). Albeit the social model of disability is a valid way to approach of disability, it is not the only valuable approach (D'Alessio, 2011). As much as social structures can play a role in promoting inequalities and can be oppressive, an understanding of disability that is only social can reduce the importance of people as social actors, reifying social structures without recognizing how single individuals and groups actually relate and even resist these structures, thus, even if these critical researchers do not seem to suggest that emancipatory research is needless, they pinpoint to the fact that it is not the only valid way of doing DS research, nor the only way to contribute to social change, which can happen through different approaches that are not necessarily mutually exclusive (Davis, 2000). The specific contribution of the ethnographic approach might be in the ethnographers' capacity "to produce writing which counters hegemonic discourses and their capacity to represent the complexity of peoples' lives through recognizing the importance of individual experience, culture and structure" (Davis, 2000, p. 203).

No ethnography can be performed without an underlying theory or model – whether an explicit or implicit worldview– that helps define the research problem and how to tackle it (Fetterman, 2010). Theory is used in ethnography as an interpretative method to interpret or illuminate a social phenomenon. The ethnographic writing process is one of a "reflexive or dialectical interplay between theory and data whereby theory enters in at every point, shaping not only analysis but how social events come to be perceived and written up as data in the first place" (Emerson, Fretz, & Shaw, 1995, p. 167).

Most researchers, Fetterman (2010) argues, explicitly or implicitly use one of two types of theory, based on their personality, trainings or interest: ideational theory or materialist theory. Ideational theory sees change as resulting from mental ideas and beliefs. Ideational theories include: cognitive theory, which assumes people can be described by listening to what they say; personality theories, like psychoanalytic theory, which focuses on how childhood experiences can contribute to adult functioning; and symbolic interaction theory, which analyzes the subjective meanings people give to objects, events and behaviors.

Materialist theory, instead, sees change as stemming primarily from "tangible" behavioral and material processes. Materialist theories include: cultural ecology, focusing on the interaction between people and environment; historical/dialectical materialism, presenting cultural superstructures as founded on an economic base (with economic forces and class struggles as driving change); and behavioral reductionism, based on Skinner's psychological approach emphasizing stimulus-response to understand people's actions (Fetterman, 2010).

Of course, there is a gray area, where theories do not let themselves be "locked" in any one of these two theory types. For example, within feminism theory we find both psychoanalytic feminism and materialist feminism, thus drawing from different background and theoretical frameworks.

Due to my personal interest in human relationships, inner landscapes, and persons' beliefs and emotions, my inclination as a researcher is that of an ideational approach; however, that is not the only approach I have used. Coming from an interdisciplinary background (BS in Theology and Communications, minors in Philosophy and in Mental Health and Human Services, an MS in Clinical Psychology, and PhD studies in Disability Studies) I approached data

as a multi-layered complex reality that could be interpreted at different levels borrowing from different disciplines and theories.

My use of theories and my potential emphasizing certain things over others, however, did not go unchecked. As part of my reflexive stance as PI, I reflected critically on my role, my knowledge and my own positionality throughout the research. In this sense this study may be considered a post-critical ethnography. This is a type of ethnography that, beyond being critical, and thus sensitive to the relationship between human agency and social structures (Anderson, 1989), calls for a genuine reflexive stance on the part of the PI to "give up the implicit assumption that they know how the world works and power operates and the researched don't" (Hytten, 2004, p. 96). Albeit I will mention in greater detail reflections on my role later on in this chapter and in the Discussion section, suffice to say here that besides being the Principal Investigator of the researcher I was also an employee of L'Arche Southown, in a working relationship with the informants. This, as well as previous knowledge, potentially brought bias to the research process, but, as I shall explain later, I tried to keep note of these elements and keep them in check as much as reasonably possible.

2. **Grounded ethnography**

I allowed my data analysis to be informed by previous knowledge, but not be bound by it. This helped me not to be limited by my theoretical interpretative knowledge but to focus on what grew out of the data. This is the approach that gives rise to grounded theory research (Glaser & Strauss, 1967), which is the ethnographic research type my study falls under. Grounded theory may be understood as the development of a theory underlying a community or socio-cultural system/process. This theory stems directly from research data, without preceding it.

Since theory development occurs continually in qualitative data analysis (Coffey & Atkinson, 1996), it may be important to specify here that a grounded ethnography (grounded theory and ethnography) study differentiates from an ethnographic study alone insofar as it gives a certain priority to process rather than simply the description of a setting. Thus, grounded theory ethnographers study what happens in a site and give a conceptual rendering of that (Charmaz, 2006), while other ethnographies might focus on full descriptions of the topic of study as an object to be described, without conceptualizing and highlighting the process that constructs it. The conceptual rendering and theoretical work included in the Analysis section does not aim to necessarily discover and prove a whole new theory, but it hopes to expand, build on or challenge existing self-determination theory. Much of ethnography using grounded theorizing has generally not led to 'new' theories but to conceptual variations of well-established themes (Timmermans & Tavory, 2007).

C. **Research Methodology**

As we have seen, ethnography is the study of a culture or cultures shared by a group of people, with rich descriptions of social interactions and an exploration of the meaning these hold for members of the culture under study. Hence, as Spradley writes, "rather than studying people, ethnography means learning from people" (1980, p. 3). Genzuk (2003) mentions it is very difficult, maybe impossible, to provide a clear set of procedures and rules for conducting ethnographic fieldwork, as that which an ethnographic researcher does depends on the situation, study purpose, nature of the setting and the skills of the observer.

There are, however, generic guidelines for conducting ethnographic research. Wolcott (1999) mentions that ethnographic research requires three things:

- Detailed *description* of the culture-sharing group under study.

- An *analysis* of the group in terms of perceived themes.
- An *interpretation* of the group by the researcher in regards to the meaning and significance of the analysis, explaining descriptive patterns and looking for linkages among the descriptions.

I will now present in greater detail the methodological elements that were employed in the study.

1. **Framing the research question**

We have already mentioned that my research sought to answer the question: What is the relationship between self-determination and community life in adults with ID?

The lack of research in this area, and my extensive experience in L'Arche homes – which are not simply group homes but community homes, made this question both interesting and intriguing to me but also relevant and needed for the wider ID and self-determination/community research areas.

As this was an open-ended question it allowed for qualitative openness, which generally avoids simplistic yes-or-no questions, as the research is expected to provide insightful analysis based on rich data. Albeit the question was clear enough, giving the research a clear focus, it was important as an ethnographer to give the question the flexibility to unfold or change throughout the study as appropriate.

This flexibility is typical of ethnography. There are even ethnographers that enter the research sites without any question in mind so as not to be influenced by preconceived ideas or perceptions, giving rise to an exploratory research that often results in descriptive findings rather than analytical ones (Murchinson, 2010)! I tried to let the research question inform my data collection and analysis, but also to allow the latter to frame – or re-frame – the question.

As my research question dealt with both individual and community I wanted that to inform my methodology. Indeed, in ethnography if the researcher is interested in personal perspectives, then interviews and conversations would be a key research component; if, however, the interest is on communal dynamics and group events, participant observation would serve as a primary source of data collection. In most cases, as in my research, a complete ethnography utilizes a combination of methods, with the researcher employing that which would yield the most pertinent types of information (Murchinson, 2010). As I researched both self and community I thus employed both data sources and sought to give them equal importance.

2. **My role as the researcher**

I was the Principal Investigator (PI) and participant observer of the research. In ethnographic research it is common to have the researcher in the role of a participant observer involved in the culture being studied. Bernard (1994) defines participant observation as establishing rapport within a community while also learning to act in a way that blends in it so that its members will act in an as much natural way as possible, but then also removing oneself from the community to focus on the data so as to write and understand it. Because of my relational and work experience with Serenity House over some years I didn't sense that establishing rapport or acting naturally were major concerns, nor did I feel informants acted awkwardly around me because of my research, as I tried to perform it in non-obtrusive ways.

In speaking of ethnographic observation, Merriam (1998) suggests that the question is not so much whether it affects the situation or the informants, but how the researcher accounts for the effects on the data. Ethnographic researchers are generally on a full-participants and full-observers continuum. As Merriam and Tisdell (2009) note: "Some researchers might be more involved participants than others. In reality, researchers are rarely total participants or total

observers. Rather, there is often a mix of roles wherein one might either begin as a full participant and then withdraw into more of a researcher stance or the reverse" (p. 145). I myself found that there were times in the study in which I was more involved in the life of the home and times in which I needed to step back and just observe; often my participant observation was a mix of the two. I made sure to account for my participation in my notes and in my data write-up.

As previously mentioned, I have also been involved in the community studied as an employee. I have years of lived L'Arche experience. My involvement in the community gave me an "insider knowledge" that is both affirmed and encouraged in ethnographic research. However, I was aware that this needed to be treated with great delicacy and clear boundaries, and I thus informed myself/researched the literature on doing qualitative research as an "insider" within a network of pre-existing work relationships. In my search I came to discover that it has been argued that a researcher is never completely an insider or an outsider (McDermid et al., 2014; Ogilvie et al. 2008). It may therefore be best to conceptualize a continuum between insider and outsider, rather than viewing them as binary opposites (Carter, 2004; Labaree, 2002).

If the researcher studying an organization is also its member he/she is already immersed in its minutiae and can thus have a developed sense of awareness and understanding of the organization itself (Galea, 2009). He or she may also have practical experience and knowledge that can help to identify the research needs of the organization (Costley & Armsby, 2007), which may make the information particularly relevant.

As an example of this dynamic, Goodley (1999) mentioned how his involvement in a self-advocacy group both on a personal level and as a researcher studying it, was advantageous to his ethnographic project. It gave him an awareness of group dynamics that outsiders might not have had; it helped him divide a questioning narrative from a theoretical narrative; and it helped

him understand the complexity of the group, rather than falling in a cynical danger of social research by looking only for the failings in the social world (Barton, 1996). I did, however, find it difficult at times to be detached from my view and opinions as a worker in the community. I thus took note of this, and of where the difficulties were, so that I could be aware and account for them.

Throughout the research I wanted to be sure that my "insider" knowledge and relationships – as rich and insightful as they might have been – were kept "under check" so as to prevent potential bias and to respect research boundaries. To do so I practiced reflexivity, trust/rapport and confidentiality, ensuring them as follows:

- *Reflexivity.* As the PI I made sure to include, alongside my research notes, critical self-observations and self-reflections on preventing potential bias. Thus, reflexive notes have been kept throughout the research. This follows Corbin Dwyer and Buckle (2009) suggestion that a researcher's ability to be open, honest, authentic, interested, and insightful about his/her role in shaping interpretations and research findings, and wholly committed to accurately and adequately representing the participants' experiences, are of key importance, even more than mere "outsider" or "insider" status. Indeed, qualitative data analysts need to show great sensitivity to the way social situations or processes are interpreted from specific backgrounds or value-systems rather than the situation alone (Altheide & Johnson, 1994).

  I am a man in his early 30s, without an intellectual disability and come from the Catholic faith tradition. I value the message of L'Arche on the beauty of becoming a community of friendship together with people with intellectual disabilities. I also integrate in my outlook on disability reflections from the Disability Studies discipline. As a researcher I

am human, and thus rely on my mind and sense to process information; by locating myself through reflexivity I sought to help readers determine whether, or how, my perspectives influenced my conclusions (Nieswiadomy, 1987).

- *Trust/Rapport.* I sought to respect informants and valued their trust, while taking precautions so that they would not feel pressured into partaking in the study simply because I worked for L'Arche Southown. McDermid, Peters, Jackson, and Daly (2014) mention how rapport between the research and the informants involves trust and respect for the participants and the information that is shared and thus, in terms of pre-existing relationships, the voluntary nature of participation needs to be reiterated. The risks and benefits of taking part in the study need to be outlined, including the right to withdraw as a participant at any stage of the process without explanation, consequence or repercussions (Mcllfatrick, Sullivan, & McKenna, 2006). I made sure all this was included in the informed consent packet and process.

  In addition, in the packet I spelled out that consent and assent would in no way affect the relationship with L'Arche Southown or UIC, and mentioned the support that potential participant could receive in case they became upset during the research. I also gave potential participants the opportunity to ask any questions they had about the research.
- *Confidentiality.* One of the PI's most important tasks in the research is to protect the privacy of participants and ensure anonymity. For this reason pseudonyms were used in the research, in this final report and will be used in the presentation of research findings. I have also changed the name of the community and of the home studied. Data from interviews and observations was kept private and confidential. For example, I did not share it with the Community Leader/Executive Director of the organization, who has

executive responsibilities in the agency. The interviews were held in private spaces within the house, and before the interview began I always double-checked with the informant if the place for the interview was good for them. Data was ultimately conglomerated for analysis.

I needed to report, as my responsibility as a UIC researcher, cases of abuse, harm, self-harm and/or neglect. This was specified in the consent process and thus made clear from the beginning. In the end, I did not need to resort to this. As another precaution to ensure confidentiality and privacy of information I have omitted or altered some identifying information from the write-up that were minor, not relevant to the research and thus did not affect the research data and results. For example, I changed the soda brand an informant liked or the name of a restaurant an informant went to, minor details that had no relevance in the study.

3. **Sample**

This research focused on the L'Arche Southown's Serenity House site. Serenity House is one of L'Arche Southown's homes, located in the United States. During my research period, Serenity House housed four core members with intellectual disabilities (George in his late 30s, Matthew in his early 40s, Jenna in her late 50s, and Alfred in his early 70s) and three live-in assistants/support staff (house coordinator Ellen in her early 20s, Michelle almost 20 years old, and Jane in her mid 20s). At a certain point during the research, Jane finished her one-year commitment, left the community, and live-in assistant Paul (in his mid-20s) joined the house as a live-in assistant. All of them consented (or assented if they had guardians consenting for them) for participation in the research. Two other people, namely live-out part-time assistant

Anna (in her late 30s) and L'Arche Southown's Community Leader and Executive Director Steve (in his early 30s) were also included in the sample and consented in the research.

As I sought to analyze house dynamics, Anna was selected because she shared time (the L'Arche term for working/being on the schedule) in the house on a weekly basis, had been involved in the community the longest and was part of the house team to such an extent that she even participated in house meetings (generally only attended by live-in assistants).

Community Leader/Executive Director Steve was selected because his community and executive decisions can influence the life of Serenity House; he was often present in the life of Serenity House, for example attending community celebrations and going there on various visits. He, Anna and Paul were the only staff informants that had previous live-in L'Arche experience (Anna in different international communities, Steve and Paul in other US communities).

The research sample thus consisted of 10 informants. This was the sample of the site under study, an appropriate size for ethnographic research, which seeks thick in-depth descriptions and insight. Many researchers often employ convenience sampling, which consists of having a sample group of subjects readily accessible to the researcher that might reasonably be assumed to possess qualities that are relevant to the study (Schensul, Schensul, & LeCompte, 1999). I selected people relevant to the site, which included all residents and some key external informants. I did not include emergency part-time assistants and volunteers that worked for a few hours once week or more rarely. I also did not include other external people that might have been influential for core members: families (parents, siblings, extended members, etc.), workplace employers and fellow employees, and people from their religious congregations. These relationships have probably influenced core members' self-determination and community life at different moments of their lives and in different ways, however, they were outside the

community context this research focused on. Needless to say, it would be interesting to eventually research family, outside social networks and other support systems beyond the immediate community that might influence core members' self-determination.

4. **Consent/assent process**

Before including informants in the research, I needed to receive their consent or assent. Informed consent means making a voluntary (free from undue pressure) and reasoned judgment about participation in the research, based on enough information to make a decision (Department of Health, 2001). Assent was sought from core members who were not their own guardians; this was done only after asking for and receiving consent from their guardians.

Informed consent/assent was sought from Serenity House members of L'Arche Southown (and their guardians if needed) after the approval from Institutional Review Board (IRB) at the University of Illinois at Chicago (UIC) was secured.

To share the overall idea of the research with potential informants I approached them individually and privately with a scripted information sheet containing general information about the research. Only after reading this and asking if they had questions did I proceed to ask whether they were interested in moving to the informed consent or assent phase. All said yes, and only after they did so did I read to each of them, as usual in a confidential space at Serenity House, the informed consent/assent form. The form presented more in-depth information about the research, highlighting potential informants' freedom to choose whether to participate in the research or not, without negative consequences and without affecting their relationship with UIC and L'Arche Southown/Serenity House if they chose to participate or not. The form also informed them of confidentiality measures and that they would have received a compensation of $25.00 at the end of the research. McDonald, Kidney, and Patka (2013) have shown how persons

with ID participating in research considered receiving a compensation for their contribution and time a matter or respect.

The process of consent/assent differed slightly between staff and core members, only in so far as I created a more accessible visual version of the forms for core members, with the intent of facilitating comprehension so that they could make an informed choice. All potential informants without guardians ended up consenting to research participation. The two informants with guardians assented, only after their guardians consented. To approach guardians I asked the Executive Director to send a flier about the research to guardians, with my contact info for more information. The guardians contacted me, the consent form was shared with them and they consented for the core members they were guardian of to participate in the research.

Most informants (nine out ten) consented/assented to being recorded during their interviews with me. If the informant did not want to be audio-recorded I transcribed interview replies right during the time of interview.

5. **Data collection**

Ethnography focuses on three basic research data: what people do, what people say, and documentary data (Reeves, Kuper, & Hodges, 2008). During their observations recorded in field notes, ethnographers are to routinely use interviews/informal conversations, which allow them to discuss and investigate emerging issues or to ask questions about events in a naturalistic way, hopefully eliciting candid accounts from the individuals, and they also gather documentary data, such as reports, pictures, or other documents (Reeves, Kuper, & Hodges, 2008). In my study I observed life at Serenity House, interviewed informants (both formally and conversationally), and gathered documentary data.

I observed and participated in the life of Serenity House, for example sharing meals together with informants, engaging in other home activities or in related outside community events. My observation focus was on how the relationship between self-determination and community living manifested in the concrete life of Serenity House.

Throughout observation I kept thick field notes while the events were happening, but most often developed on them afterwards while they were still fresh in memory. This is so because, considering the limited space of Serenity House and the close proximity to people, it would have been awkward and distracting if I were writing things as events unfolded. I thus sought to perform note-writing as naturally and unobtrusively as possible, which often implied writing short notes during the events and expanding on them right after the event in a more private space. Angrosino (2005) advised that "after the event" note-taking should be dated and done as early as possible after the event.

Albeit initially my observations and notes were informed by my general research question, I made sure to observe and take note also of seemingly unrelated or insignificant elements (for example, I would take note of the smell of the food while informants were cooking or the colors of the table décor). As time went by, however, I focused on things that were more relevant to the research question, as led by the data. Since self-determination and community living are constructs that carry a lot of meanings and elements in them, I didn't want to put too much control on what should and shouldn't be included in my observation.

Different models have therefore been proposed to gather and order ethnographic observation data. Without going into detail on each model, I focused on the "9 dimensions model" created by Spradley (1980). He mentions how all participant observation takes place in social dimensions, which may be identified by three primary elements (space, actors, and

activities) followed by other six social dimensions (object, act, event, time, goal, and feeling), listed here:

- *Space.* The layout of the physical settings where the social activities take place, such as rooms, outdoor spaces, etc.
- *Actors.* The people playing a role in certain situations.
- *Activities.* The recognizable patterns of behaviors/set of related acts that people perform (for example, entering into conversation with someone).
- *Objects.* The physical things present in the setting (furniture, decorations, etc.)
- *Acts.* Specific individual acts, which together can make up activities.
- *Events.* Particular occasions people engage in (meetings, etc.)
- *Time.* The sequencing of what is observed (taking place over time).
- *Goal.* The things people try to accomplish.
- *Feelings.* Emotions expressed in specific contexts.

Spradley suggests these nine dimensions can serve as guides for the participant observer (1980). I found that as the research process went by I was able to zoom in on specific elements that seemed particularly relevant. For example, peoples' activities generally took great priority over description of objects. During my note-keeping I made sure to observe both the relational aspects of the community being studied and also the ecological/structural space in which relationships happened.

My observations and notes generated conversation questions, which I coupled with a more formal semi-structured interview to each informant. The interview questions covered personal history of self-determination, community experience of self-determination and miscellaneous questions related to personal identity, understanding of community and

biographical context. The style of the interview was exploratory, typical in ethnographic methodology, as it sought to probe at issues of concern that were believed to be important to the study (Angrosino, 2005). I sought to ask open-ended questions and to have the interview be more akin to a conversation between friends –some ethnographers call the interviewees their "collaborators" – than an impersonal interrogation of a "subject" (Angrosino, 2005).

The interviews took place in a private space – most often in the lower level room of Serenity House – agreed on with the informant himself/herself, so that they would feel comfortable enough during the interview. They generally took one hour to one hour and a half. Interviews were also coupled with informal conversations with informants that I had throughout the study. Often these conversations were grounded in my observation and data gathering.

In addition to observation and interviewing, I also gathered documentary data. I had access to policies, guidelines and documents that have shaped the procedures and philosophy of L'Arche Southown and Serenity House. I used different types of documentation: paper-based (training materials, policies and brochure/mailings); web-based (the agency web-site and its social media presence, both containing pictorial elements); and writings by L'Arche's founder Jean Vanier highlighting the principles of the vision of L'Arche (L'Arche USA, n.d.b; Vanier, 1989; Vanier, 2012a; Vanier, 2012b). Albeit the latter were not necessarily used often by informants, they influenced assistants' formation/training and L'Arche Southown overall philosophy/vision. I thus used them sporadically only insofar as they might have helped add a layer of contextualization to the data.

It must be noted here that during data collection it became clear that the L'Arche Southown policies binder was kept mostly for reference rather than actual use (as will be shown in the next chapter); thus written policies did not carry enough authority nor influence to

meaningfully be included in the data. On the other hand, assistants' role responsibilities as well as "unwritten" L'Arche traditions and practices seemed to have much more weight and influence on the day-to-day and overall community life.

6. **Data management**

The audio recordings of the interviews, interview transcripts and research notes, were saved and stored on the PI password-protected computer drive. The drive was encrypted using PGP Whole Disk Encryption. The data was not accessible to other people than the PI. Identifiers were removed during data analysis and recordings and transcripts will be erased one year upon completion of the study. These precautions were put in place to safeguard the privacy and confidentiality of research participants and of the data.

7. **Data analysis**

Data analysis was a process by which I paid close attention to informants' perceptions of reality (emic perspective) while also allowing myself to be a "research instrument," reflecting on my positionality, finding data threads, selecting what I deemed to be relevant to the research (etic perspective) and interpreting data.

The beginning part of the analysis felt challenging. I had hundreds of pages with data, primarily coming from interview transcripts, observations and reflexive research journal notes. Suffice to say, it felt like a lot of data. My questions: Now what? What was I going to do with all that data? Where was I going to start? Committee members and peer support, some who had gone through similar qualitative research issues, encouraged me: "You can do it" or "The 'ah ah' moment will come eventually." I kept researching for clear ethnographic analysis methodology, sought advice from qualitative researchers themselves, and found great resources. One thing, however, was clear: I had to get "messy" with the data, going through the data forest, immersing

myself in it, making connections in what I saw and finding my way through. This took time and effort, but as familiarity with the data grew so did analysis become more interesting and "meaningful."

As the study went by, I experienced a challenge in integrating ethnography with grounded theory because of the newness of such approach: this integration of the two approaches has only been developed in recent times (Babchuk & Hitchcock, 2013) and both ethnography and grounded theory are quite flexible in their methodology. "The method should work for the researcher," wrote Timmermans and Tavory (2007, p. 509), who also recognized that for ethnographers doing grounded work ethnography and not grounded theory should come first. Support from researchers and existing literature (particularly Babchuk & Hitchcock, 2013; Battersby, 1981; Charmaz & Mitchell, 2001; Timmermans & Tavory, 2007) was helpful in navigating this challenge.

The analysis process took several steps – both linear and circular. Linear insofar as one step led to the other (I could find themes only after coding); circular insofar as each step "pointed at the other" in a to-and-fro dynamic (for example, during the observation period I could sense "emerging themes" and potential theoretical insight in what I saw or heard, and during data analysis data was compared various times to elaborate and extend categories).

The first step in the analysis process was to code the data line-by-line through open coding, thus not using pre-established categories in reading field notes but identifying elements and events that could eventually become the basis of categorization. I thus coded all of the data even if I thought some codes were not relevant for my focus, as the focus could have eventually changed (Emerson, Fretz, & Shaw, 1995). Open coding was thus an inductive process, open to surprises and possibly fresh insight and categories; however, it was not naively inductive but was

informed to some extent by my research interest and theoretical frameworks, thus being an iterative-inductive coding process (O'Reilly, 2009).

As I coded the data I practiced memo-writing, making notes about the codes that could serve at a later time. For example, as I coded childhood social network experiences of assistants I noticed shared experiences of isolation or loneliness during the high school period; I took a side note of this aware that this could have allowed me to see general trends beyond specific instances and that such notes could have proven to be helpful at a later time, potentially giving rise to themes as well as theoretical insight.

The basic codes found through open coding (for example, "food," "prayer," "laughter," "anger") led to and were gathered into more general themes (like "spirituality" or "behavioral challenges") and sub-themes (like "personal spirituality" and "house spirituality," or "behavioral challenges with staff" and "behavioral challenges with other core members"). As codes emerged and overall themes were drafted I could go through the data again with specific themes increasingly in mind (O'Reilly, 2009), performing focused coding, a more fine-tuned coding emerging from previous open coding.

Through coding I paid close attention not only to descriptions present in the data but also to the social processes that emerged from it, which is important for a grounded study (Charmaz, 2006). As themes emerged, so did theorizing. I kept track of cases that confirmed or contrasted emergent theorizing in my memo notes, ultimately situating those findings into theoretical frameworks, in dialogue with existing theories and research findings (Charmaz & Mitchell, 2001).

The research process took quite some working with the data, for example cross-checking codes found from observation data with those from interviews, reflecting on data consistency

throughout. The process eventually led to saturation, meaning that the categories/themes were filled with data and that no significant new information or ideas emerged.

To aid myself with coding and finding themes I used the ATLAS.ti software. It greatly helped with organizing the interview transcripts and the observation data, keeping record and track of the codes, and allowed for grouped output by code/theme. Besides the software, however, to facilitate code organization and the categorization process, when I entered a new "now what?" forest, I made use of matrix support. Inspired by the checklist matrix created by Miles and Huberman (1994), I created a table: themes were divided in rows (for example, "influence from staff" or "personal spirituality"), and informants categories by columns (core members and staff). This helped record systematically particular features and different instances of the data that made up each theme and helped bring connections to light.

8. **Authenticating conclusions**

Although there aren't set standards to evaluate the authenticity of the conclusions of a qualitative study (Nieswiadomy, 1987), I ensured some elements were taken care of to guarantee the research's trustworthiness in terms of credibility and dependability (akin to validity and reliability in quantitative research).

In regards to credibility I made sure the research truthfully represented the voice of participants. I used triangulation, a "cross-checking" of information, by adding a member to the research team. She was not involved with any data collection but reviewed a selection of my data and the emergent themes. I also used member checking at different times during the research process, making sure to double-check certain data/information and interpretation from the appropriate informants before finalizing data collection (Mactavish, Mahon, & Lutfiyya, 2000).

In terms of dependability, I carried out the research in a consistent manner, with the aim of having accurate findings, accounting for the possible influences of the ever-changing context within which the research occurred. I thus took care of the following:

- *Context:* I linked this research to other existing literature and theories (please see the Literature Review and Discussion sections).
- *Data and procedure:* I gathered the data from a sample that was adequate for the purpose of the study and used procedures that took into account the needs of the population studied (for example, using consent/assent forms for accessibility, simplifying questions as needed and performing interviews in an environment sensitive to informants' privacy).
- *Analysis*: I made sure the conclusions reached in the research stemmed from thick data descriptions, with research procedures and strategies clearly described, and employed/recorded critical self-reflection so as to prevent potential bias but also to see myself as a source of information by assessing my experience, formation, and tacit knowledge.

V. RESULTS

Research findings will be presented and categorized in three main categories: Self, Determination, and Community. The Self section will explore informants' relational and decision-making life histories, as well as individual identity questions related to disability and faith. The Determination section will explore informants' decision-making instances, processes and dynamics at Serenity House. The Community section will present informants' experiences and understandings of community and of their place in it.

A. Self

In order to explore the dynamics between self-determination and community living in core members at Serenity House their self-narratives, as well as those of the assistants (staff) supporting them, needed to be heard. Considering this study focuses on decision-making within a faith community in which persons with and without ID live in relationship with one another, self narratives will focus on informants' relational lives and decision-making experiences before joining L'Arche, their understandings of disability and their faith journeys.

1. Individual life stories

Informant's individual stories mostly emerged through interviews and partly through observation data. In my interviews with both core members and staff, I made sure to include specific questions on their life histories (childhood, teen and young adulthood) and paid careful attention to elements having to do with their decision-making and relational/communal backgrounds. Presented here are the narratives that emerged from these interviews and from observation data elements, beginning from the four core member informants and ending with the six staff informants (including L'Arche Southown's Executive Director).

a. **Alfred**

"I shot him in the shoulder (…) That's the only choice I remember."

Alfred is an African-American male with ID in his early 70s. He grew up in the south of the United States and later moved with his sibling to other two states, eventually joining L'Arche Southown. Alfred is his own guardian. On his free time he enjoys playing and listening to music, watching sports and relaxing in his own space, for example, sitting on the porch while observing his surroundings in the quiet or turning on some incense in his room in a calming atmosphere.

When not at home Alfred is usually at work in a food service place not far from downtown, where he helps make food and wipe tables. There he comes in contact with a lot of people, some of whom he has gotten to know through time.

Albeit for years Alfred went to work by himself using public transportation, Alfred is now transported to/from his workplace via the city's Special Transport system that specifically caters persons with disabilities. This change happened as staff had age-related concerns regarding Alfred's memory and stability in walking, but also because Alfred wanted this change to happen.

Alfred is part of a Christian church congregation and values spirituality. He often refers to the *"man above"* to imply God. He enjoys speaking and sharing about his history with people, but also has a certain reserved and recollected temperament.

For our interview together, Alfred chose to be interviewed in his bedroom, where I sat on a chair and he sat on his bed. His bedroom was full of pictures, posters and gadgets of different kinds. There were some trophies and medals scattered around the walls and on his furniture, as well as some papers stacked on his drawer by the bed. Of all the core members interviewed

Alfred was the most talkative, and the one that seemed to enjoy sharing his story the most: at the end of the interview he told me, *"We should do this again!"*

During the interview Alfred used a photo album with pictures from his life, and thus partly employed photographs to describe his story.

i. **Relational background**

Alfred was born in a southern US state and mentioned living with his mom and brother when he was a child. Interestingly, he did not mention his sister nor his father when asked whom he lived with, but he did mention them later in the interview. Alfred said he felt close to his mom and that, albeit it was fine growing up with his brother, it wasn't so with his dad – *"it was hard with him."* Alfred showed me a photo of him as a younger adult with his mom – he had a tuxedo and his mom was wearing a white dress and hat. Alfred seemed to value her, as well as his sister, whom he had a lot of pictures of.

Growing up, Alfred went to school for a few years; there he learned to improve reading and writing skills, even if he didn't finish with schooling. He mentioned that his teacher *"was white and she was nice,"* hinting at race issues present in the context he grew up in. Besides school, Alfred also helped his father work the field (for example, chopping wood), together with other workers, both black and white. His boss was white and *"treated me like shit, pardon if I say the word. I worked, not pay (…) he was mean with everybody."*

Alfred recalled his dad being mean to him: *"he drink a lot, he'd beat my mama up, he pushed her down the stairs. And he hit me (…) I was hurt."* Alfred's dad used to hunt and he taught Alfred how to shoot a rifle, even buying him one. Alfred said one time he shot his dad in the shoulder because *"he hit my momma. 'Don't hit my mom no more!'."* During the interview, as Alfred indicated on his body where he shot his dad he pointed by the shoulder quite close to

the heart; I mentioned how his pointing seemed close to the heart and Alfred smiled. There still seemed to be resentment towards his dad. Eventually Alfred would move to another state with part of his family, away from his dad, before moving – helped by a state case manager – into L'Arche Southown.

ii. **Decision-making background**

Alfred said his decisions as a child were made by *"my parents. My mom."* When asked who decided for him that he would be working in the field he said that the white man *"was the boss."* As a teenager, instead, Alfred's decisions were made at times by his mom and at times by his sister. There is a choice, however, that Alfred recalled as his own: shooting his dad. "*That was my choice,"* he made clear. When asked if he remembers other choices he made he replied, *"that's the only choice I remember."*

As the years went by and Alfred moved to different places, he cultivated interests he had. For example, he decided to train for Special Olympics, focusing on running and softball. His athletic involvement led him to win various medals, proudly displayed in his Serenity House bedroom to this day.

b. **Jenna**

"I don't want to be treated the wrong way."

Jenna is a Caucasian woman with Down Syndrome in her late 50s. Jenna grew up in the American mid-west, one of the youngest kids in a family of almost ten siblings. A sibling of hers is her guardian. During the day Jenna works in a workshop, and a favorite hobby of hers is art-making. Jenna's art style generally employs warm tonalities and colors, with symbols and words signifying spiritual and meaningful themes. Jenna also enjoys music, particularly pop music, to

which she dances to from time to time, sometimes even involving her housemates at Serenity House.

When at home, Jenna is proud of her weekly cooking dinner assistance and enjoys speaking about food and recipes; as she is overweight and is strongly drawn to soda and sweets she has been working, with the support of assistants, on healthier eating habits with mixed results. Lively, talkative and often quickly changing in mood, Jenna can often be heard talking excitedly to assistants and at times can be heard screaming and crying, mentioning being upset over a variety of issues in her life. At times she can also be heard talking by herself processing thoughts from her day. A sensitive, personable, and hospitable person, Jenna often has open arms whenever guests come to visit community. Jenna also belongs to a Catholic parish where she is a lector (reader).

For the interview I set a specific time with her, which happened to be on her cooking night. Our interview lasted about an hour after which she speedily went to help continue cook dinner.

i. **Relational background**

Jenna did not remember whom she lived with when younger, but remembered living in a big house and that her father is now deceased. Growing up with siblings, she said, was *"kinda rough"* and she was not up to explain why. Out of her siblings she mentioned feeling two as particularly close to her – one of whom is currently her guardian – and mentioned how her grandmother was close to her as well.

As a teenager Jenna attended school and there were people there, she recalled, that *"treated me the wrong way, but I don't want to go that far."* Later in the years Jenna mentioned

she had an internship at a college where she helped with secretarial work while living in a campus dorm room with supports.

ii. **Decision-making background**

Jenna claimed she made her choices as a child and sometimes asked for help. She believes she probably made more choices as a child than now, but it was not clear what she meant by this. I thus checked again with her on that statement and she said, *"I don't remember as a child, I was born with Down syndrome. I don't remember a lot. My brother knows a lot of things."*

Jenna did not recall her decision-making as a teen but remembered that while living in the campus dorm decisions were made by herself and *"people downstairs"* (Jenna mentioned living in a residential context with aids: *"assistants checked in on people"*). During that time Jenna gained a lot weight, had to get rid of junk food and during the first year of college was not feeling well and *"passed out because I didn't eat enough,"* she said. At the time she took on swimming but it was not clear if someone had encouraged doing so.

Jenna would eventually choose to move and live in L'Arche Southown, which she mentioned hearing about from her brother. She thought L'Arche was important: *"Jean Vanier speaks about people with Down Syndrome not wanting to be treated the wrong way (...) I don't want to be treated the wrong way."*

c. **George**

"It was just too strict all the way around (...) pretty different than L'Arche homes."

George is a man with autism in his late 30s. He has a multi-cultural background, spanning from the Middle East to the United States. In his younger years George attended a

special education program, where he was involved in various sports. Before moving to L'Arche, George lived in a residential/rehabilitation developmental center for about a year.

George has specific people he tends to like, usually older adults that have a comforting attitude, and things he focuses on and is fascinated by, for example objects that can move like ceiling fans and cars. He enjoys speaking about these things he likes, repeating them and focusing his conversations on them on a consistent basis.

George values routine and having a clear schedule, generally finding unexpected changes upsetting and challenging to deal with. When those happen he can get quite agitated and express challenging behaviors for people that live with him. Therefore, to give him time to prepare for our interview together and to process that this was going to be something new in his schedule, I asked him to pick a date for the interview himself, which he did. I did not want him to be anxious but wanted to give him the space and time he needed to plan ahead. The interview went well: George was direct and clear in his answers, seemingly feeling quite involved and interested in replying to my questions. He kept great attentiveness throughout and held the conversation for almost an hour.

i. **Relational background**

Before moving into L'Arche Southown George lived most of his life with his parents, changing home various times always within the same geographical area. He mentioned growing up as an only child *"was really really hard"* and remembered someone close to him in his family as being a *"real mean angry alcoholic,"* treating George in a way that he has a hard time forgetting, even after years of therapy that have helped this family member deal better with his anger. To this day George seems to be very sensitive to voices that might sound angry to him, causing him distress or concern. He has mentioned not linking angry voices, as he

did not like when his dad spoke to him angrily. Amongst his family members, he seems to identify strongly with the person that he mentioned being *"way way way better than me and my dad,"* namely his mother.

George recalled his school years mentioning he had friends from his special education program that treated him well and were in turn treated well by George, *"with respect."* As time went by he would still meet up with some of these friends at a restaurant gathering on a weekly basis to have fun.

For some time George lived in a "developmental center," where he had a roommate: *"it was not like L'Arche at all. It was a school. It was a place to learn how to live. There was a residential unity, a cafeteria, and independent living, basic adult and vocational services (...) It was not a home, but a school, not quite an institution."*

ii. **Decision-making background**

George did not focus a lot on his decision-making during his younger years, but did mention that as a teenager he decided to join basketball, volleyball and track activities for Special Olympics for a period of almost five years.

Later on, George experienced living in the developmental center, where he had the support of a graduate assistant and where there was a clear routine and regiment: *"they gave me a sheet of activities – bowling, meetings, rollers skating (...) to know what's going on (....) They had a real strict stern curfew. The kitchen closes at 9:30 sharp. And then they lock up."* He compared this as being quite different from his current living culture at Serenity House – *"it was just too strict all the way around (...) pretty different than L'Arche homes."* At Serenity House, due to a core member making noises in the kitchen that kept people up and eating onto late at night, staff decided to implement a kitchen curfew, but without locking doors.

George described the rules at the center as being strict and stern, and the staff as sometimes speaking in *"loud stern strong men voices,"* for example, when telling residents to go to bed. George said he *"didn't respond because I was afraid they were going to make it worse. 'Cuz I don't like to hear yelling through my door, even though I followed the rules extremely extremely well …"*

While living at the center, George met someone who was assistant in a L'Arche community in another state and told him and his parents about L'Arche. To this day this person phones George every month to see how he is doing. When I inquired with George as to who decided for him to become a core member in L'Arche Southown he said he did, adding that he loves being in L'Arche and that wants to keep living there.

d. **Matthew**

"I lived in an independent living place where I was totally independent (…) my roommate was not there that much (…) I like to have at least a meal with someone."

Matthew is a Caucasian man with ID in his early 40s. Matthew grew up in the United States but has a strong interest in traveling and in learning about other cultures; he is inquisitive and curios when he encounters people of other nationalities. He enjoys culture and is knowledgeable about historical, geographical, political and religious matters.

Talkative and sensitive, Matthew has a very relational approach in that he likes meeting new people and hanging out with them. In conversation with others, Matthew expresses himself in an articulate and engaging way. He generally seems concerned about what other people might think of him and of what he says, at times making me wonder whether some of his statements or

responses were genuine or articulated to please others. During our interview, however, he was clear on things he did not like and seemed genuinely engaged.

Matthew often likes to speak about food, bringing food topics into a lot of conversations. As he has eating issues, food and nutrition are areas of concern for him and L'Arche Southown staff has been trying to address this and support his nutritional health, for example, by being more aware of dynamics surrounding his eating and engaging with external professionals help and supports.

Before joining L'Arche Southown, Matthew lived with his family and later in an independent living center. Matthew attended grammar school, junior high, and then high school, where he was part of a segregated special education program – he said lunchtime was the time in which he'd share space with *"nondisabled"* people and always thought this as discriminatory. During high school Matthew was in a sports team and remembers joining a special education student council since *"couldn't understand why, I couldn't join a regular student council."*

Today Matthew's life seems more open to the outside world. He takes public transportation to go to work at a local art studio, has showcased his paintings at an exhibit downtown, goes on dates with friends, is part of a local Catholic parish, and often goes on walks in the neighborhood.

i. **Relational background**

As a child Matthew lived with his family – his dad, an older sister, and his mom, who died in tragic circumstances before Matthew's teen years. Matthew recalled his childhood as a fun one: his dad would play charade with him and create things for him to play with.

As a teenager Matthew had a lot of good friends, most of whom treated him very nicely, even if he mentioned experiencing severe bullying and a death threat from someone, who called him names and threatened to kill him. This was painful for Matthew: *"at that time I was very quiet so I didn't tell anyone and it just got bottled up and it made me sooo depressed I…hum end up comm…almost commit suicide (…) but there was a little voice saying stop and get help. And I think I don't know to this day I really think it was the guardian angel or something."* Matthew said he got help, found the courage to meet with the dean, and the kid was told he should never have done what he did, to which he responded that "he was only kidding." Matthew has made various friends through time and kept a certain openness to meeting new people and learning about them and their cultures as the years went on.

ii. **Decision-making background**

As a child, Matthew said, he was helped by his dad and his sister in making decisions, but *"well, when I was a little older I made my own decisions."* As a teenager, for example, he decided to join a sports team and to join the special education students' council. While at school, he eventually also had a job coach that helped him find work in food services.

As a young adult Matthew made his own decisions with the support of his dad. He decided to live in an *"independent living place where I was totally independent"* – he wanted to try it, had his dad's support but his sister was concerned about there not being enough support for him in that context if the need arose. Matthew moved into this independent living context, where he lived in a co-shared apartment room in a geographical area away from the city and lacking public transportation. To go places he would thus drive.

Matthew had some assistance in the independent living setting, but he mentioned not as much support as in L'Arche. He mentioned being lonely there. His roommate was rarely present,

and his personal assistant only present at certain times. He wanted a change of setting. After visiting other living options, which he preferred not to go to, he was drawn to the L'Arche Southown community and joined it.

e. **Jane**

"I was surprised that a 10 year old gets a say on what furniture to get for her room, that's kind of unusual."

Jane is an Asian woman in her mid-20s who came to work in L'Arche as a live-in assistant for a year, before beginning graduate studies. Tranquil and gentle, Jane is a reflective person who shows interest in knowing people and in aesthetics.

Born in Asia, Jane grew up both there and in the US. While in high school she traveled to volunteer in different countries to "give back to the community"; albeit it was requirement to graduate from school and was both tiring and intense for her, she enjoyed it and described it as the beginning of her interest in serving the community.

Before coming to L'Arche Southown she earned an undergraduate degree in psychology and had different kind of jobs – from working at a library service desk to being a classroom behavioral worker to students with challenges. She joined L'Arche as she was looking for a journey of growth as well as place to get a taste of reality beyond college before continuing her path to become a counselor.

Jane seemed to be quite self-aware and committed to personal growth. She described herself as an extrovert that socializes well with people, but *"it takes patience, time, suffering…to really listen to another person and to be professional at workplace."*

i. **Relational background**

When Jane was born her parents were young and she lived with her grandparents until the age of 10. She then moved in with her parents. She has no siblings and most of her friends didn't as well, but expressed feeling that her cousins were almost siblings to her. One of these cousins had a very severe disability; she said at the time she *"considered disability as constantly being taken care of, like emotionally or physically by other people and that support is not double way but a single way of offering."*

Growing up as a young girl Jane had playmates, however school took a lot of her time: *"the lifestyle of students in China…you didn't have much time to hangout. Hangout is not a thing in China when you are in school. During the week you can barely finish homework. More out on weekend, but even then it depends."* Jane wanted to do well in school: *"I wanted to try my best to get into top school, lot of stress, am always the child who was told to do the right thing."* She eventually continued her college studies in the United States. A friend who she met there introduced her to L'Arche Southown.

ii. **Decision-making background**

When Jane grew up in her grandparents' house as a small girl, she recalled, *"all was set: same environment, same arrangement, that's my home, just go with the flow,"* but when she went to live with her parents it was a very different lifestyle – her mother, she said, was *"very liberal"* and asked her what furniture she wanted for her room. This left Jane surprised: "*a 10 year old gets a say on what furniture to get for her room, that's kind of unusual"* She showed this off with pride to her friends: *"I got my bedroom, got to make decisions for my space!"*

While growing up Jane decided to be involved in various activities – from rock climbing to starting a Chinese club. After hearing about L'Arche from her college friend, she visited the community, had a sleepover, enjoyed the dinner, and shared laughter with residents, which she described as an important thing. She thus interviewed for a live-in assistant role and got the position.

f. **Michelle**

"We were treating each other with respect but we also always joked so we didn't take each other or ourselves too seriously (…) I always felt pretty secure with my friends."

Michelle joined L'Arche Southown as a one-year live-in volunteer after finishing high school in her native Europe. Her time as Serenity House was her first lengthy experience in the United States. Michelle did all her schooling in Europe, and often spoke of equestrian vaulting as one of her great passions. She once also was a baby-sitter and a trainer.

Michelle said she wanted to take a year off after high school *"to find myself more and to decide what I want to do with my future (…) to see my life from some distance for a year."* She thus got in touch with a volunteer organization that provided her with different options to do so. One of these options included L'Arche, which sounded interesting to her since she had never worked with people with disabilities before. She thus interviewed for a L'Arche role and she was accepted.

i. **Relational background**

Michelle grew up living with her parents and her younger sister. She liked to have a sibling to hang out with, even if there were lots of fights that nonetheless didn't last a long time. As a teenager Michelle had various friends, and together they planned

activities and gatherings as a group. She and her friends treated each other with respect: *"we also always joked so we didn't take each other or ourselves too serious (…) I always felt pretty secure with my friends."*

ii. **Decision-making background**

Albeit her parents made some of the decisions for Michelle while growing up, she mentioned they also took into account her preferences: *"(it) was always like when I didn't want that, I could always, like, talk to them and if they would be fine with other things, like, I could also decide for myself."* For example, at the age of five Michelle decided to grow her hair longer and to become a vegetarian, and he parents were ok with, Michelle recalled with a smile on her face. At the age of nine Michelle knew a schoolmate that did equestrian volting, she thought it was a great activity and wanted to start doing it as well. She eventually began doing it and became a vaulting trainer for children.

As a teenager Michelle often planned things with her group of friends, thus engaging in group decision making, for example when planning a camping trip out of the country together. I thus inquired with her how such group decision-making amongst friends took place. She said that every time it was a little different; one person would propose an idea for a group activity or maybe ask others if they had an idea, and whoever had ideas would share those and see how much agreement there was. Albeit there generally was agreement, if somebody disagreed with an idea the group would talk about it with him/her and it was up to that person to decide whether or not to join in the activity decided by the majority.

g. **Paul**

"For the first time in my life really beginning to feel that they genuinely wanted me to be there; they didn't expect anything from me."

Paul is a Latin man in his mid 20s who was born in the United States. His relatives came from South America. A personable and kind person, Paul came to L'Arche Southown after undergraduate schooling and after having been in a leadership role in another L'Arche community.

Paul is very open to help others and engages with people easily. He seems to have quite an attention to people's needs and is quickly willing to be of support when people ask it of him or when he recognizes he can do so.

i. **Relational background**

As a child Paul lived in a metropolitan city setting with his parents, his two siblings (he is the middle child), his grandmother, his uncle, his aunt and three cousins. He shared his bedroom with his father and brother. Paul mentioned that growing up he didn't feel loved by his parents and that he wasn't given a chance to speak in mind, and thus he didn't feel valued. It was also challenging to grow up with his two siblings as he felt there was competition amongst them. Paul, however, also mentioned that there was respect and understanding amongst them, which was motivational: *"competition can be destructive, but for growing up it worked well for the three of us."*

As a teenager Paul had a limited number of friends; he said he would *"never hang out because my parents were overprotective – 'We don't know their parents!'."* During college, however, Paul met new people, lived with a roommate the first year and with three of his best friends in his last year. Once he joined his first L'Arche community he eventually assumed house leadership, helping to lead the house team and supporting the quality of life of the core members in the house.

ii. **Decision-making background**

Paul recalled how his parents made decisions for him as a child and how their parenting was old style: *"there was no discussion, just whatever they said was the rule, and if I didn't like it they would just spank me until I understood."*

Paul's parents decided various activities for him to be engaged in also throughout his teen years. Those decisions mostly revolved around academic issues and college preparation; for example, he mentioned how they sent him to summer school just for the sake of continual learning so that he could get ahead for the following year. His parents thought volunteering was important in college, so Paul would also volunteer in a church. Paul also partook in math club or chess club, which his dad thought would stimulate his mind. Paul said that albeit he saw his dad as stern, he tried to agree with him. He also mentioned how his dad told him that he could eventually make his own decisions once coming of age, while his mother thought he could make his own decisions once he got married.

During college Paul mostly made his own decisions: *"my decisions making was more, like, guided. I would always ask for second opinions, I guess."* He asked for these second opinions to people he looked up to, which didn't include his parents until after college. He mentioned wanting *"to see if I could do it on my own,"* which interestingly still meant asking for a second opinion to trusted people.

Once he finished college, Paul invited his parents to have more of a say in his decision-making, particularly regarding his choice to go to L'Arche. He knew that such a decision would affect them, as they hoped for him to stay with them after college. To this day his parents' opinions matter a lot to Paul: *"we transitioned from them telling me what to do all the time, to making discussions where decision making was more shared*."

Paul discovered L'Arche during a dark time in his college years, when he was disillusioned after a romantic break-up. One of the campus chaplains he worked with encouraged him to look up L'Arche. Paul did end up doing so using the web, but thought the organization's mission was stupid – how could such a place of love and mutuality exist? Paul recalls how the chaplain saw his skepticism and told him, *"you are going to L'Arche [name of location] for a service trip. No words, no excuses."* Paul accepted and went to this L'Arche community, where he was welcomed affectionately by core members. Paul recalls, *"for the first time in my life really beginning to feel that they genuinely wanted me to be there, they didn't expect anything from me, they just wanted me to sit with me and just talk to me about life, knowing where I come from and telling me their stories."* Paul felt he belonged and came to the conclusion that he was capable of loving again. He thus joined L'Arche, which also meant declining jobs that were closer to his family and where he would have made more money.

h. **Ellen**

> *"Lots of the games ended up being wrestling matches between them and I was the referee. So a lot of the time I was the catch-all, 'make sure nothing is broken' kinda person."*

Ellen is a young lady in early 20s who grew up in the United States from European parents. A lover of art and a person of many interests, Ellen is hospitable, talkative and energetic. From theology to videogames, from movies to politics, Ellen's conversation topics seem to be wide and various.

Ellen entered L'Arche directly as Serenity House's House Coordinator. Often this role is given to someone who has had previous L'Arche experience, but the position was open and the need was there; Ellen was offered and accepted the role. During observation she seemed very

lively and driven, while at times also seeming to experience anxiety. Besides what might be her own personal inclinations, she entered a role of responsibility, in a house with people that have high needs, without previous L'Arche experience.

i. **Relational background**

Ellen grew up with her parents and two siblings (she was the middle child) in the United States. Her parents are from your Europe and she would travel there with them from time to time. In her family home, she shared one bedroom with her siblings; she said she *"didn't get much privacy, but it was still fun."* Growing up with siblings meant there was never a shortage of playmates. Out of the three, Ellen was the cautionary sibling: *"lots of the games ended up being wrestling matches between them and I was the referee. So a lot of the time I was the catch-all, 'make sure nothing is broken' kinda person."*

Ellen described high school as a *"traumatic"* experience. She recalled being a loner and not having many friends back then, besides a friend from church. During that period she stopped talking for a year, which she is still not sure why. In college, however, she lived together with four roommates and the experience of not talking was gone. Today Ellen is very talkative and friendly with people, even if sometimes social situations make her anxious. She often relates to people's interests and easily interacts with them.

ii. **Decision-making background**

When Ellen was a child her parents made most of the decisions, giving her more autonomy as she grew up. Ellen recalled a decision-making learning experience she had during the school period: *"my parents were always like 'well, you gotta go to school the next day and you are in charge if you go to sleep or not'. [I] made the mistake first time of*

staying up really late and they are like, 'you have to go to school anyway!' Learned my lesson really quickly of going to bed on a certain time."

During high school Ellen decided what activities to be involved with, namely youth group, the anime club, as well as the art club. The latter two clubs she presided. Ellen also decided her activities in college, where she helped with drama and was in the board games society.

Ellen heard about L'Arche from a relative who had been involved in one of its communities, she was interested in it, decided to apply for a live-in position and was given a House Coordinator role. She described joining L'Arche as a response to a call from God. She said she *"always felt called to help those who have never been helped throughout all of human history"* and was drawn to how L'Arche could help combine her love of art with helping people – for example, through meal preparation or organizational tasks – as well as to the "family building" aspect of the community.

i. **Anna**

"We lived as a family 'cause that's the way we always lived."

Anna is a European live-out part-time assistant at Serenity House. With previous support experience as a live-in in other L'Arche communities across the globe, amongst current Serenity House staff Anna has been involved in the home the longest (almost five years).

Anna lives away from the house with her husband but is quite present in community life as her amount of working hours is relatively fixed (at least three days per week) and she works more than any other part time assistants, who are generally needed on a more "as needed"/emergency fashion whenever there is not enough live-in support in the homes. She

seemed to bring an element of stability to the home, having been there (together with core members) through times of transition and change.

Being in her late 30s, Anna is also the oldest assistant at Serenity House. Reflective, sensitive and kind, but also very mature, Anna seemed to exhume a wise care, which took into accounts core members needs and attended to them, while also preserving boundaries and encouraging healthy living.

i. **Relational background**

In her younger years, Anna mostly grew up with her grandma and uncle, together with her older sister. Her parents had drinking issues while Anna was a child and, as Anna recalled, she and her sister *"were left alone and neglected as little girls (...) I don't remember anything of this, maybe my brain shut down and doesn't want to remember this."* Albeit heir grandmother took care of them, some contact with parents remained. This family situation, she believes, bonded the two sisters – *"we shared this unluckiness together,"* said Anna looking back.

Between the ages of 17 and 23 Anna's grandmother, father and mother all passed away. After these losses, Anna and her sister lived with their uncle. Eventually Anna got married with a man from her country and would eventually move to the United States to follow him for a career-related move.

ii. **Decision-making background**

During Anna's childhood her grandmother was the head of the family, a reality that was reflected in decision-making, too. Anna said she was always paired with her sister in doing activities, which *"was easier for grandma, she wanted us to share*

together." For example, the sisters did First Communion together and started and quitted ballroom dancing together.

Anna, however, also experienced a certain freedom in decision-making. She recalled, for instance, making decisions by herself around her teenager years, always being given the *"freedom to make my final decisions, even though sometimes grandma wasn't very happy."* Anna liked to travel and during high school would go on hitchhiking trips or would partake in cultural activities with her friends, even if her grandmother, she recalled, was *"always a bit scared, she was overprotective. [She] never wanted us to end as our parents. [She] always said to be careful what friends we associated with; people can hurt us…"* Anna's grandmother would also highlight to the sisters how *"we are friends and that's enough."* Anna, however, had other friends already from elementary school days and throughout high school. Together with them she shared in various activities: watching movies, having discussions, cooking together, sharing coffee times, etc. Anna said they treated one another well.

Anna left the family house when she became a university student in a different town and came back to share the apartment with her uncle after her Master's degree in elementary teaching – with him, she recalled, *"we lived as a family 'cause that's the way we always lived."* Anna felt her uncle trusted her and never felt he needed to parent her (and her sister): *"we were responsible and independent women I guess."*

Anna was attracted to working with children, and people around her affirmed this as a natural talent of hers. Albeit she failed a university entry exam, she kept trying: *"if that's what everyone think I should do, I can try it."* Her thinking of "what to do next" didn't stop there, however, and a friend from college invited her to visit L'Arche in another European country.

Since Anna was looking for a job, she applied for a position there and was accepted. She stayed in that community for almost five years.

At some point Anna had an idea of going to Africa. She would have experienced the challenge of moving to a different country again. She decided to continue in L'Arche, moving to a community overseas. There was more safety in the L'Arche option: *"[I] decided to go to a place I knew of, rather than jump from the bridge and do something I never did before."* Anna would finish her time in that community too and eventually move to L'Arche Shouthown due to her husband's job move to the area.

j. **Steve**

"*I felt more myself when I was there than any other places I have been. I felt accepted and welcomed."*

Steve is the Community Leader/Executive Director of L'Arche Southown. A native of the United States, Steve is in his early 30s. He felt he *"didn't fit very specific molds"* growing up in his city. Intellectually stimulating, interested in cultures and amicable with people, Steve is a man of various interests, ranging from music and politics to spirituality. A trained chaplain and minister, Steve learned about L'Arche through the writings of Henri Nouwen, whom he had discovered while volunteering at an orphanage for people with mental disabilities. Nouwen's description of his time working in the L'Arche Daybreak community inspired Steve to contact various L'Arche communities and eventually go volunteer in one for a few months. Steve established friendships there but eventually moved to another part of the country.

Steve currently leads L'Arche Southown, after having been a part of it for almost six years in different capacities and leadership roles. He had initially begun as a part-time assistant. This was a limited participation in community, but he noticed how it was quite different than his

previous exposure to L'Arche: *"[It] felt there wasn't anything different about L'Arche [Southown] than your average group home (…) no international assistants, one small house, small cramped space, in poor area (…) subtly contributed to a lack of what I considered, what I loved about L'Arche."* Steve felt he was given little training in how to support people during his short work times there and he felt drained from time to time. However, he continued establishing relationships there and was later given an opportunity to help out with administrative office duties. When the Community Leader/ Executive Director position eventually became vacant, a live-in assistant at the time encouraged him to apply for it. Steve did so and was hired for the role.

In his leadership approach Steve seems to value commitment to the vision of L'Arche and to the behind scenes work needed to support the homes. His leadership and administrative qualities are practical and bold. For example, he bought a new house for L'Arche Southown and created new leadership roles to support life in the homes. Within the relational context of community he is present and available, at times being on the more timid and shy side.

i. **Relational background**

Steve grew up with his parents and six siblings, some of whom were adopted internationally. He said growing with siblings helped to *"know myself better because I wasn't always the center of attention, and had to learn how to occupy myself and discover my own gifts and interests."* In that context, he said, he could learn to relate to people, *"how to befriend someone, how to understand someone, how to forgive, how to ask for forgiveness, a sort of miniature lab of life."*

Looking back at his high school teen years, Steve recalled how he *"never fit in"* and how he didn't treat his friends very well: *"I was fairly self-centered and looked at what they could*

offer me, and was bad at being emphatic and recognizing (…) how they'd feel when I made certain actions." He had one best friend, however, who taught him the significance of how he treated people. This support and approach was important for Steve and his social awareness, as he grew up in a household that, he recalled, had passive aggressive tendencies and was poor at expressing certain kinds of experiences.

Albeit in college Steve was given a lot of independence and responsibility, and was also known as someone beyond his family, he still did not find, as he put it, his *"groove in a friend's circle."* He thus bounced from one group to the other, while also grappling with life and identity questions college students can often experience: Who am I? What matters to me? How do people know me? This was particularly difficult for someone like Steve who felt that in his hometown *"didn't fit very specific molds."*

Steve is now married and has one baby boy that he often brings to community events. People in community enjoy welcoming, laughing and playing with Steve's son and Steve appreciates being able to share his family with the community.

ii. **Decision-making background**

Steve felt that growing up his parents gave him a lot of agency in decision-making. For example, one time his parents sat him down with two of his siblings and told them that they felt called to adopt another child. They wanted to know if that was something that they wanted, too: *"[they] posed it in such a way that the decision was ours. I don't now looking back on it now how seriously they would have taken us if we had said no, but I remember it as being a very important experience in learning to trust my own intuition and decision-making capacity."*

His parents, Steve said, would let him decide things that typical children his age wouldn't necessarily decide. He noted that during high school years his activities, *"were absolutely decided by me, my parents were always – uhm, maybe to a fault – able to allow me make my own decisions. You know, looking back I wish they had encouraged me to, you know, take up an instrument, be more disciplined with my homework etcetera but, you know, my parents were very hands off and interested in having me kinda find my own way."*

Steve eventually worked with computers and had a job in a fast food place. Before beginning college, he traveled abroad to volunteer in a Christian youth hostel, where he was in charge of working with homeless men. Once back to the US he recalled being *"kinda just home existing"* while his mom *"almost dragged"* him to enroll in college, which he eventually did. He said this approach that his mother employed with him proved that there was *"always a watchful eye"* ensuring that he wasn't going to *"make any decisions that would adversely or negatively impact my life in a long range sort of way."*

Once he began volunteering in L'Arche Steve decided to become more involved in it: "*I felt more myself when I was there than any other places I have been. I felt accepted and welcomed."* Steve also appreciated its community model and its mission of giving back to society.

2. **Disability identity**

To better assess their understanding of self as persons having intellectual disabilities I inquired with core members as to their sense – or lack thereof – of disability identity. This is an important concept in exploring the self-determination of persons with disabilities in a community where they are at the center – "core" members– because they have a

disability. Hence, what does disability actually mean for the people these categorizations pinpoint to?

Somewhat surprisingly, most core members didn't seem to identify as persons with disabilities in the first place. When asked if he had a disability Alfred replied, *"No. Never did. Mh mh,"* and, after some silence, said he was a core member because *"I want to be one!"* Matthew replied to the same question with a categorical *"no."* He mentioned how "*I just feel that I am just me (…) I don't see myself, I mean I know I have a disability but I don't see myself 'oh, I am a person with a disability'."* From observation and assistants' feedback it often seemed Matthew related more with staff than with core members, for example reminding people of their routines/schedules (usually a staff task) or emphasizing the things he did that other core members couldn't (for example, taking public transportation alone).

George replied to the disability question saying, *"I know disability. People with much much worse autism they don't hardly speak and that's it."* Interestingly, he did not include himself in the group, but included people with more severe autism than him in it. He then mentioned other disabilities, saying, *"I know it all":* Williams syndrome, Tourette syndrome and Asperger syndrome. In her sharing, instead, Jenna mentioned various times having Down syndrome, categorizing it as a disability. Jenna has also been a strong advocate for people with disabilities and Down syndrome, attending advocacy conferences and often mentioning to people about the work of Vanier and Nouwen on behalf of disability and adding how people with Down Syndrome don't want to be treated the wrong way.

Albeit most core members didn't seem to self-identify as disabled, the outside world has categorized them as such (through clinical testing, special classrooms, specific residential placements, etc.). I thus made the conversation less personal, moving from self-identity to what

disability meant in general. Jenna said disability *"means disability, Down syndrome, doesn't want to be treated the wrong way*," and Alfred limited the disability definition to people with Down syndrome. George, instead, found it tricky to say what disability is.

Matthew's understanding of disability started from disability and ended with ability: *"[disability] means to me that I learn maybe a little bit slower than let's say my* sister*, but once I learn something I never forget,"* mentioning as an example how he learned to drive and how to this day he is a very good driver who never got a speeding ticket. To Matthew persons with disabilities can have various positive qualities: *"I don't know if it's true or not, but to me people with disabilities tend to be more kinder towards people, to other people that are different."* Matthew claimed his view on disability was a personal perception that was based on experience: *"as a child we grew up very hard because (…) there's always somebody in the community that is a bully,"* which in turn makes persons with disabilities stronger because *"they don't like being called names so that makes us more gentle and more accepting of people."*

I brought the disability identity question to staff informants as well. As in their roles they were asked to support and live with core members, I was interested in their perception of disability and of people with disabilities. In general, their opinions ended up emphasizing an array of different elements in disability, from more medical ones (cognitive impairment, activity challenges) to more social ones (diversity labeling), including a mix of the two (partly biological, partly social).

In their understanding of disability, Steve and Michelle focused on developmental or cognitive impairment, thus locating disability in the individual. Paul, instead, mentioned challenges in daily living activities, first mentioning disability as an unfortunate circumstance but then correcting himself saying, *"I mean we are all born the way God wants us to be born.*

We are just unique in our own way." Both him and Michelle mentioned the need for assistance/support people with disabilities have.

According to Ellen disability is partly individual – *"sometimes things don't biologically develop,"* she said – and partly socially constructed. Both her and Paul found the question on the meaning of disability challenging: *"I never know how to answer the question,*" said Paul and *"This is so hard,"* said Ellen.

Jane located disability in society, focusing on the social construct: *"at this point I think [disability] means it's a label that society put to get a say what people can do and cannot do and how different they are from the rest of the population."* This emphasis on society is designed to support the so-called non-disabled, Jane said. Such interior realization on the social construct of disability, Jane believes, has mostly grown in her through the influence of L'Arche since before joining the community, after her experience with her cousin with a disability, *"I considered disability as constantly being taken care of, like emotionally or physically, by other people and that support is not double way but a single way of offering, and this changed."* Anna found the question on the meaning of disability good but didn't want to answer it.

3. **Personal spirituality**

L'Arche identifies itself as a community with "trust in God" as part of its mission. It also has specific spiritual practices tailored to each community and home. Besides the spiritual community/home practices of Serenity House, which I will present later, I inquired with informants as to their own personal spiritual and religious journeys, and how these might or might not shape their understanding of self and of their actions/interactions. Interestingly, house coordinator Ellen believed that spirituality/faith in God *"plays a lot more of a role privately with*

each core member than it does communally in the house." In this section I will touch on both core members and assistants' personal spiritual and religious inclinations.

Alfred attends a Protestant church by himself on a weekly basis. The church is located walking distance from Serenity House, and there Alfred is involved in musical ministry by playing the piano during services. Alfred said the Bible, which he considers as the word of God, helps him make decisions: *"good decisions and good faith."* He often refers to God as the *"man above"* who says in the Bible *"to help people."* Alfred thus has a belief in helping others grounded in his religious faith. Attention towards others is also how he spoke about the meaning of prayer: *"It means for everybody, who got no home, no food, pray for who is sick or hurt. Uhm, as a matter of fact, I feel good about it."*

Matthew identifies as a Catholic and provided a rich description of his spiritual identification: *"In my personal life I identify spiritually is when I get up in the morning and I (…) walk outside a little bit and meditate a little bit and then go to church."* He said he likes the message of Jesus because it helps him be more peaceful with himself, for example giving him *"more courage with myself and help me so I won't put myself down."*

Jenna identifies as Catholic and usually goes to Mass, accompanied by an assistant, at her Catholic parish not too far from Serenity House. At her parish she is a lector (reader) from time to time and she enjoys doing that, practicing her readings and then reading in front of the congregation from the pulpit. Jenna said spirituality and faith in God are very important to her and considers herself *"very spiritual."*

George is the core member that was less explicit about his spirituality or religious identification. He did mention however that house-check ins – a one-to-one practice in which assistants ask core members how their day went – relate to faith *"cuz I wanna keep God and*

everybody real real happy so I don't bring up anything that negative or much worse at all in general."

Assistant Paul was introduced to L'Arche by his chaplain, a Catholic priest, in a dark moment: *"[I] decided to just stay away from God for however long it was, I think a few months, just hated the whole idea of God."* He then had a "re-awakening" while visiting a L'Arche community and today he sees his personal spirituality as calming and reflecting. Paul mentioned how his spirituality greatly affects the services he offers at Serenity House, for example, in his calming way of doing prayer and of leading short-guided meditations after dinner, encouraging people to look back over their week.

Michelle described spirituality in very practical terms. She said her spirituality influences her support towards others, encouraging her to be there for the other person. For example, when she cooks she tries not to leave a mess so other persons don't have to clean after her – *"I just think people should be supportive for each other."*

Jane said spirituality has had an increasing influence on her. She thinks this is partly influenced by her Catholic host parents in the United States who, albeit *"never tried to introduce religion to my life,"* welcomed her to pray and meditate together with them. This, for Jane, was a soothing experience, giving her hope and the desire to forgive herself before forgiving others, which has been a support in her community life. A spiritual practice that she has enjoyed in community is the prayerful passing of the candle from assistant to assistant during the L'Arche Southown weekly assistants gatherings. As the assistants take turns in holding the candle in their hands they are invited to vocalize a prayer or to remain silent as they wish: *"for me it's more of people come together wishing that something good will happen, and that's very powerful and soothing to me."*

Anna was brought up Catholic and feels most familiar with its faith traditions, but doesn't often go to church by herself (she accompanies interested residents there however). Even if she doesn't go to church Anna mentioned feeling *"very connected to the earth and to what's happening in the nature"* and always tries to be present to changes, reflecting on what is happening within her as situations arise: *"if I am more in tune to what's happening inside and around me I'd call this spirituality."*

Ellen comes from a Christian Evangelical background and mentioned seeing spirituality as affecting her entire way of life and everything she does. For example, it helps her be more patient. Ellen said she came to L'Arche feeling that God led her to it.

Steve comes from the Protestant faith tradition and said that his spirituality brings *"to everything I do a commitment to a certain way of life that has implications for every decision, choice, relationship that I make or engage in."* He believes that every person is created in the image of God, and that this affects his interactions with people in the community and the supports he offers, seeing this *"as being an interaction with this sacred sort of identity we each have within us, so my supports are naturally going to come out of a place that wants to hold that well."*

B. **Determination**

As we have examined informants' personal narratives, "who they are/where they come from," we can now focus on core members' self-determination in community. We will first examine decision-making in what emerged to be relevant life areas (food, social networks and leisure). We will then explore influences that emerged as shaping core members' choice-making, both in relationship with support staff (having options and reaching compromise) and structural (the presence of agency policies/responsibilities, house practices and physical space).

1. **Making choices**

The ability to make choices and thus "determine" oneself and one's choices happened on a daily basis at Serenity House. On a general level, Vanier wrote about choice-making saying "our community life is beautiful and intense, a source of life for everyone. People with a disability experience a real transformation and discover confidence in themselves; they discover their capacity to make choices, and also find a certain liberty and above all their dignity as human beings" (L'Arche USA, n.d.b). Choices, however, did not exist in a vacuum and were often the results of challenging compromises.

The specific life areas that the data emphasized as particularly relevant in the self-determination and community dynamics at Serenity House were: food/meals, social networks/inclusion and leisure. In each of those areas, individual preference and staff influence gave rise to relevant dynamics in the enactment of self-determination within community.

a. **Food practices**

Food at Serenity House occupied an important place in daily life. On weekdays core members had morning breakfast, went to work carrying with them their lunches prepared at home, and every afternoon a core member and an assistant cooked dinner together for the house. In between these times, snacks and food talk happened periodically amongst core members and assistants. Food for the house was purchased weekly by Ellen at two different supermarkets. She encouraged and asked core members to join her in the grocery shopping, but only occasionally did they want to do so.

Each core member had at least a weekly cooking night, in which he/she was invited to choose what to cook for the house. This meal was chosen during the menu planning segment of the weekly house meeting. Both this meeting and the actual eating of the meals were attended

and shared by core members and assistants together, even if one core member (George) often did not join the group for either, saying he didn't like too much talking and that he needed space.

Core members' choosing what to eat on their cooking night was accompanied by actually cooking the meal chosen, together with an assistant. This seemed to run quite smoothly and core members seemed very proud of their cooking night.

Most of the actual cooking work was generally done by assistants. It seemed core members often got easily distracted or at times were fine in doing little tasks, still participating in their own way in the meal creation. Oftentimes I saw Jenna very proud of her cooking, even if it was as simple as putting taco toppings in different bowls, while the assistant did the rest. She would still ask other people if they liked her food however, or *"my cooking"* as she would put it, and would talk about it with pride.

During special events, Alfred usually was the "grill guy." As he very much enjoys grilling meat he was given the opportunity to grill at every barbecue or celebration I witnessed whenever the weather and the menu allowed. During one of the community barbecues, volunteers from the city came to meet the community and joined for dinner. As two of these volunteers approached Alfred cooking by the grill he said, *"I do it."* He wanted that role and, even if he was supported in it (he often stops grilling the meat too soon), he always seemed very at ease in the task and wanting to do it.

Day after day, the dinner meal was eaten together around the dining room table. Core members and assistants helped set up the table, and when the food was ready they sat to pray and eat. During the meal conversation generally abounded, usually about things that happened during the day, spontaneous topics of conversations, and sharing of how people are doing. After the

meal, each person brought dishes to the kitchen, where an assistant and a core member helped with the clean-up.

On core members' and assistants' anniversaries in community or on birthdays, special meals were prepared. The persons celebrated were generally asked what foods they wanted to eat and staff paid special attention to accommodate their preference.

From time to time core members went on individual dates with their friends of choice (both within and outside L'Arche) to local restaurants. Once a week, instead, all core members and assistants of Serenity House went out together at a local restaurant/pub to eat their food of choice.

Three core members out of four experienced health challenges related to food: Jenna was overweight and had challenges limiting her Mountain Dew soda intake; George had weight issues as well and often sought canned food rather than home-cooked meals, and Matthew seemed to have image/food/weight related anxieties.

i. **Choosing what to eat**

Since breakfast at Serenity House was "on your own" (people making food they liked for themselves) and lunch was either made at home by the core members (usually a sandwich and sides) or bought outside, dinner was the main meal consistently shared every day at the house.

Each core member, paired up with an assistant, had a consistent cooking weeknight on which they cooked their meal of choice. Menus and cooking assignments were decided during the weekly house meeting, when Ellen asked each core member for their cooking preference and thus created the menu for the following week. Core members seemed to have specific dishes they liked to cook on their cooking nights; thus on Tuesdays (Jenna's cooking night) tacos were often

on the menu since that's what Jenna liked to cook and Sundays (Alfred's cooking night) fish was often on the menu, since that's what Alfred enjoyed.

During my observation, selection of the meals during the house meeting generally prioritized core members' wants, even if assistants had different preferences. For example, one time Matthew mentioned he wanted to cook falafel hummus. As this had already been recently cooked, Ellen replied: *"falafel hummus again?!"* Matthew replied, "*Yes"* and Ellen was ok with that, writing it on the menu and respecting his choice even if she would have opted for something different.

Overall, choosing what/how to eat was something that deserved specific attention for this research, considering the important role of food in the life of the community as expressed by the data. Data also showed particular dynamics in the area of food that are relevant to better understand the relationship between self-determination and community. These dynamics describe ways in which assistants affirmed, supported, directed or influenced core members' choices in their food selection, and could be divided as: encouraging core members to choose what to eat; catering to specific food preferences; zooming in or simplifying food options; providing new options; and choosing not to support a particular choice or option.

Encouraging core members to make food choices, as we have seen, was exemplified by the house meeting practice of having core members select their cooking night meals. This was taken to the extent that even George, the only core member who would consistently choose to not sit in at the house meetings, was encouraged to choose food for his cooking night. During the meetings, George would often be in the kitchen cleaning some dishes or would sit on the couch in the adjacent living room. Ellen, however, still wanted him to choose his cooking preference. During one meeting, for example, she spoke loudly from her seat to the kitchen where George

was, asking him what he wanted to include in the menu for his cooking night. As he didn't know what to choose, she provided him with some options: meat, fish or enchiladas that, as she mentioned, *"we haven't done in a while."* George chose to cook enchiladas.

On another instance George was sitting in the living room and when Ellen asked him what he wanted to cook on his cooking night he said, *"I am too sad,"* to which she replied, *"Ok, you want me to make the decision about food?"* He told her "yes" and Ellen offered the option to the other people at the meeting, brainstorming different meal ideas and selecting one.

Albeit core members chose what to cook and thus what residents ate, there were rare times in which some core members (and/or some assistants) had preferences or dietary needs different than what was presented at the table. In these cases alternatives were found to cater to individual needs or wishes. For example, on a pasta night I noticed Michelle had made two batches of pasta, a bigger non-wheat one and a smaller wheat one. She mentioned Matthew wanted whole wheat and said, *"I made two portions, so people that want whole wheat can have it."* On another night, during a house meeting, chicken was put on the menu but Michelle said she couldn't have it because she is a vegetarian, to which Ellen replied that she would have cooked tofu for her instead.

Sometimes assistants simplified or zoomed in on specific food options to help focus core members' decision making. For example, Matthew could get very specific with food and often presented very specific requests (for example, a specific kind of bread, from a specific store, with specific characteristics), which could have come from food-related anxieties. During a house meeting, Matthew mentioned wanting to have stir fry on his cooking night and started to mention many side ingredients; as the list kept going Ellen asked, *"How about a green salad?"* Matthew was ok with this. In so doing Ellen heard the list of ingredients Matthew was mentioning but,

being too long and extremely specific, tried to find a simple and practical alternative – a green salad, asking him if that was ok before writing it on the menu. A similar thing happened another time when Ellen asked Matthew if he wanted to make a crepes-based "breakfast for dinner," zooming in on a specific option, to which he replied yes.

Providing new food options to choose and to try seemed to generally go quite well, coming from both assistants and core members. For example, one time Matthew wanted to make an English drink, which he had heard about from an English person he knew. Since when he visited England he didn't have that drink, he said he wanted to try it. He was supported in making it, and people enjoyed trying it.

Another time Anna made a pumpkin risotto for dinner and asked Alfred to try it, even if she thought he might not like it because he prefers things with meat. Alfred, however, tried it and was enthusiastic, saying, *"I really like it!"* and asking Anna to *"make it again!"* This was the first time Alfred had risotto. Alfred even had leftovers for lunch the next day and Anna was surprised as she had never seen him eat leftovers. She had suggested that he try and new food item; he liked it and thus it became a new food repertoire option for him to choose from in the future.

There were a few challenges, however, related to core members' choosing what to eat and the assistants' role in supporting or not supporting these choices, particularly regarding food that was not planned on the menu and that was not conducive to core members' personal health. Episodes involving George and Jenna are quite telling in this regard.

George liked eating chili from cans and, as the one core member that often did not join others at the table for dinner, would end up eating quite a few cans of chili in a week. Due to his weight issues there were concerns as to the lack of balance in his diet. With time and

professional input, however, George began to watch his weight more and ate less canned chili; staff at Serenity House also bought less canned foods and provided healthier snacking alternatives, like apple crisps instead of potato chips, giving George and other residents healthier options to choose from.

Sometimes George's snacking was "hidden" and created challenges, as when Jenna was upset that George had drank her special milk as well as a lot of the ham that she would have used to make her lunch sandwiches. Another time as I walked by the kitchen pantry at 8:30 pm, I saw George profusely eating chocolate chips that were to be used in a house dessert. As I tried to approach him he said, *"I need my space."* Did he really need space? Or was he trying to use the language of need for other purposes? Was his choice not to share dinner with others a way to eat, hidden in the food pantry, other food like chocolate chip cookies – affecting his diet and what other people in the house would or would not have been eating?

Another food choice that presented challenges was Jenna's strong attraction to Mountain Dew, an attraction so strong that sometimes if she didn't get soda she got upset to the point of screaming through the house, making others feel uneasy. Assistants periodically tried to encourage her to drink less sugary soda, for both her health and so as to avoid negative repercussions in the house, since caffeine and sugar intake could keep Jenna up late talking loudly in her room, which other core members took issue with. As Michelle said, if Jenna *"buys more soda she might stay up longer at night and she might be yelling and that would affect other people."*

Although at times Jenna agreed to drink less soda and eat fewer sweets to be healthier, her follow-up on this has not always been successful. She often wants to get Mountain Dew, even right after finishing one cup, claiming, *"that's my choice."* Assistants then seem to

experience a challenge in trying to help Jenna respect a diet with a more balanced soda intake while letting her make her soda decisions. The following dialogue is quite telling of this challenge and its complexity, experienced by both Jenna and staff. The conversation took place in the dining room between Jenna, who can't leave the home unaccompanied and who wanted Michelle to accompany her to the store to buy Mountain Dew, and Michelle, who tried to remind Jenna of weight concerns and who did not want to support the Mountain Dew "unhealthy choice:"

> Jenna to Michelle: Are you ready to go on a walk?
> Michelle: You didn't tell me we were going to.
> Jenna: Can we go get soda?
> Michelle: We jut bought soda. Why would you need more soda? I thought you wanted to lose weight.
> Jenna: I want to have a drink.
> Michelle: How much drink do you have left?
> Jenna: Two bottles.
> Michelle [with an upset voice]: How do you have two left? We just went on Sunday. It is making you gain weight. [Jenna had bought a 6 pack and a 2 liters bottle just a couple of days before, promising Michelle she would save some.]
> Jenna: I know.
> Michelle: If you want to drink something you can drink tea.
> Jenna: Not tea, 'cuz I want to go to (…) store with you.
> *Ellen comes in and tells Jenna:* Hey, you know what's a good alternative? You can help me make little bread. Why don't you think about it? It's really fun.
> Michelle to Jenna: I'd really like to come with you walking. If we make promises we should stick to them.
> Jenna: I don't want you to buy anything at corner store.
> Michelle: We can go but not to buy anything.
> Jenna: I wanna buy something.
> Michelle: You bought enough for week. I am just afraid that in a few months you won't be able to get in car anymore if you gain weight.
> Jenna: I am working on that.
> Michelle: No, you are not.
> Jenna: I am waiting to go please.
> Michelle: (…) I don't want you to buy anything at the store because you told me you wouldn't drink that much soda.
> Jenna: I don't wanna talk about it, I wanna get something please.
> Michelle: Didn't you promise you'd only get one six pack a week?
> Jenna: I know that, I just want to go to the corner store with you.
> Michelle: Well, we could go but we shouldn't buy anything.

Jenna: Well, I wanna get something.
Michelle: Yeah, you bought enough for the whole week.
Jenna: I know that, I don't wanna talk about it [silence]. I know, I just need to get something.
Michelle: I am just afraid that in a couple of months you won't be able to get in the car one morning.
Jenna: I know that.
Michelle: Or you won't be able to get out of bed in the morning.
Jenna: I know how to do that.
Michelle: Now you do, but if you keep getting weight you won't be able to do that.
Jenna: I know that, I wanna get something (…) I am working on that.
Michelle: On what? That's the thing (…) you still drink as much soda as before if not more and then you start drinking a lot of protein instead of water.
[As this was happening in the dining room, George came in the room and complimented me on something, while Paul passed by saying he had to water the plants.]
Jenna: I can go by myself.
Michelle: I know that [silence] but you still have soda and you promised me to save some.
Jenna: I know that, I need to get something.
Michelle: But (…) you are not sticking to your promises.
Jenna: I know that, I don't wanna talk about it.
Michelle: But I can't encourage you and help you (…) if you are not sticking to your promises.
Jenna: I know that, I don't wanna talk about it (…) I wanna walk with you.
Ellen [passing by]: If you wanna go on just [emphasized] a walk I am sure that somebody would want to go on just a walk.
Jenna: No.
Michelle: Yeah, I told her. I'd love to go on a walk with her.
Jenna [raising her voice]: That – won't – work!
Michelle: I am just concerned about your health.
Jenna: I know, I just wanna get something (…).
Michelle: You promised me.
Jenna: I know that, I wanna get something. I wanna get gum!
Michelle: You wanna get gum?
Jenna: Yeah.
Michelle: No soda?
Jenna: Yeah.
Michelle: And you are promising me that?
Jenna: I am promising that. Can we walk please?
Michelle: Uhm, what happens if you just grab a soda bottle and buy it then?
Jenna: Ok, that makes sense. It's just for gum.
Michelle: Only gum?
Jenna: Yeah.
Michelle: Are you sure?
Jenna: Positive.
Michelle: Ok, I am fine with that.

Jenna: Ok, let's go.
Michelle: I just gotta help clean up and then we can go, ok?
Jenna [smilingly]: Ok!
Jenna to other people around: We are just getting gum!

After this conversation took place, I accompanied Jenna and Michelle to the store, wanting to see how the situation was going to continue. Once we got into the store Michelle helped direct Jenna to the bubble gum section, where she was undecided between two flavors and asked Michelle about it. Michelle told her, *"I like mint, but you like it more sweet, you like it different."* Jenna picked her flavor and proceeded to go to the cashier and pay for gum. As she gave money to the cashier she smilingly told him, *"today is your lucky day!"* During the walk back home from the store, Jenna was very bubbly, smiley and making plans for future trips (she mentioned, for example, wanting to go to the east coast to see where a TV show was filmed). Her mood had changed. Later in the evening, while watching TV, Jenna vocalized to herself a couple of times the words *"less sugar,"* seemingly rehearsing and vocalizing health concerns in her mind.

A similar situation happened during an after-dinner house outing for dessert in the Little Italy section of town. Jenna wanted to buy a bottled sugary drink. Ellen encouraged her to try hot tea, to which Jenna said, *"no way."* Ellen replied, *"the one you are wanting has a lot of caffeine,"* to which Jenna said, *"oh, ok."* After some "negotiating," once the waitress was asked for herbal tea options, Jenna opted for chamomile with ice.

In both situations there was a quick change in Jenna' mood: from an upset sounding voice asking to go get soda to a cheerful happy talker after she bought gum or got tea. Various times I have witnessed Jenna (and assistants) struggling over soda issues in the same vein as these episodes, but thanking assistants afterwards for helping her stay healthy.

Often Jenna also chose healthier food options herself, without much staff input or influence. Paul noticed how Jenna had been making *"better decisions about her weight."* For example, during a weekend night outing at the pub that Serenity House went to right after a big community barbecue, fried fish was served at the table where Jenna was. Trying to hold back, she mentioned how good the dish looked and that that was enough, she would stick to only having a diet soda drink. Paul mentioned how surprised he felt: *"just like 'what what'. Surprised! Good for you."*

ii. **Choosing how to eat**

Serenity House's breakfast, being "on your own," happened at different times for different core members before they went to work. Dinner, however, was set at 6 pm. That was the only house set time in terms of food.

Eating together has been a practice from the beginnings of Serenity House. George is the only core member that, during the data collection period, often didn't join for dinner. Even with encouragement from assistants to join he often decided not to, hinting at noise and space as concerns. However, the times George did join for dinner he often was quite talkative and engaged with others and did not seem to be bothered by noise or by number of people present in the room.

One evening, once dinner was ready, I went to the second floor to let George know that the meal was about to start. He was sitting by the computer. I told him dinner was ready and he replied, *"I am not interested"* to which I told him, *"We'll miss you."* He said he didn't like the smell of the soup and re-iterated that he was not interested. I told him he didn't need to eat the soup and that in community it is important to eat together. He replied he was feeling mischievous and didn't want to get too upset. Trying not to push, I told him I knew he was capable to share

meals with others, encouraged him to make adult choices and simply suggested to think about it. I then went back to the dining room, joined the rest of the house for dinner and at a certain point George came by the table, asking if he could have sausages, which were cooked with him in mind in the first place since he likes sausages. I said he could have the sausages and also invited him to sit down to eat them with us. George sat down and stayed with us through the whole dinner, talking about cars and other passions of his and asking people around the table how their day was. He seemed to be doing well throughout dinner and did not seem to be bothered by the context.

At L'Arche the practice of sitting together for the meal usually goes hand in hand with sharing food communally. This practice has been a tradition of L'Arche worldwide since its conception. Vanier, who has helped shape and give words to L'Arche traditions such as this, wrote: "Food is important, and it should be good. Meals shouldn't be just something slopped onto the table: they should be times of communion (…) Meals are sharing, so it's important that the food should be shared too. Nowadays there's a tendency for everyone to have their own little part of butter, their own little bottle of Coca-Cola, their own little packet of salt and pepper. One bottle for everyone to share may be less hygienic and less efficient, but it will bring more friendship. Even if you can find nothing else to say to someone, you can at least ask him for the salt, and this is the beginning of communication" (Vanier, 1975, p. 82-83). Vanier also wrote on how meals shouldn't be serious times, but times of laughter and relaxation where love can grow (1975), emphasizing the relational component of mealtime.

Even at Serenity House, sharing the meal at the table seemed to be quite meaningful: everyone sharing from the same food cooked by a specific core member and assistant could be interpreted as a symbol of unity and as an affirmation of the core member/assistant that cooked

the meal. Core members and assistants, in fact, generally seemed glad when they were told that the food they cooked was good, or when people went for a second serving of it. As mentioned before, at times food modifications were made for specific people and even in shared meals people could often add individual touches. For example, during handmade pizza nights people were invited to choose the toppings they wanted for their pizzas.

There were times, however, that the tradition of sharing the same food communally was not practiced by all informants. At a certain point in time, for example, Alfred started bringing his own "take out" food from an outside restaurant for dinner once a week, usually on Jenna's cooking night. Considering the two have had a challenging relationship of ups and downs, this was very upsetting for Jenna. At times she cried and screamed, *"[Alfred] doesn't like my food!"*

Alfred, who differently from Jenna can go out without supervision, generally got his sandwich after his workday at a nearby fast food place, brought it home, put it on his plate right before dinner and ate it instead of the home-cooked meal. When asked about this he said, *"it's my choice.*" As he ate the sandwich he often gave glances to Jenna, who got upset at him for this behavior, sometimes to the point of tears. It seemed to me this behavior exhibited by Alfred was not just about food choice but also about a power struggle (in this case Alfred was free to go out, buy his own food and choose not to eat Jenna' cooked meal).

Assistants did not seem to be overly concerned with this behavior exhibited by Alfred, but at times recognized it as a challenge. With time however they encouraged him to eat house food, often times indirectly – for example implying, in conversations with him, that the house dinner food was going to be exciting. Leadership in community, albeit not wanting to force Alfred to eat house food, took issue with Alfred's behavior as it seemed to overly individualize a meal that was supposed to be shared and because it seemed to bring in a power dynamic that

seemed unhealthy and that made Jenna upset. It was not easy to approach this however. Staff had to thread the individual preference/community practice line.

One time, as Alfred was going out of the house to buy his own food I told him the house had already prepared a meal for him (please refer to the Reflexivity section for commentary on my role in such situations). He stopped walking, thought for a bit in silence but then went out anyway, buying the food and bringing it back. On another night, right before Jenna' anniversary dinner, Alfred went out to buy his own food. Staff encouraged Alfred to either eat that food before the dinner or to save it for later. He did end up saving it for later and during dinner sat with all the anniversary attendees eating some house food and drinking a beer he bought at a nearby store. He was also encouraged to have some more food, but he chose not to. He ended up eating his fast food meal later in the evening.

b. **Social networks/inclusion**

Home life house at Serenity House is relationally rich – in the L'Arche model people without disabilities choose to live and share life together with persons with disabilities, adding a component of intentionality or of wanting to be there on the part of the assistants. Core members and assistants seemed to develop close bonds with each other – enjoying being with one another, sharing activities together, and mourning when separation occurred, usually due to the assistant finishing their time living in and moving out of state.

Two scenes struck me as symbolizing the joy of being together, and the grief of separation. The first instance spoke about a certain gaiety of togetherness and took place when Paul, Jenna, Ellen, and I were walking back from the train station to Serenity House after an outing in the park. Paul was holding Jenna's empty lunch-bag and started playing with it, throwing it in the air and catching it back. Jenna loudly told Paul, with a smile on her face,

"Don't act like a child!" Paul then started passing the lunch-bag to Ellen as if it was a ball, increasing laughter in the group.

There were other moments of fun during data collection – from Jenna and Alfred dancing together during Jenna's anniversary to spontaneous jokes and laughter happening every day in the house – but this episode of people playing together with a lunch bag was a simple and telling moment. An ordinary activity like walking home and a simple object like a lunch box could be transformed into moments of laughter through togetherness. A person with disability could tell an assistant to "not act like a child." It seems that in society such a remark would often be made from a person without disabilities to one with disabilities, but, through a joyful relationship, this was reversed: it was the person with disability telling a support staff member to not act like a child.

Relational closeness between core members and assistants, however, was also demonstrated in times of sadness and mourning, whenever an assistant finished his/her term and left, as in the case of Michelle leaving for Europe after her year as an assistant volunteer. During her farewell anniversary night Jenna wrote a goodbye letter to her, which she read to her word for word in front of all attendees. Some days later, on actual departure day, residents of the house blessed Michelle before she left for the airport, singing a blessing and thanksgiving song for Michelle. George was visibly moved, but as teary Michelle hugged him, he was the one telling her, *"it's ok, it's ok"* (once again, "reversing" roles: a core member supporting an assistant). Jenna then brought a songbook out of her room, approached Michelle in the hallway and sang a song in the hallway for her. Michelle, Ellen, Jenna, and I were all standing close together and Michelle sobbed as she heard Jenna's voice singing the song she was dedicating to her. Michelle then thanked Jenna, gifted her with a photo of the two of them together, and departed in the van

for the airport, accompanied by house members. Jenna mentioned to me, *"I don't like when assistants leave. I want them to stay."*

These examples show a unique side of inclusion and social networking, particular to the L'Arche model. Namely that people with and without disabilities at Serenity House live together and share a profound human connection and meaningful relationship, living inclusion and bridging the gap between persons with disabilities and those without, a gap that might be more stark in ordinary group home settings where mutual friendship/belonging philosophy is not emphasized and staff might work for certain hours without making the house a home for both staff/residents.

Thus, as I present data and observation on core members' inclusion in the greater social milieu it seemed relevant to emphasize the way inclusion was already lived within community rather than it being simply an effort to get people "out there."

Through observation and interviews, core members' inclusion in social networks external to Serenity House and their having access to external resources were both relevant inclusion areas.

i. **External social networks**

Overall, core members seemed to receive support in their relationships with people outside Serenity House and external to L'Arche. If they wanted to go places assistants generally helped cater to that and if they wanted to meet people they would often go on outings with them.

At times there didn't seem to be much accountability, as when Jenna scheduled dates with friends without double-checking with the house and its calendar. Often there were community events, medical appointments and other scheduled things that were overlooked when

making personal plans. It did not seem that many restrictions were put in place when core members wanted to see people from outside the home nor did it appear that core members were pushed to have/not have external relationships against their wishes and needs. Jane seemed to touch on this when she said, "*I think for their already-existing social networks core members make the final decisions. For core members that tend to be more quiet, like regarding their age or health condition…we are considering to introduce them to more social activities outside L'Arche, you know, to bring more friends to their life. But I think it's up to that person if/she want to join."* Core members' inclusion into social networks thus seemed to grow and be supported organically, rather than being pushed on core members.

The core members that seemed to have a wider variety of social contacts with people outside of community were Matthew and Jenna. Matthew seems to enjoy befriending people and during data collection had various dates with people he knew. One day he mentioned having three dates in one afternoon – one with a L'Arche employee at a café, one with a friend visiting from another country, which Matthew said had to be re-scheduled last minute, and one with an external L'Arche volunteer whom he went to a popular beer place in town with. Other times Matthew met with his accompanier, as did other core members and assistants (in L'Arche each member can have an accompanier to meet periodically with to converse on how their community journey is going). Matthew seemed to be very fond of his accompanier, a university student in town, speaking about their meetings together with enthusiasm.

Matthew is also close to his family. During data collection, he went to visit his aging dad and his sister for family weekend, which all core members that have families nearby do, on a monthly basis. In addition, Matthew nurtured relationships that extend internationally. As he is involved with a L'Arche related international commission he had the opportunity to visit Ireland

to meet with them and took some days while there to visit a friend he knew in the area. Thus, Matthew's social networks were interwoven with both L'Arche and non-L'Arche people.

A similar social networking dynamic is true for Jenna. Jenna is very fond of setting dates with friends, often persons who were once involved with the community but that have stayed nearby, workplace staff, her accompanier and family members. During data collection, Jenna usually enjoyed going with them at restaurants or to the cinema. As an active member of her Catholic parish where she is a lector, Jenna has met many parishioners through the years. In addition, oftentimes whenever the community had external guests over for dinner or for an event, Jenna passed out her *"L'Arche business cards,"* as she calls them. These cards have her name and contact info printed on the front, and the Identity and Mission statement of L'Arche printed on the back.

As Jenna and Matthew had periodic dates or outings, these were usually shared during house meetings, when the calendar for the week was reviewed. Core members were generally invited to bring their individual outing appointments to the meeting so that if they were missing dinner with the housemates this could be shared and checked with other community commitments. Ellen and staff were generally very approving of such outings – if core members wanted to go on individual outings their choice was respected and, if those appointments were not on the calendar, Ellen made sure to include them. At times, during data collection, core members directly wrote their appointments on the calendar as they came up.

George and Alfred's external social relations seemed more limited than Matthew's and Jenna's. The former seemed to enjoy more time alone or in quieter places, while the latter seemed to get energy from gatherings and from being with people. George experiences challenges in social relations and likes to have personal space; the fact that he shares a house

with other six people might already be quite a social experience for him. He did however see his accompanier from time to time and had occasional dates with L'Arche related friends. He visited his family on a monthly basis. In moments of difficulty and challenge, particularly when he felt overwhelmed, George had a wide array of contacts in his phone that he could call (ranging from family members to old L'Arche assistants). He would call these people seeking reassurance and comfort, expressing his challenge and at times seemingly wanting to hear different things than what house staff might have told him.

Alfred's main external connections came from his job at a food service place, where he meets and interacts with many people, and from his church congregation, which he attends every Sunday and where he plays the keyboard. Alfred had occasional outings with his accompanier in which the two would go for beer or to play pool together. He even attended his accompanier's wedding in the city, inviting Ellen to be his date.

Most social relations core members sought external to the house were with people without disabilities.

i. **Access to resources**

Closely related to core members having interactions with people from outside the community is their access to outside resources, both for meeting people external to the community and for enjoying what the city has to offer. During data collection, which took place in warmer months, residents of the house generally went on outings together as a group at least once a week. One time, for example, Serenity House members took the train to go to a movie in the park downtown, while another time they went for an after-dinner walk and dessert in an ethnic area of the city. Other outings included a visit to a famous religious temple, a visit to an auto museum, movie outings and dinners at old community assistants' homes. On a weekly

basis Serenity House went to a local restaurant-pub outing. Some people also went to the YMCA bi-weekly and to church services once a week.

On a more individual level, Matthew, who could go out without support and who used public transportation independently, had direct solo access to city resources and possibilities that were obviously different from someone like Jenna, who couldn't take public transportation independently or go out alone. Matthew generally enjoyed meeting friends at a local café and often took long walks around the neighborhood. As part of house routine – with time he got to be the only core member keeping it – Matthew went to the local YMCA with an assistant to exercise twice a week.

Matthew took the train by himself to and from work. During data collection, he had an art show downtown, in which his paintings were exhibited and people from the community could get to know his art. He also traveled internationally to bring his L'Arche experience and reflection to the international L'Arche committee he is part of. Communication-wise Matthew used his cell phone, from which he often sent text messages to people, and an Ipad, periodically used for email, finding information and web browsing.

Jenna relied on staff transportation to move around. To go to/from work, however, she used rides from the city's Special Transportation service, which she scheduled herself via phone by calling the Special Transportation customer service. A simple reminder from assistants to do this was needed at times but, Anna said, Jenna *"has the ability to do it and she can read – if she had the address in front of her she can tell the lady where she is going."* Jenna used the house phone to make calls to people outside the community and, although she mentioned wanting a cell phone, she never received one. For her dates with friends at restaurants, visits to family and for attending Mass she relied on people driving her (staff or the person she is going to see).

Alfred used to take public transportation on his own to go to work, but concerns over his memory and walking stability as he ages became more prominent and Special Transport service was arranged and provided for him. He generally needed support to schedule rides as, Anna said, *"he won't remember the address he is going to and won't read it, so he needs support with it."* For transportation, Alfred also relied on staff driving.

Alfred could often be seen walking in the neighborhood to nearby stores (usually to buy a can of beer) or going to his church on Sundays. Alfred has also been part of a local university advisory committee board. At his workplace he has received an award for his years of service, proudly displayed on the wall of Serenity House's second floor.

In regards to communication access, Alfred wanted a cell phone and the community helped him buy an accessible cell, with a few numbers memorized in it that he can access and call as needed. He mostly uses his cell phone to call home after work to let the house know he is coming.

As there were a couple of days per week in which Alfred didn't work and stayed at home by himself working on personal paper-work (he likes writing numbers), the L'Arche leadership team opted to provide him with more one-to-one support during that solo time, by having Anna be present with him, letting him be as relaxed and quiet as he wanted but also helping him, if he so wished, to find new activities to stimulate his mind. I asked Alfred if he was ok with this and he said he was.

Anna began to be present in the house with Alfred during the day while other core members were at work and she respected his space and his slow-paced inclination. She also helped him find two new activities that he enjoyed: having a meal once a week in the other L'Arche house and joining a guitar course, where Alfred got to play music using a new

instrument beyond the keyboard he so likes. After a couple of months, however, guitar classes stopped – Alfred seemed content with how much he had done and he didn't have enough money to pay for other lessons. He clearly said, *"done!"* when asked about the guitar class.

The one-to-one support Anna provided him with seemed very beneficial to Alfred; as a quiet and older person he could easily get "looked over" amongst other core members who might be considered a little louder and behaviorally noticeable. It seemed that with Anna Alfred felt comfortable and she, a reserved and kind person, seemed sensitive to his needs.

George generally liked to stay home, but enjoyed going on walks with an assistant and got excited anytime he got to the drive the house van (he has a license but drives with an assistant in the passenger seat). As he was unemployed throughout the data collection period, during the day George went with his job coach to look for jobs around town, meeting and talking to business and stores owners.

During the summer, George liked going to the city's public outdoor swimming pool. Although the assistant he went with was not fond of going to the pool, she did so as she wanted to support George. For communication purposes, George used a cell phone to call and text friends with.

An activity George enjoys doing in the community is going to restaurants. One afternoon he was upset about an assistant leaving, and I offered him to go on a walk together. He accepted the invitation and we walked for about half hour to The Irish restaurant, where he wanted to drink cold water without ice. George, who has an inclination towards routine, had already gone to The Irish various times just to drink water cold to his liking. This time, however, it was with me, who had never seen him in that context and wondered if he actually really wanted only water.

The moment we stepped in the restaurant George went to a table with two seats and we both sat there. The waiter saw George, smiled, went to the counter, prepared him water without ice and brought it to him. Surprised that the waiter knew right away what George wanted without even asking him, I inquired with George as to how often he went to The Irish to get water. He said that he did so every Saturday, with one assistant, just before joining the rest of Serenity House at the pub across the street during the house weekend outing. As the evening progressed, George and I talked a bit about different topics but also stayed in silence..

Once George finished the first glass of water the waiter brought him another one. Another waiter passed by and greeted him asking George how he was doing, to which he replied, *"it's too hot outside"* and *"I am good now, thank you thank you."* As the evening went by, and the waiter kept refilling the water, George looked around and smiled. I asked him if he liked playing baseball, to which he replied that he likes watching it. He asked me the same question, and I told him that I had been to a game but that I didn't understand the rules. After the fourth glass of water George was ready to go and we walked back home, in an atmosphere refreshed by the rain and filled with cricket sounds. I had observed how he could walk in a local restaurant (local resource), have people know and relate to him there (inclusion), ask for what he wanted (self-determination), and walk back home.

Albeit core members' outings with people external to the community were generally supported by staff they also gave rise to questions regarding accountability and safety. For example, Jenna often chose restaurant dates with her outside friends, without them necessarily knowing her health and weight needs. Matthew mentioned various times meeting up with friends when going out solo, but some staff started to wonder if some of those friends actually existed or if Matthew simply wanted to be out of the house and go on one of his long walks. During a

house meeting, while the house calendar was being created, Matthew said, *"the third I am going out with [name of friend]"* and Ellen said, *"thank you"* and penciled this in the calendar, without inquiring much. During my interview with her, Ellen said she didn't know the people Matthew saw *"but he is also his own guardian and I think he can make the decisions of who is ok to talk to or not."* She also mentioned, however, inquiring with core members during her check-in times with them as to who the people they went out with are, not so much to "screen" but as a safety issue: *"for example, one of the core members is going out on a date with somebody they work with and I don't know that person so I asked them who it was and I asked the other assistants if they knew this person..."* One evening, after Matthew came back after a dinner outing with his friend, Anna inquired with him a bit about this friend; Matthew said they knew each other from college. When concerns over Matthew and food issues came up, however, staff started to wonder more about these outings, what "dates with friends" meant and if he experienced food struggles during those times.

A challenge regarding access to resources that emerged from the data seemed to be a questionable use of modern-day telcommunication devices (cell phone, iPad, etc.). Of course, electronic communication devices can be used in positive ways – whether it is to keep in touch with friends (via email or Facebook, which both Matthew and Jenna used), to play games (as Jenna did), to discover information (as Matthew did), to look for images (as George did), or to watch music or movie clips. However, in the case of Matthew, who seemed to get anxious when too many options are presented to him and is very sensitive to health issues, staff started to wonder whether his online searches might include searching for health information or nutritional options that might increase his worry. As positive as health web searches could be, they could also be quite negative when they got to a point of causing needless anxiety to the person

browsing. This is a challenge that most people using the Internet might experience. When anyone chooses to look for health or medical information online he/she might not be unlikely to get concerned over whether "I might have this or that" considering the myriad of information readily available.

In regards to phone use, Ellen mentioned that George's use of his cell device to call friends and old assistants when upset had turned into a challenge. In moments of distress he called various people from his contacts list, asking them to go out and get soda with him, without telling staff. Even in this case, however, phone use seemed to be instrumental in connecting him with others for potential support during challenging times.

If challenges with technology are experienced by core members and the general population, assistants were not exempt from this. During data collection I observed various times assistants choosing to use cell phones and technological devices during sharing time. This seemed to distract from the actual relationship building or practical work at hand, while other times the use was only minimal or was inclusive (as when Ellen watched a movie with Matthew on her laptop or when Michelle showed pictures from her life abroad to core members on her cell phone).

c. **Leisure**

Serenity House generally was quite an active and vibrant house – with house trips organized to other states to visit assistants' families and friends, to other L'Arche communities or to visit city cultural resources and special events. In daily ordinary life, too, the house had quite a rhythm with people active in a wide array of activities. Some people prepared breakfast or cooked dinner, some people went on outings or walks, and others watched television or set the table.

There were also moments of quiet and rest, such as in the evening once the dishes were done and some people watched TV together on the second floor, while others enjoyed the quiet in the first floor living room, or on weekend mornings, when some people slept in a bit more and enjoyed some restful activities (like writing or taking a walk).

During my observation I paid close attention not only to those moments in which there were clear tasks or "things to do," but to moments of leisure as well, those moments that were often spontaneous and even if planned had a certain element of relaxation and/or enjoyment.

Individual leisure interests differed for each core member. Alfred enjoyed writing numbers on paper during his afternoons at his own time and pace, usually in an atmosphere of quiet while sitting on the couch. *"On my free time I do my numbers,"* he told me; when asked if this activity was primarily a decision of his he replied, *"Yes. I make my own decisions, depending on how I feel."*

From time to time Alfred also enjoyed playing the keyboard. He said he first discovered the piano at his church and learned it *"all by ear, listening (...) I can't read no music, I've never taken no piano lesson. It comes. I don't know why but it does. It does."* He said maybe it comes from *"the man above"* and that he decided to play the piano with encouragement from his pastor: *"I saw a piano over there, went over there, uhm, I played it and he told me to keep it up, you know. I did."* One evening a board member came for a visit at Serenity House and Alfred played the keyboard for him, improvising songs and providing him with musical enjoyment. Besides me, it was only they in the room, as a ray of light came in the room from the window reflecting on the wooden floor. Alfred bluesy sounds resonated in the room, and I could feel an atmosphere of leisure and relaxation.

Leisure-wise Jenna enjoyed doing art-work – from coloring on the dining room table in the evening just before going to bed to making occasional special colored signs for people. She also enjoyed playing a specific video game in the evening. During data collection Jenna took a trip with her family to another state for a wedding. As a movie watcher, instead, Jenna liked going to the movie theatre, which she usually did accompanied by at least one assistant. Michelle mentioned that when going to a movie Jenna *"mostly decides what movie she wants to see and we see if assistant has time (…) and we see who wants to see that movie too and someone goes with her."*

In his free time, George cultivated his interest in cars by collecting car photos and talking about them with assistants and visitors. He also seemed to enjoy one-to-one chats with assistants, processing the day and talking about how things are going in his life. Sometimes he specifically sought one-to-one time with assistants, which usually seemed to work out. One time, for example, as people were planning on a restaurant outing during the house meeting George dropped in the conversation and said that he wanted to go on a walk with a volunteer that was going to be there on that outing rather than go to the restaurant. *"I'd rather have a walk with her and not go to [restaurant name],"* George told Ellen. *"All right, that sounds great! I'll make a note,"* replied Ellen in an enthusiastic high pitch tone.

Matthew generally enjoyed going on walks during his free time and socializing and talking with assistants and visitors, often about international cultures. Matthew often asked me to go on walks with him and I usually joined. During our talks we would have a lot of conversation. One time he texted me letting me know that he was tired and wondering if we could postpone our walk to the following week, which we did. At times Matthew also wanted to try pasta cooked

by me and has inquired about coming to eat at my place; I invited him a few times over for dinner.

Matthew mentioned that in regards to leisure time decision-making is primarily up to him: *"I feel it's mostly me that I decide. I mean I do what I enjoy. I do my artwork, watch TV with [names of core members], or just talk to [George] about his cars and stuff."* Matthew has shown interest and enthusiasm about having international assistants and volunteers in community, learning and speaking about their cultures with them. He has traveled with his family, with his L'Arche community and individually. With L'Arche, for example, he went to a national L'Arche celebration in a major American city; there he spoke about his experience in L'Arche with a radio personality. When he traveled to Ireland by himself he said upon his return, *"I was excited to go to [Ireland]. I was excited to come back. They missed me [at L'Arche]."*

Group leisurely activities and outings as a house were generally scheduled with input from core members at the house meetings. Even if scheduled, core members still had a say in attending them or not. As Michelle mentioned, *"the core members always decide if they actually want to go or not, so then if not everyone wants to go there might be an assistant staying here [at the house] and one going. If they don't wanna go to a social event we won't force them to go there."* For example, Ellen once asked who wanted to go to a Valentine's Day dance organized by a local organization and Jenna and Matthew decided to go, while Alfred and George opted to stay home. One assistant went with Jenna and Matthew to the dance, and the other stayed at home with Alfred and George.

Sometimes assistants suggested things they liked to do to core members as potential activities to share together, but overall they shared agreement on leaving final say to core members. For example, Michelle wanted to watch a weekly television-show after dinner, when

most of the house gathered to watch television. Matthew got particularly interested in the show, and it became a weekly event to watch it. Michelle mentioned how core members were open to watching that television show *"but afterwards I said that if they didn't want to watch it again they won't have to. But then suddenly they thought it was a very cool show and now we watch it every week and people are excited to watch it every week."*

Overall, then, leisure activities – or lack thereof – generally involved core-member decision-making. Assistants seemed to echo these sentiments. Jane: *"in terms of picking what to do, how to do it, core members generally make the final decisions."* Assistants' help, for example, would occur if help were needed in finding time to engage in a certain activity. In the instance of only one person wanting to do an activity (like George wanting to go to the swimming pool), that got worked out with the schedule so that that activity could happen when an assistant was available for support. Michelle: *"in like free time core members have more decision in what they want to do (...) mostly it's the core members that are just like 'hey we want to do this'."* She saw the assistant support role as one of suggesting options, but ultimately mentioned that core members *"have probably more power there, in deciding where we go."* Both Jane and Michelle's stances are similar to what Ellen mentioned as her approach in supporting core members with leisurely activities: listening to what they'd like to do, helping with scheduling, giving suggestions if needed and *"help them in any way I can to achieve it."*

An example of a core member doing a leisure activity she liked with support is Jenna's watching a movie in a city park together with other community members. One summer evening Jenna took the train, accompanied by some assistants, to go to a park event to watch a famous comedy. Once Jenna, Michelle, Ellen, Paul, I, and a core member from another house got there, the park was full of people but we all sat in adjacent chairs ready for the movie start. Throughout

the movie Jenna would make sporadic loud comments about some of the scenes, one time even clapping her hands. She would exclaim, *"Oh yeah!"* during particularly engaging scenes, or she would speak fuller sentences like, *"I am glad the guy didn't get electrocuted!"* Assistants did not tell her to be quiet but allowed her to make those comments freely. At the end of the movie Jenna gave a high five to the couple sitting in front of her and commented about the movie to them saying, "*it was great!"*

Jenna smiled during the movie, commented freely at various scenes, clapped with other people and seemed to be a vibrant participant of the audience. After the movie event, on the train ride back, Jenna sat next to Michelle and played with her, squeezing her hand and telling her, *"I am stronger than you*," then asking her to take pictures while she was gone on vacation the following days. The conversation and the action between Jenna and Michelle seemed to be very friendly and enjoyed by both. Seeing Jenna having fun and being involved in both the movie and on the train ride back seemed to be a meaningful sign of inclusion through leisure.

Leisure activities were often shared between core members and assistants, with both enjoying them. For example, during our interview, Anna recalled having been part of bowling games with core members. Michelle, instead, mentioned how enjoyable sharing leisurely activities could be: *"when people decide to have free time or sometimes they want to hang out with us, like go to a movie or something, then we are always willing to do those fun things. I mean it's fun not only for them but also for us, and if we have time we are always open."*

d. **Personal care**

Personal care encompasses a variety of self-care issues having to do with overall personal health and hygiene. Each core member had specific personal care and health

needs. Previous sections discussed many of the health needs related to eating. The next section focuses on the personal care issues that seemed relevant during the observation period.

Alfred mentioned making most personal care decisions by himself. A health concern involving him, however, was his habit of chewing tobacco. Albeit in the past Alfred was able to stop this and replace tobacco with a snack, his habit made a comeback. I often saw him talk to others while having tobacco in one corner of his mouth and I often saw chewed tobacco in the bathrooms' trash cans, with the pungent smell that entailed. Staff saw this as a preventative health concern, for the obvious risks that tobacco can cause to one's health not only in the present but also in the future. In communication with other professionals, Alfred was encouraged various times by assistants to go back to snacking rather than chewing tobacco, and was told that tobacco can have unpleasant health consequences. Alfred heard these comments, but seemed quite set in his wanting to continue chewing tobacco, mentioning how a family member used to chew it too when Alfred was younger. Staff realized they couldn't force Alfred to stop chewing tobacco, but, considering the visible periodic presence of tobacco in his mouth, they observed that his oral health might have benefited from better teeth brushing, an activity that, together with showering, all core members do alone and without supervision. Jane thus decided to show him how to brush and rinse his teeth more thoroughly so that less tobacco would remain in his mouth.

Alfred kept his room relatively ordered, but did not do in-depth cleaning. Towards the beginning of my observation period he said, *"I do my own room myself"* even if at times assistants helped him. He said that even if he didn't need the help, *"if they want to, I don't mind."* This help became more consistent when Anna was given the opportunity to share time with him on a more individual basis. She paid close to attention to help provide Alfred with a

healthier bedroom environment. In a matter of weeks Alfred got a brand new mattress and sheets, since the sheets he had were old and stained and his mattress was uncomfortable for his back.

Jenna mentioned making most of her personal care choices herself: *"I know how to do everything by myself"* Weight issues are something she –with assistants' help – have been trying to work on, with mixed results. At times she coupled sentences like, *"I am working on it"* with requests to go out and buy soda. It was not clear how much she really wanted to work on weight issues, and thus how much the motivation behind it came from her or whether it was something that mostly other people wanted for her.

A soda-related episode similar to the one mentioned before between Jenna and Michelle was recalled by Paul during my interview with him. In this instance, Jenna wanted Paul to walk her to the store to buy Mountain Dew. Differently than with Michelle, in this instance other elements came into play: Paul was trying to lose weight himself so he let Jenna know that weight was a personal health issue he was dealing with as well. Jenna brought in the conversation the concept of rights, telling Paul that it was her right to get soda if she wanted to. Paul replied to Jenna, *"exactly it's your right [Jenna], but also as a friend you know we talked about how we need to lose weight, about the sugar, how we are working together to watch what you drink, like sugary things, for weight loss, so it's your choice but it's also my choice to say 'no' because I am doing that because I want to support the decision you made before about losing weight."*

Jenna got upset and went into her room, later coming out telling Paul that she understood sugar is not very good and that she didn't want to be pre-diabetic. Paul: *"we are just trying to make sure that your health is very important"* and that *"it helps me too because I like sweets, I like to drink soda (…) so when I go with you I have to watch what I drink too!"* Jenna said, *"oh,*

that's right." Paul mentioned how her decision affected him too because *"when I am with her I have this guilty pleasure of getting pop if she gets pop."* In the end they walked to the store and got a decaffeinated drink.

Albeit Jenna often spoke with pride about making her own decisions, her bedroom upkeep has been a question mark for some staff, some not being sure when Jenna cleaned it last. Like other core members Jenna did her laundry by herself on her specific weekly laundry day. Albeit Jenna had a sense for fashion (for example, dressing more elegantly for special events and matching colors) and, like all core members, picked her own clothing, at times some of her clothes seemed a bit thorn or dirty. In rare moments staff provided feedback on this. One evening for example, Jenna asked me for help with tying her shoe, which I offered to her. As I looked at the shoe I realized that its front side was relatively thorn and worn out, and asked her if she wanted to throw them for a newer pair. She said no as *"they are not broken, they are thorn."* Days later I learned from Jenna that Ellen asked her if she wanted to get rid of those shoes for a new pair of the same color. Jenna mentioned, *"that's right, they are old. I told my sister, she knows about it."* This time, when I asked her whether she thought she needed new shoes and if she thus wanted a new pair, she said, *"yes, I do."*

George, too, regarding personal care decisions mentioned how *"I always make them for myself,"* with occasional support. I have previously presented health concerns regarding George's diet. During the data collection period, although at times George ate house food often adjusted to fit his taste, he often had canned chili. Thanks to nutritional advice from a professional, it seemed that George's understanding on the importance of a well-balanced diet increased and, together with staff buying less canned food, healthier changes were observed in his eating habits, as well as some weight loss.

In regards to his space, George was very protective of his bedroom and rarely allowed people in. If visitors came to the house, including repair personnel, he got easily worried as to whether they'd enter his room or not. This has made cleaning accountability particularly challenging. Although he said he did some cleaning and there has been talk of an assistant supporting him for a deeper clean, I haven't observed it.

Matthew's health concerns with food have been mentioned before. Albeit when he came back from his monthly weekend with his family he usually had a "clean-cut" look, shaved and clean, he seemed to keep such style only occasionally while at Serenity House, as one evening I noted: *"[Matthew] looked pretty clean cut, shirt, shaved relatively well, short hair, even if he hadn't gone to his dad's house."* On a day-to-day basis, however, Matthew looked less "tidy." At times he shaved but seemed to miss some beard spots and his hair didn't look combed. His clothing too was often relatively baggy, stained with coloring paint. There didn't seem to be much assistant feedback on these appearance issues.

One time I pinpointed to him how he missed a spot in his beard shave. I did so with a smile and pointing out that I myself might miss a spot while shaving. I chose to employ this approach because I knew Matthew could easily get defensive if someone mentioned to him he did not do something a certain way and could do it in another way, seemingly taking this as a threat to his independence or possibly feeling he is being told that "he is not good enough."

Another time I went with Serenity House to a barbecue organized by a community board friend. Before leaving the house I noticed Matthew had a big patch of dried blood by his neck, which he said was due to shaving. I suggested he put a band-aid on and felt he was getting on the defensive side when he said that the blood didn't bother him. I mentioned to him how it might be good to put a band-aid on for hygienic purposes and that some people at the barbecue might not

like seeing blood. After we spoke, Matthew walked to to the restroom and decided to put a band-aid on.

In regards to room cleanliness Matthew was the only core member that cleaned his room regularly with the support of an assistant, which he himself wanted. He decided that having regular support was helpful and that regular room cleaning was important to him.

Assistants' responses in regards to supporting core members in their personal care tasks were relatively similar: they affirmed being ready to support core members but also ultimately giving them final choice.

Jane mentioned how assistants should support core members personal goals decided once a year in their Individual Service Plan meeting, an agency required meeting when core members meet with team members and friends to describe goals and wishes for the upcoming year, but that ultimately *"there is a fundamental attitude that it's their decision, nothing should be forced upon them."* She gave the example of when a core member didn't want to put on a lotion beneficial to the skin - *"I might go on my way to persuade them, re-emphasize, re-introduce the idea that 'this is why you are doing it, this is what's gonna happen if you do it'…again, they make the final decision. If they wanna put the lotion on or not. Assistants are more like support."* On a similar note Michelle mentioned how *"core members' personal care is mostly their business, so we always encourage them but we can't force them"* She too brought up the lotion example, saying that when the core member didn't want to put on hand lotion she reminded the core member that doing so was important but that *"I couldn't have put lotion on [the core member's hand] hand, you know?*"

According to Ellen the four core members at Serenity House are *"pretty autonomous when it comes to personal care in the sense of hygiene and thing like that."* She added that if she

noticed someone hadn't showered in a while then she'd gently suggest *"hey, taking a bath tonight would be relaxing"* or the like. One time, for example, as the summer was approaching, during a house meeting Ellen told a core member how he needed to take a shower twice a week, rather than his usual once a week.

I asked Ellen how she'd notice if someone didn't take a shower in a while and she mentioned, besides the obvious noticeable smells, how *"living with them you kinda know what their daily routines are and you kinda know if they are not following them. All of them have a set schedule of when they want to take baths, but it's kinda on their own and on their own choice that they do it."* Showering/bathing schedules ranges from a core member bathing once a day and another doing so twice or three times a week.

One instance Ellen recalled brought up a challenge regarding personal choice and supporting personal health. A core member didn't want to shower for two consecutive weeks. To convince the core member to take a shower, assistants explained that getting rid of dirt was a good thing and that it was unhealthy not to shower often; the core member replied she was doing ok. Ellen recalled how at that point the feedback the core member got was, *"well, for the sake of everyone else maybe you should shower,"* since the smell was getting to the other core members. As negotiations failed for a couple of days, it got to the point that the core member was asked to change rooms because the smell was so bad and, Ellen recalled, *"at that point we are like 'that's a health concern (...) you gotta do it'."* The core member finally showered and resumed a normal routine.

Although assistants emphasized willingness to support but left final choice to core members, there was one issue in which personal choice was less emphasized, namely medical appointments and responsibilities. Ellen mentioned that if a core member didn't want to go to a

doctor's appointment first *"you try to (...) tell them the importance of the doctor's visit, tell them what is for and let them be as informed as possible about it."* If, however, the core member still did not want to go, *"at that point it's like 'no, you have to go, it's a doctor's appointment, it's a very important doctor appointment' and at that point I think it just has to happen."* On a similar vein Jane mentioned how *"when it comes to medical stuff is more serious"* and the persuasion stronger.

2. **Support and decision-making**

We have tackled relevant life areas in which core members often made choices. As we have seen their self-determination and choice-making happened in the relational network of community, especially in relationship to their receiving support (or not). Indeed, it became evident through data collection that decision-making and support were closely related. For example, if Jenna wanted to go see a movie at the cinema but no one drove her there, she wouldn't have been able to see it. If George wanted to eat chili but staff did not buy it, he wouldn't have been able to eat it. If Alfred wanted new bed sheets but no one was there to hear this request, he wouldn't have been able to buy them. If Matthew wanted to go to Ireland but no one helped him buy the ticket and make travel arrangements, he wouldn't have flown across the ocean. I was thus interested in exploring in more depth how core members and assistants both saw the role of support. Beyond the official explanation that assistants are support staff, and thus have support as a role responsibility, I wanted to get to the personal understanding people had of support and how that took place in the relational contexts of Serenity House. How did they live out support and how did they look at it? What meaning did support have for them? In what ways did it relate to choice-making?

a. **The experience of support**

I asked both core members and assistants about their experience of support. When I asked Alfred in what ways – if any – he wanted to be supported he said, *"I don't know. I take my pills in the morning. Mh. I get up on time, fix my breakfast, get dressed and go to work. I call when I come home. Go to church on Sunday. I do my chores."* On a similar vein Matthew mentioned, *"I don't think there's any at all right now, I feel like everything is ok pretty much."* He then stated assistants support him well in decision-making, without making decisions for him, a difference he explained saying, *"making decisions is that you make it for them and say 'ok, you have to do this', whereas supporting you is that they support you and say 'yeah, we'll help you support you do this because we wanna see you achieve'."* If somebody made a decision for someone else, he continued, *"then it's made already for you without you saying 'I don't like this decision, why did you put this on me?'"* He didn't feel this happened at Serenity House.

Jenna and George both brought the concept of support to a more psychological and emotional level. Jenna mentioned that assistants can help her make choices in talking privately with her. Considering how, when asked to make a decision, she often said, *"I have to think about it"* and how she could often be heard vocalizing and processing things in her room or while she was on the computer, it seemed Jenna really valued intimate calm processing time, and saw this as a valuable support.

George, instead, mentioned he did not need more support, but mentioned Steve as someone who " *helps me out and he is a super super comfort person."* George referred to situations in which he might experience hardships or challenging behaviors, and how Steve could help him find ways to respond to that in ways that don't cause, as he said, "*trouble."* George, in fact, in particularly challenging situations of anxiety or distress, has at times physically

threatened people or called them names. As a response, staff has worked, together with a professional behavioral therapist, to help him cope with those situations better.

George mentioned Steve specifically during the interview as a support person he liked going to, in addition to other people that he saw as comforting. These included his mother and old assistants, as well as another core member (Matthew). The people George found comforting, and that would thus influence his decisions as to who to go to in difficult moments, all seemed to share similar characteristics, which George himself explicitly mentioned. George was drawn to people who were reassuring, who didn't use loud voices, and who were gentle with him. He mentioned how screaming reminded him of a family figure from childhood who at times raised his voice, while softer voices and approaches seemed close to the approach his mother had towards him.

As I inquired with assistants about support, they emphasized both its practical components and its emotional ones. Anna mentioned providing practical supports – like helping with appointments and cooking – but also partaking in community celebrations, relaxation time and fun times. Michelle mentioned helping core members with *"normal things in the house,"* like cooking, cleaning dishes, making phone calls, talking, checking on meds, and even mentioning helping people not fall on the snow as they walked. She also mentioned empowering them and not "doing things for them" if it wasn't appropriate, like when Jenna *"doesn't want to carry something she would just say 'hey, carry it for me'. I encourage her to carry it herself; when it's her soda I say, 'it's your soda, you wanted to buy it, you can carry it'…I saw her carry it before, so I know she can do it."*

Michelle said she wants to encourage people to be as independent as they can be, while being aware that sometimes they do need help: *"We are kind of interdependent too, so that*

people, like, need help from each other and are dependent on each other, but I just think that they want to get more independence so they can do more things by themselves too, because everybody here wants to basically make their own decisions, so I just think that it's good if they can do as much as they can too (…) we are assistants and help them with things they can't do, but we are not servants that do everything for them." Jane thought independence and community *"must come together I think, and it takes time. Just considering a family, like, they may share similar values, the same last name, but they have very distinctive personalities and they wanna do things in different ways. But I think their freedom and distinctiveness should be respected. It's like in the rainbow you get different colors, that's why it's a rainbow. If it's all white it's not a rainbow anymore."*

Ellen mentioned offering support to core members in *"any way they need help."* She mentioned practical supports, like helping some core members in getting their medications so they can start their day, cooking and cleaning, and taking care/monitoring injuries as needed. But support, she added, *"is also emotional. If they have any issues they wanna talk about or problem solve I am there to sit with them and talk about it or go on a walk with them if they need it."* On a similar note, Jane mentioned offering supports to core members in *"every single way I would say."* She too hinted at practical supports, but emphasized behavioral and psychological ones, for example, helping core members communicate and express their emotions. That is an area Jane mentioned as wanting to provide more support in: *"how to express your thoughts through words especially. How do you not get so much riled up or affected by another person's behavior, reaction, words. I am still practicing that but I think that's the area I would love to offer the most support"* she said.

In his leadership role Steve said a big way of giving support is to provide *"core members with a sense of security, maybe that's not the right word, but I think as a leader in community people tend to look at you and if my response is, you know, peacefulness I think it sends a message that we are going to be ok, life is well."* Steve thus not only emphasized the practical sides ("what one does") of support, but the quality of presence ("how one is") in giving support. For him being a presence of peacefulness is a way of being supportive to core members and the rest of the community.

Steve, however, also took the conversation around support to a "higher" level, mentioning a desire to support core members in the "bigger things" that core members might want: *"I'd still love to have more robust conversations about the aspirations of our core members. What are the bucket lists our core members have, and how can we help them take steps towards achieving those things."*

During my observations assistants seemed in tune with core members day-to-day desires, but conversations about "bigger pictures" dreams were not often present. Some spaces to have those conversations could be present, but it seemed "day-to-day" conversations and goals took priority. For example, once a year each core members, as previously mentioned, has a person-centered state-mandated Individualized Service Plan meeting. During these meetings the core member and his/her chosen interdisciplinary team (which includes family members, work staff, community members, professionals and friends) meet and talk about how the past year was for the core member and how/she wants the next year to go. Yearly goals in the domains of daily living, community integration, finance and medical/health are chosen during that meeting, with primary input ideally coming from the core member. Serenity House staff is then responsible to help core members implement those goals. However, those goals often seemed to focus on

periodic routines and activities. House conversations on wider core members' aspirations were not often present during my observation period.

Overall, core members generally had a strong sense of making decisions themselves and didn't think they needed more support than what they were already receiving. Assistants generally mentioned how their support towards core members spanned across different areas, emphasizing its practical and emotional aspects.

b. **Options availability**

Assistants' support, beyond its practical and emotional elements, was inter-related to core members' choice-making when it came to providing or supporting options. If choice implies choosing from different options, assistants' ways of supporting, affirming, rejecting, or influencing core members' option availability directly influenced core members' choice-making.

In general it emerged that assistants sought to provide core members with options to choose from, and not take those options away from them. These options, however, were at times limited by different layers at play in the community level, most clearly support availability.

Five major approaches to option support emerged from the data. Albeit not mutually exclusive (different approaches were at times used together), it seemed relevant to distinguish and examine them so as to shed greater clarity on the "options making" process. These approaches were: asking core members to choose between two things; trusting core members' experience to provide options; suggesting new options interpersonally; using external resources to increase options; and focusing on "one way" rather than different options.

i. **Choosing between two options**

The first approach to options making consisted of assistants asking core members to choose between two things. A very "basic" yes/no approach, this way of providing options usually involved closed-ended questions, as in the example of Ellen asking George, *"Do you want to join us for prayer?"* or "*Do you want to join at least for check in?"*

This approach was also employed in a more open-ended way, as when Ellen, in communication with other leadership members, wanted to replace the old window blinds of the living room with curtains, allowing for more light to come in and brighten a relatively dark looking room. Ellen and the assistants brought this up as an option to core members. One option could be to leave the window blinds and the other to put curtains instead. As Matthew recalls assistants *"brought up 'how would you like to have curtains instead of blinds?' and (...) I said 'yes, I would like that!' Then you gotta tell [George] and [George] was a little iffy about it but finally decided we can try it."*

ii. **Options stemming from personal experience**

The second approach to option making was rich and open ended. It seemed to rely on trusting the individual's inner knowledge and experience as a source of options, through consequence discovery and experience recognition.

In terms of consequence discovery assistants relied on core members learning things through their own choices and the consequences these implied. Jane called these natural consequences "teaching moments." She mentioned that even if she presented different options (*"plan a, plan b, plan c*") she could trust that the natural consequences of core members' choices would "teach" core members not only that they have options, but that these options have consequences.

Jane gave the example of making a deal with Jenna of getting up on time so as to make a sandwich together; if Jenna didn't get up on time the following day then making the sandwich together couldn't have happened. In the end Jenna didn't end up getting up on time and thus learned from experience that the option she chose (getting up late) had a specific consequence (not making the sandwich together). This happened in more positive contexts too. For example, when Jenna had to choose a movie to watch at the movie theatre she would be the one suggesting the movie and assistants allowed her to make that choice, with the consequences that implied (in this case positive), trusting that she based her choice on her likes and interests.

This is akin to experience recognition, or supporting options and choices that grow organically from the core members' experiences. As Michelle mentioned, core members *"usually already experienced different things,"* and tapping into that could be a way to help them make choices. For example, when Alfred was asked what he wanted to cook on his cooking night he had his options wide open and often ended up choosing fish based meals, as that's what he liked to cook and to eat, thus basing his decision on taste and experience.

People's choices were also shaped by previous relationships, messages heard from others, cultural contexts and availability of previous options given to them. One day I was walking with George in a residential part of the neighborhood. As we passed by different homes he noticed a ceiling fan through the window of one. He moved his head forward to look at it, but turned away right after a few seconds. Albeit ceiling fans fascinate him and he could have looked at it longer (at times he stared at ceiling fans for minutes), he opted to look at it only briefly as he told me that it was better to just take a quick glance rather than stare for too long in someone else's house, otherwise people in that house would feel weird about it. As I inquired more as to where that understanding of boundaries came from, he mentioned his mother and how "*mom is*

smart on detail." George had thus chosen to only take a brief peak at the object he liked not in a neutral way but grounding that choice on his mother's past feedback.

iii. **Being provided new options**

The third approach assistants employed was suggesting new options to core members interpersonally, thus increasing the number of options available to them. Ellen, for example, mentioned that she saw it as her job to give as many options as possible to core members and to support whatever choice they made. Michelle seemed to resonate with this when she spoke of her role as *"showing different options, different consequences, then just like, yeah, try to help them make a decision but not make it for them."*

Paul mentioned how sometimes core members can have a *"narrow mind of doing things,"* and giving options to them that they have never thought of before broadens their decision-making: *"'Oh, I never thought about this before, that's a good point Paul', 'Yeah Jenna'."* One time for example Paul went to shop for some car materials and Alfred decided to go with him, as he wanted to go see cars. Alfred wouldn't necessarily have thought of this option if Paul had not suggested going to the car place.

This approach of assistants increasing options availability to core members was generally coupled with hearing the options core members came up with in the first place. Ellen mentioned how each core member learns of different options differently, so that with those core members that communicate better through writing and reading she sits down with them and *"we'll write out different options that can be done (...) I basically try to write as many options I can think of and ask for their opinions on options and what they think are some options."* With other core members, instead, she would simply chat about options.

At times, the number of options was limited by community events core members were part of. For example attending community night, a monthly event in which visitors gather with the community, is a set tradition, and core members didn't have many options besides attending it (never forced to do so, however). Even within that, "sub-options" were often provided. For example, considering George's uneasiness with big crowds, before community night Ellen would sit down with George and come up with him with options and possibilities to decrease the likelihood of anxiety and to find ways to cope or avoid an anxiety-provoking situation while there at the event.

iv. **Increasing options through external resources**

A fourth approach consisted in enabling external resources to increase options available to core members. This could easily be a subcategory of the latter approach (providing core members with new options), however, the fact that it relied on input from people who were not in the community or on resources not directly provided by the community differentiated it into its own category.

Media was used various times as a resource for finding options. Jenna, for example, learned about a new movie at the cinema through a television commercial; she expressed wanting to see it, which she did with assistants' support. Matthew would often use the internet on his personal iPad if he needed information regarding things of interest to him. The web was also used in the house meeting context to find information about events happening in the city. Besides media use, other resources for options included guardians, family members, work staff, and community friends.

v. **Focusing on "one way"**

The fifth approach, which happened rarely, consisted in not emphasizing any variety of options but focusing on one way. For contextualization sake this approach did not imply forcing the core member into one choice. This, for example, happened in the previously mentioned instance in which a core member refused to shower for two weeks and the odor was spreading through the house. Staff obviously did not encourage the option of staying dirty with him, but focused on making it clear that, for his own health benefit, the core member had to wash himself.

The same approach – but with a different tone – happened when an assistant was about to have a guest from another country visit her at Serenity House, staying over for a few days. As this assistant was not going to be there the day of her friend's arrival, she told a core member, *"When my friend comes I won't be there so you are gonna host her."* This statement was part of a longer conversation on the train on the way back from an outing, in which this assistant and the core member also joked with each other, spoke about making plans to stay in touch once the assistant left, and hugged each other various times. The conversational context and assistant's tone of voice – soft but direct – could almost be interpreted as if she was partly trying to "empower" this core member by saying "I know you can do it, I trust you to be a host in your house." However, it also gave me a sense that the assistant was speaking to a kid, like a parent saying to a child, "We are going to have guests over so you are going to act nice." After the event I asked this assistant for greater context about her friend's stay-over, and she mentioned how she had *"asked everyone if they are ok with my friend staying in my room. They were, and were happy about it."* In conclusion, whether the statement was meant to be serious or not, and

whatever her intentions were, it still focused on doing one thing, without leaving the core member with great room for other options.

c. **Reaching compromise**

It clearly emerged from observations and interviews that compromise was a constant both in options-making and in subsequent choice-making. Making choices while living in a community context where other people made choices too, while at the same time having a specific limit of support available, often implied finding a compromise.

Compromise usually took the form of an assistant helping to find one or more options that a core member and another party/parties (generally another core member) would agree on. Compromise was generally needed whenever there was a support issue, a health concern, a set of responsibilities or a community practice that required some options to be negotiated.

Reaching compromise was generally exercised in four different ways: finding a happy medium amongst different options, postponing decision-making giving options time to "settle," catering to preferred options at different times, and making clear what practically is and what isn't a realistic option in the first place.

i. **Finding a happy medium amongst options**

The process of assistants helping core members find a happy medium amongst different options was well described by Ellen when she mentioned that often core members could get stuck on things they wanted to do and an assistant helped navigate through that: *"let's try to find something all three of us can do together or all five of us, and enjoy it."* In such situations, Ellen brought together suggestions and invited core members to express their preference until reaching a point of positive agreement for one specific option.

This is exemplified by a week-end morning episode recalled by Ellen in which she was the only assistant sharing time with three core members, two of which wanted to go to the bank and one to the market to buy Sprite. Ellen proposed to core members to all go to the bank first and then to the market, or to do so in reverse order (store first, market second); one of the core members, however, didn't like either option and got agitated. He started calling Ellen names, pacing around frustrated. Looking back at it Ellen recalled it being "rough." She decided to sit, stay quiet, and let the core member know that he seemed aggravated, suggesting him to go use one of his "safe" private places in the house (rooms he likes to go to relax and calmly process things in). He took the suggestion, went to his room, and after about 10 minutes he came down, as Ellen recalled, *"much calmer, willing to listen, and we worked on a compromise of how we could go to the bank first and then we could all go to McDonalds and grab a [Sprite]."* Ellen then asked the other two core members if this was ok with them as well and *"that seemed to work for all of them, cause they all wanted a coke at that point in time."* The outing went well, people went to the bank and to McDonalds to get Sprite, the tension was de-escalated, and people joked with each other as they hung out together.

ii. **Postponing option-gathering and decision-making**

The story just mentioned highlighted another element of finding compromise: postponing option-gathering and decision-making (even if only by a short time). This was usually employed in moments of high tension. As George was agitated, Ellen invited him to go relax; he did so and came back into the conversation readier to find a compromise. As Ellen described, often *"when there's conflicting things that people want to do the core members get agitated and the best way to stop the agitation is for them to go spend some time alone, because when they get agitated it can escalate very quickly, or sit down, 'cause a lot of the times*

standing up can cause even more agitation." This agitation, Ellen said, was often due to the fact that some core members *"don't like to be told they can't do something, that it's not possible to do something at that moment in time. So they start pacing, yelling, raising their voices ..."*

In the episode with George, Ellen had helped find a creative compromise, but needed to give him time to cool down and thus postpone the outing decision by some time. Sometimes the core members themselves asked for time. Jenna, as we have seen, often times asked to have time to think things through to consider options before making a choice. One time I asked the house if someone could come over as a guest for dinner, and, albeit most said yes right away, Jenna mentioned needing a few days to think about it. I accepted that and she ultimately said that person could come over for dinner.

iii. **Catering to different options at different times**

Often, when compromise was needed, catering to different options at different times worked successfully. During a house meeting, for example, staff asked core members what they wanted to do over the weekend. Alfred chose a visit to the car museum and Jenna an outing at the park. Staff mentioned how the weather was still warm and how it might have gotten colder as the days went by, so that an outing in the park could have been more enjoyable at an earlier time and a museum visit at a later time. Core members agreed with this and the park outing was scheduled for that week-end and the museum visit for the following week-end.

iv. **Clarifying what is/isn't feasible**

At times staff clarified what was and what wasn't a realistic option. Differently from finding a middle ground amongst possible options, this approach identified some options as "non-feasible options" in the first place.

An example when this approach was employed was in the context of an Anniversary Night, a monthly community gathering, with invited guests, to celebrate core members and assistants that joined community on the same month. During my observation period it happened that on a specific month a core member was going to share his Anniversary Night with an assistant. The core member, however, spoke to Ellen and I about wanting to have his anniversary separate from the assistant, suggesting doing them on a different month or postponing his own to the year after. He claimed that having too many people (the homes plus a few guests each celebrated person could invite) "got to him." Both Ellen and I found this situation challenging, as this core member was quite animate about this.

For Ellen and others, including me, this was a delicate line to walk on: how to cater to this? It became clear to staff people that having two separate anniversaries was not really an option in the first place. Not only would it potentially ask for extra energy (schedule change, driving, cooking, etc.) from other community members, but it could also have become a precedent in which people picked and chose who to share their anniversary with, potentially encouraging individual favoritism and communal tension rather than grounding community on its rhythm/calendar and, potentially, if the core member was having a hard time with the assistant in question, on what Vanier sees as the two pillars of community: forgiveness and celebration (1989).

We thus sought to go to the root of this. Why was the core member asking this? He seemed to be concerned with number of people rather than with the assistant, but his motives still remained unclear. We mentioned to him that having two separate anniversaries was not a very feasible option, making clear to him that even if the anniversaries were shared on the same night each individual would still have a focused personal time, during which attendees would affirm

and celebrate each person individually. By that time, however, the core member had already changed his mind and was fine sharing the anniversary with that assistant.

Ultimately, the anniversary went well, the core member had about five guests (chosen by him) and the other assistant one guest (chosen by her). The core member seemed fine during the celebration and proud to receive affirmations from the people present.

v. **Process vs. consensus**

A mention should be made here of an observation made by Steve, which seemed to be quite relevant to his executive role. Steve highlighted the importance of having a clear decision-making process: *"at the end of the day our community makes decisions not through consensus, which is what I think is often a misperception of what community is, but we make decisions with clear processes, and I think that sometimes can be a challenge – in which process is core members/ input required and to what extent."* Having clear decision-making processes, therefore, was more important to him than having everyone agree on something.

For example, before welcoming new assistants in the home they are generally invited to visit the house first if they are nearby or to video-conference with core members and assistants. Leadership staff then gets a sense of what the feedback from the home (including core members) is, but ultimately the decision as to whom to welcome/hire is done without going to each resident asking for previous approval. The idea would be that new staff gets hired by a leadership staff member who has that responsibility, but that at the same time that input from the home is also heard. How much to involve each core member in that process and at what level of the hiring decision-making is not always clear.

3. Environmental and structural factors

Relationships in L'Arche don't happen in a vacuum, but in a specific context, including the environmental and structural elements that context implies. This section will examine some of these elements (major ones), particularly as relating to their influence on community and on its members' decision-making.

a. Agency policies and regulations

Besides being a community, L'Arche Southown is also an agency. As such it receives most of its finances from the state and abides by state group home regulations, with its employed assistants having the same responsibilities as support staff in other state group homes while also receiving a modest stipend plus room and board, and with its general practices held accountable to periodic state review.

What emerged from the data was that agency expectations and regulations had a place in the life of the community primarily as emerging from assistant's training and by leadership work of making sure state regulations and deadlines were met. However, agency policies did not seem to be a major focus in the day-to-day life of Serenity House agency policies and practices. Steve, Executive Director, was himself very honest in his reaction when I asked him how familiar he was with L'Arche Southown/Serenity House policies: *"do we have those?"* he said smilingly. Observation, however, made it clear that in his supervisory role Steve was aware of state policies and regulations for L'Arche Southown and Serenity House, for example, making sure that core members' goal sheets were complied and gathered by a specific time, or that fire drills were done every so often.

As I inquired with him about L'Arche Southown agency policies he pointed to binders by a wall saying that the policies were in one of those binders. In regards to Serenity House

governing policies he said he *"never heard anything."* He kept smiling as he answered these questions and I could sense the ironic tone in his replies, knowing the history behind L'Arche Southown's agency policies. L'Arche Southown, in fact, was part of a group home agency before becoming independent just a few years back, and, Steve mentioned, its governing policies *"were copied and pasted"* from that agency. Albeit he didn't think those policies should necessarily be changed, he would like to go through a review of them. Steve mentioned that to him governing policies are not a documented guidance on daily life, but a resource for crisis situations: *"at the end of the day a lot of these things are, uhm, almost like a protection mechanism so when problems occur you have a foundation to return to that sets a common denominator for everyone."* However, he felt that since *"we rarely deal with the types of issues they address"* people are not very familiar with them, even if they are an essential reference to consult as needed.

None of the other informants seemed familiar with Serenity House governing policies, with responses ranging from Paul's *"I don't know what they are"* to Michelle's *"uhm not too familiar I guess (...) what are the actual governing policies?"*

b. **Agency responsibilities and expectations**

Besides formation ("training") on the philosophy of L'Arche, centering on relationships of friendship and belonging between core members and assistants, new assistants in L'Arche Southown also receive state-required training on being direct support service professionals. This training, which other group homes in the state share, covers various themes and practices relevant to the role: respect of human rights, prevention of abuse, confidentiality, supporting health and wellness, person-centered planning, and human communication.

The responsibilities of the agency include providing a healthy, safe, professional, and supportive environment to its residents or clients (core members). Data brought to the forefront three particular themes/responsibilities as particularly influential or relevant to choice-making at Serenity House: health support, respect for privacy and safety precautions.

The major theme that consistently came up was related to health support, particularly as related to food. As we have seen, core members generally experienced food-related issues (from weight to diet challenges) and assistants' responsibility to encourage healthy eating and a balanced diet was not without its challenges, particularly as they sought to respect core members' personal choices.

There were other health concerns assistants tried to cater to, threading the line between supporting choice and promoting a healthy lifestyle, as in Alfred's tobacco chewing. Despite being encouraged to stop, he decided not to. Assistants however kept encouraging him to find alternatives and to take better oral care.

Another issue related to health that emerged from the data was that of cleanliness – both in personal bedrooms and in communal spaces. Albeit new house cleaning routines had been created by Ellen, involving core members' involvement (particularly in their bedrooms), these seemed to be taking time in becoming part of daily life at Serenity House. This, however, still seemed to be positive step, since before these routines were introduced there didn't seem to be any clear sense of who cleaned what and when, and a lot was left to assistants' and core members' spontaneous initiative. Albeit even before the cleaning schedule core members had specific cleaning roles, generally focusing on post-dinner cleaning (George helping wash the dishes, Jenna taking out the trash and Alfred cleaning the floor), overall house and bedroom

cleaning was much less planned and there seemed to be a lack of accountability, to the point that assistants themselves did not know when bedrooms were cleaned.

Steve mentioned that in the history of Serenity House cleaning was not always well catered to: *"I think our core members were told their rooms are their domain and they can do whatever they wanna do in there, and if that means it's a pig sty, it's a pig sty and no one is gonna go in and no one is going to have any standards for how they keep their bedrooms."* Steve mentioned a past rodent problem at Serenity House as being an effect of this lack of cleanliness. Over time, Stevie mentioned, *"we have kinda learned that (...) while that decision is the core members' it may not be a decision that serves them well and that they may not have considered what the results of having a pig sty for bedroom are (...) I think these days we are getting better at helping them I hope recognize what the results of their decisions could be."*

When Ellen first introduced the new cleaning schedule during a house meeting it was met without resistance from core members/assistants and Jenna even clapped saying, *"Yeah!"* Ellen mentioned that some tasks were to be assistants' duties that core members could help with, but that core members' primary responsibility was being in charge of their bedrooms, which they would have needed to clean with the support of an assistant. As this was mentioned Jenna replied to her, *"I'll do it myself."* Ellen clarified, *"even if you do it by yourself, we need an assistant to double check it's clean."*

During the meeting Ellen suggested core members sign the new cleaning schedule as if it were a contract; in other instances at Serenity House contract types of agreements were suggested by an external behavioral professional to reinforce positive behaviors and seemed to work successfully. I, however, suggested that before making it a contract it might have been best to try practicing the cleaning routines first. However, in the weeks following the meeting,

keeping up with the routine had been met with mixed results and it didn't seem that the schedule got ingrained in the rhythm of the house.

Throughout the data collection period core members remained faithful to cleaning tasks they had before the cleaning schedule, assistants did some cleaning on a daily basis, and the need for greater cleanliness was vocalized and emphasized various times by staff. In addition, people's spontaneous initiative in cleaning still happened, as when Paul and Ellen majorly cleaned and ordered the basement, or when Alfred helped Ellen clean the pantry area by the kitchen. At times cleaning intentionality came from core members too, as when Matthew asked staff *"can we use a steamer? I want someone to show me because I have never done it"* and Michelle was willing to show him.

However, there remained some confusion as to when more in-depth and thorough cleaning of the house and bedrooms should happen, and the extent to which core members and assistant should partake in it. Michelle advocated for a middle way in which both core members and staff are involved in cleaning: *"it'd be a good option if core members try clean their room as good as they can, but then if like their room wouldn't get fully cleaned then assistants can help them then, because in that way they can take responsibility for their own room and just get the help they need."*

Ultimately, at Serenity House, the line between supporting healthy behavior as an agency and allowing people to make their choices seemed was not always clear nor easy to navigate. As Anna mentioned giving the example of encouraging people to wash their hands when needed, *"if I want them to wash their hands because I know it's important, it's more what I want (...) but then it's up to them also. That's hard."*

c. **House practices and structures**

Serenity House practices and structures encompass the residential environment that core members and assistants share life in, with its routines and traditions as well as its spatial characteristics. House practices mostly encompassed house meetings, pre and post dinner prayer, shared dinner, cleaning routines, medicine checks, and joining community events. As some of these elements have already been touched on, in this section we will focus on house meetings, as that was a relevant core members' decision-making weekly event.

House meetings, which was a new practice that began while I was gathering data, happened once a week after dinner, as a time in which core members and assistants came together to speak about the schedule for the upcoming week, any needs people might have, and to create the menu for the upcoming week.

Led by house coordinator Ellen, these meetings happened after post-dinner evening prayer around the dining room table. They usually lasted 30 to 45 minutes. As mentioned before, all assistants sharing time and all core members, besides George, attended these meetings. Albeit George was invited to join various times, he often mentioned he didn't like meetings and having too many people talk. On other occasions, he did join meals and events with many people, talking and actively engaging in them. During the meetings he would thus wash part of the dishes, go upstairs or sit in a nearby room, even if it often seemed that he ear-dropped in the meeting and sometimes participated from afar. For example, one time during menu preparation time he screamed from the kitchen *"I want turkey tacos this week"* right when it was appropriate to share that.

House meetings were a chance for core members to speak out on how they wanted their week to go and on things they wanted/needed. During a meeting, for example, Alfred voiced his

need for toothpaste and shaving cream; right after the meeting an assistant took him at the store so he could get those. During other meetings, Jenna suggested going to bowling as house on a weekend or mentioned how she had a date with a friend from outside the community on a weekend night, which Ellen wrote on the calendar so everyone was kept in the loop. In other words, meetings were occasions to talk a bit about the practicalities, needs and desires of daily community life.

Meetings were structured so as to encourage core members to help plan the week ahead. During one meeting, for example, when core members were asked what they wanted to cook on their cooking night, Jenna said she needed time to think. After a certain amount of time, however, Jenna was reminded by staff that the choice needed to be made that night, as menus were created during the house meeting. In the end Jenna chose to make a pizza dish.

As house meetings became a house practice and Ellen kept practicing leading them, it became clear that some topics were not suited for a group gathering like the meetings were. During the first house meeting, for example, after core members voiced personal health items they needed (shampoo, toothpaste, etc.) Matthew said, looking down in a seemingly shy fashion, that he didn't know what he needed. Since Matthew always seemed to value his independence and easily responded to things in an "all is fine" or "I don't need anything" fashion, I got the sense that his shyness was due to both not being sure as to whether to admit he might have needed something but also to the fact that the approach of discussing personal health things in a group meeting was not private enough. He thus stayed silent. In subsequent meetings, however, he seemed more open and willing to share and Ellen also got to be more aware if particularly personal things needed to be addressed in a one-to-one fashion rather than in the group. One time Jenna hinted at this during a meeting in which she mentioned needing something but wanting to

mention it *"not in front of the guys, I don't wanna be embarrassed."* Ellen also invited her to speak privately.

Core members generally had a voice in the meetings and Ellen took turns in asking them one by one what needs they had, activities they wanted to schedule (besides those already "set" in the community calendar, like monthly community gatherings or doctors appointments) and what they wanted to cook.

Little touches, however, could have aided the meetings' accessibility. Albeit Ellen diligently wrote things that came up during the meeting on the big poster-sized house calendar (always kept on the kitchen wall so people could refer to it throughout the week), the calendar was close to her as she wrote on it, making it hard for other people around the table to see it and visualize what was written on it. Albeit all core members were verbal and most could read, some more visual supports could have been helpful.

d. **Physical space**

Serenity House is a three-floored house set in an economically poor to moderate neighborhood. On the second floor there is one living room, four bedrooms (one inhabited by an assistant and the rest by core members), a bathroom, and an office space. On the first floor is the kitchen, dining room, living room, a bathroom and three bedrooms (one inhabited by a core member and the other two by assistants). The house also has a basement with laundry machines, storage room and various supplies, as well as a very small backyard that is partly a parking lot.

On the wall throughout the house there are paintings, pictures of core members and various decorations. A set of big canvases painted with the help of core members to be put in the dining room was an idea that was being concretized during data collection. Ellen, who enjoys art,

had been wanting to paint and thought of involving core members to do artwork for the house altogether. Matthew was most interested in this idea and, together with Ellen, had a vision of how he wanted to create the artwork. Ellen: *"I think it's great he wants to take charge of a piece."* Other core members were asked whether they wanted to help with this project, but they declined, albeit they seemed interested in adding minor personal touches to it. The project was started, but not completed, by the end of data collection.

Being an older house maintenance needs came up periodically at Serenity House, and some "modern amenities" were lacking. George, for example, could get quite upset during warm periods because the house did not have central air and the heat bothered him. George mentioned he likes his room *"ice cold"* and that he'd prefer a central air system rather than the AC window units Serenity House provides to each room.

For the seven people living in the house the space seemed to allow for a moderate amount of living space, but at times people tended to congregate in specific rooms and the space felt tight. For example, it was quite common for assistants and core members to speak in the kitchen as a group while cooking or cleaning were happening.

The noise level at times was particularly high; some people spoke with a higher volume pitch and at times there were emotional outbursts that were easily heard throughout the house. This, for example, became a concern with Jenna, who sometimes spoke loudly by herself or screamed alone from inside her room. This at times happened late into the night, with the core member sleeping in the room above her complaining of staying up because of the screaming and the core member sleeping in the room nearby deciding to change to a room upstairs for more quiet. As Alfred mentioned, *"I am not mad about it, but sometimes [Jenna] gets on my nerves.*

At nighttime I have a hard time sleeping because of the screaming. I know she is working on it. It's real bad now."

Sometimes the house was relatively quiet. Before dinner, for example, it was not unusual to see Matthew on his iPad, Alfred doing some writing, George resting on the couch and Jenna taking care of her things. Also, at times, an assistant would meet individually with a core member, often in the living room, and "check in" with him/her as to how their day was. These were usually quiet private conversations and people respected that space, not getting too close and trying not to interrupt. One time for example, Matthew approached Michelle asking if they could have a check-in time and the kitchen was suggested as the place to do it since Jenna was crying in the living room. Michelle and Matthew found it important to meet in a quiet space.

C. **Community**

Referring to community has its challenges due to the different meanings people give to it. People, for example, often speak of "the community" as a person's social milieu (as in "the person works at a local grocery store and is thus integrated in the community"). L'Arche however identifies itself as a community of people coming together in a bond of friendship, living out the same identity and mission across its international communities. It, therefore, has its specific understanding of being a community. This too, however, doesn't completely define what a L'Arche community is either, which may be fine enough if the experience of community is understood as too broad and multi-layered enough for exhaustive definitions.

As an ethnographer I was not satisfied with only the "official" understanding of what community is in L'Arche, but wanted to know what community was in the world-view of the people living it, the informants: whether they chose to be in community in the first place, how they experienced its shared life components and what community meant to them.

1. **Choosing community**

In analyzing self-determination and community, a key question was: did informants choose to live in community in the first place?

Both core members and assistants mentioned that community was their choice. Overall, core members seemed to proudly claim the decision to live in community as their own. As Michelle said, *"Most of the time I get the feedback from core members that they really want to be here."*

Alfred wanted to move into L'Arche the very first day he saw the house. He said that he prefers living in community than in independent living and that he was the one who decided to live in L'Arche. He called L'Arche his home. When asked why he thought he became a core member at L'Arche he remained silent for a bit and then exclaimed with a smile on his face, *"I want to be one!"*

George too said that he decided to become a core member in L'Arche, re-emphasizing this was a decision of his a couple of times during the interview. He added, *"I really really really really really, five reallies, love it here no matter what, since I love doing fun activities – walking outside in mid to late spring and summer."* He mentioned how, "*I wanna be living here for the rest of my whole entire life."*

Jenna mentioned how her brother knew about L'Arche and how, *"I wanted to come, too."* This, however, was not a decision that she could only make once. L'Arche Southown, has a practice of asking each core member, during their community Anniversary Night, whether they want to commit to live in L'Arche for the year ahead. While gathering data, I was present at Jenna's anniversary celebration, attended by her community members, friends and family. Towards the end of the celebration, after people affirmed the gifts they saw in Jenna, Steve asked

her if she wanted to stay in L'Arche Southown another year. Jenna, who seemed in a playful mood, seemed to want to create some suspense, stayed quiet for a bit reflecting, and went to Steve to say into his ear, *"yes!"* At that moment people clapped and some danced, celebrating over the notes of one of Jenna's favorite pop songs.

Matthew was introduced to L'Arche by his father, who had read books by Vanier and who suggested the idea of L'Arche as a living option for him. Matthew was in favor of it, but L'Arche was not present in his geographical area at the time and he didn't want to go far from his family. At one point Matthew lived in an independent living setting with a housemate and occasional support. His personal assistant would come visit him only once in a while, unless there was an emergency. Matthew had a roommate there, but he wasn't there very much. The main time in which time they shared time together was during a dinner when Matthew first moved in. The setting was also located away from the city. Matthew didn't like spending so much time alone *"because I like to have at least a meal with someone. Because at my dad's house, in my family, we'd always have a family dinner together."* Albeit Matthew would make dates with friends to go out *"so I won't be in the apartment living alone"* it was lonely. He didn't want to live there anymore and told this to his father, to whom he'd go anyways to visit and share dinner with. Matthew eventually left and went to see other living options but, as he put it, *"I said 'no, I don't wanna go to these places, don't take me to these', don't send me to let's say [name of a campus-style residence in town] or other independent living places [in the area]."*

Once L'Arche opened not far from him, Matthew's father brought their interest to the community's director, who encouraged Matthew to visit the new community. Matthew thus visited L'Arche Southown: *"[I] didn't move in right away because they wanted to make sure this was my calling, and it was but. Then we did trial days where I'd come and join different events,*

come over sometimes for dinner (…) I came back and really wanted to move to L'Arche," which he did.

Staff mostly heard about L'Arche from different sources (volunteer organizations, books, word of mouth, etc.) and generally applied to L'Arche Southown for a one-year live-in commitment, besides Steve and Anna because of their live-out roles.

Michelle was connected to L'Arche through a European volunteer organization she contacted upon finishing high school. She was interested in doing volunteer work abroad, selected L'Arche, applied to it and was accepted.

Steve joined L'Arche because, he said, *"I felt more myself when I was there than any other places I have been. I felt accepted and welcomed. It was fun. There was always a lot of laughter, and yeah, fun things going on."* He said he also appreciated being part of a movement that was doing good for society, in a more revolutionary way than other traditional group home settings he had worked in: *"it just felt so right to live together in such a natural way."*

Whereas Michelle, who wanted to have a post high school volunteer experience abroad for one year, discovered L'Arche through a volunteer organization, Jane, Ellen, and Anna all heard about L'Arche through a personal connection. Jane and Anna through friends who were L'Arche assistants and Ellen through a family member.

Jane recalled how as she finished her undergraduate studies she was looking for a journey of growth and to *"get my feet on like the reality outside college before I start my journey of becoming a counselor."* She heard about L'Arche Southown from a friend who had been a live-in assistant there, researched more information about it online, and visited the community for dinner and a stay over. Jane: *"[I] had a sleepover, the dinner was delicious, I remember the laughs…that is important."* She mentioned how she found fascinating that people in L'Arche

tried to live together as a family. She eventually applied to join the community and was welcomed into community.

Paul gave up post-college career options (he was looking for teaching jobs) in order join community. Touched by his experience after visiting a L'Arche community, he said, *"'you know what, screw it, I am just gonna go to L'Arche.' First big decision of my life, and never regretted it. This was extremely a good decision."*

2. **Experiencing community**

a. **Sharing life**

I observed a certain mutuality and reciprocity in shared life between core members and assistants at Serenity House. Michelle tackled this when she said that assistants help core members a lot, but that also core members try to help assistants as well. She spoke of this as one of the great elements of community and recalled a specific example to support it: *"one time I came back with the van maybe around 10 or 11 pm and [Jenna] left the light on for me, she is like 'Oh yeah I left the light on so you wouldn't fall down the stairs' and those are just…little parts of it [community]…but I think it just shows community a lot too, that people are there for each other."*

However, there were also different power levels at play in sharing life together. Albeit L'Arche discourses emphasize mutual relationship of friendships as being at the heart of L'Arche, in practical terms assistants and core members have different "roles," and thus different power levels. The role of an assistant includes being a support worker, rather than simply being a friend living together with core members.

L'Arche terminology, however, is primarily not one of work but emphasizes the relational quality of the assistant/core member relationship. For example, in L'Arche assistants

are not merely working shifts to support residents, going "on" and "off" the schedule, but they rather share life with core members, sharing time with them and being on time away two days a week and for some hours during the day.

In their view of what sharing life meant, core members and assistants emphasized different aspects. Overall, they viewed sharing life as doing activities together, catering to persons' needs and being a part of each other's life.

George expressed how sharing life is about sharing passions. This was exemplified when he and I took a walk in the neighborhood and he stopped to watch a parked car he liked. He spoke to me about details specific to that car model, sharing with me his passion for cars. For Jane cooking together, doing fun things together and even having time alone, were first things that came to mind when she thought of sharing life.

Paul saw sharing life as seeing what the needs of people are and catering to them: *"for me it's encouraging and motivating to see someone who is like 'well, I wish I could have more time to have more fun' and then we go out to a movie or something. Or 'I wish I had more time to play piano' [Alfred] said, and I play guitar so let's have a jam session!'"* Thus, when Paul went to the movies with Jenna or played music with Alfred he was catering to their needs and desires, while being encouraged and motivated in the sharing of these experiences with them. On a similar note, Alfred said that to him sharing life at Serenity House meant talking to the people there and trying to help them. He thus saw himself not only as a receiver of support, but also as a provider of support. As he said, *"if somebody be down, they had a bad day, I talk to them, you know. Say 'hey, don't worry about it', you know."*

Steve took the sharing life concept beyond home life. To him sharing life with core members and assistants also implied sharing his own family with them and, he said, *"just being*

part of their life and allowing them to be a part of mine." Various times, for example, Steve has brought his wife and child to community events.

Steve was not the only one to share his family or to share from his personal life with the community. In the past core members have vacationed out-of-state to visit families of assistants, or assistants have welcomed their family members, friends and loved ones to visit and stay over at Serenity House. When Michelle's parents came from abroad and joined Serenity House for dinner, for example, George was excited to meet them and to talk about Michelle's father height. Jenna, instead, wanted to be pulled up by Michelle and her father because she wanted to play around.

Some core members' family members often joined community events and at times invited community members to their homes, as when Matthew's father organized a barbecue for the community in his backyard.

Besides the sharing of families, however, sharing of different aspects of one's personal life also happened on a daily basis at L'Arche Southown. Jenna and George often told assistants, and at times visitors, about their personal struggles, about the people they love, about difficult moments in her lives, and about their families of origin. At the same time they also asked assistants and visitors about their own lives, as when Jenna inquired with a visitor over for dinner as to why he did not have a wife, or when George asked male staff what type of razors they use to shave with.

Assistants generally shared with core members about their backgrounds, relationships and ideas; core members did the same. Personal life sharing, therefore, was something quite common in the life of the house. These conversations generally happened naturally, whether

around the dinner table, during walks, in front of the television during commercials, in the van or at outside events.

b. **Friend and/or staff?**

L'Arche discourses generally tend to emphasize the aspect of friendship. The assistant in L'Arche is both asked to be a staff person providing services to core members but is also invited to enter into relationships of friendship with them. Historically, in fact, Vanier began L'Arche as a response to the cry for friendship institutionalized persons with disabilities faced. The L'Arche philosophy grew out of that experience (Vanier, 2012b).

Looking at L'Arche Southown advertising material one can see many pictures of core members and assistants hugging one another or having fun times together. In one photo, an assistant looked smilingly at a core member as he embraces her, in another a core member danced in the kitchen with an assistant, and in yet another core members and assistants marched together at a disability pride parade. Images picturing such gregarious and affectionate scenes could easily be pictures taken amongst family or friends, rather than workplace photos.

I thus inquired with informants about the friend and staff dichotomy, intrigued as to what friendship meant for them and to how that was related to professional support at Serenity House.

Jenna made a clear distinct distinction regarding friendship and staff roles: *"Core members are my friends. Assistants are separate. (…) Assistants are trying to support me."* Even if Jenna didn't classify assistants as friends, she said that she can trust them. She mentioned feeling close to the assistants and admitted, *"I don't like when assistants leave, I want them to stay."* Out of the assistants she mentioned Michelle as being *"very special to me because I can trust her."* I have observed Jenna and Michelle going through different moments together (from food decision-making conflicts to having fun on outings together). Ultimately, when Michelle

left community, Jenna chose to put on her bedroom door a picture of herself laying her head on Michelle's shoulder. In the picture Jenna looked at ease and Michelle quietly pensive, showing a certain quiet friendly bond that seemed to have developed "through thick and thin."

George said core members are his friends, besides one of them whom he singled out as having a hard time with. In describing friendship George emphasized the importance of communication. He said, for example, that if Matthew is in the mood *"I say '[Matthew] can we talk about the here and now or general'"* and Matthew responds letting him know when he is ready to talk. Matthew generally seemed to have a calming effect on George and George described him as a good friend.

I have observed George communicating with his core member friends various times. One time the Serenity House van was returning after a celebration and George was sitting on the van's passenger's seat, while Alfred was quietly sitting behind him. George asked multiple times, *"[Alfred] are you ok? Are you ok?"* until he heard a response from Alfred that he was. He was communicating concern for Alfred. George often asked his housemates if they were happy or sad, wanting to relate and communicate with them.

Using the symbolic imagery of a bubble to describe levels of relationship, George mentioned that all core members are "*inside the bubble,"* like *"the core of an apple."* Assistants are there to help, however they are *"outside the bubble,"* because *"assistants come and assistants go."*

To Alfred assistants are both staff and friends. He said, "*friend is someone you trust…I don't see anything wrong with them [assistants], I trust them."* Alfred also saw friendship as relating to need: people needing one another. Matthew took the concept of needing others and called it companionship. *"Each of us needs companionship,"* he said. To him assistants are not

only staff, but also friends and family, even if not blood-related. He said family is *"where you get together, gather, have dinner together, visit one another, watch TV, play games."* Matthew mentioned fellow core members as being both friends and adopted brothers and sisters to him.

Assistants generally viewed themselves as both friends and staff to core members. Michelle said that role responsibilities were something she needed to do as part of her job, but that there was also an element of unconditional friendship in her relationships with core members. This element, however, differed from her friendship with people outside community. She said smilingly that when *"a normal friend of mine would get totally angry at me then I wouldn't just say 'ok, that's fine', I would probably be angry at those people."* It seemed with core members, however, Michelle did not take challenging moments of anger or nervousness from their part personally, as if she might have with intimate friends back home. *"I know it would not be helpful to get angry here at all (...) and I know it's like they don't mean it that way,"* she said.

Ellen considered herself both friend and staff to core members *"kinda at the same time"* – for example, wanting to *"hang out with them after work, or in between my work hours and stuff, like, I wanna go out and have fun with them."* However, she also mentioned having to perform administrative duties as part of her house coordinator role.

For Jane the friend and staff dichotomy is both exciting and challenging. She considered wonderful to *"play both roles: a friend – supportive, accept the person as is, letting them make decisions/mistakes, my role is to be there for them offer comfort - but at the same time this is a workplace – I have responsibility to give support in terms of finance, schedule, and maybe polite behaviors, mannerism in public, so that people would have more harmonic moments with each other."* The struggle with playing both roles, Jane said, came with the different attitudes and

behaviors these roles implied. Which attitudes to adopt when? Sometimes, she said, she even felt like a sibling to other residents. She wondered how other people would view her approach: "*is it more appropriate to be like a sister or an assistant?"*

Jane also mentioned how growth in friendship helped her grow in her willingness to be more supportive, for example when core members had an incident and staff sharing time might have been new. When she first started being an assistant, she mentioned, *"if someone else is around on duty I'll try to walk away if I think they are capable to handle it."* With time, however, she became more willing to be supportive in those situations. She related this change to the fact that *"care and friendship grow over time, I feel I wanna do this for people. The priority changed I guess [smiles]."* She pointed out the possibility that friendship can lead to greater support.

Paul, Anna and Steve tended to see themselves primarily as friends rather than staff. Paul said that even while doing staff chores the approach he employed was that of a friend wanting to help core members with their needs. It seemed that for him many things he did as a staff person were also things that a friend would have done for core members. For example, encouraging core members to work on a specific issue, as in the episode of encouraging Jenna to work on her weight loss and not buy soda. Paul said, *"even with a friend you'd be honest and say this is something you could work on. A good friendship is someone who is always willing to say the things you need to hear, even the tough things. So I bring that approach with core members and assistants, because I'd hope they'd do the same with me if I did something wrong or something else."*

Paul also mentioned the issue of shared living space as affecting relationships differently than in other jobs. In other work environments, if disagreement emerges amongst employees, the

latter can leave the workplace to go home and process. In a live-in community, however, assistants' workplace is also their home. This could be a challenge, but could also be an invitation to deal with conflict. Paul: *"We don't want to leave this on a bad note and have it affect relationships in the house."*

Anna saw herself as a friend to core members, but also mentioned that, as a live-out assistant, it took time to build trust and be in relationship. She recalled how *"the first months I felt more like someone that comes and helps out, now I feel more as a friend, especially with core members, because they are here since I came, assistants come and go."* Anna identified friendship as having the important values of loyalty, care and support. It seems she has demonstrated all three to core members: she has been the assistant that has shared time at Serenity House the longest (loyalty), she often saw needs and catered to them immediately with care (as when Alfred needed new personal care supplies on a weekday after dinner and they went to buy them to the store right away), and she supported core members by listening to them and keeping a calming demeanor even when core members might have been upset about something.

Steve said he didn't resonate with executive director language, preferring the term community leader instead. He said that in that role he thought of himself as someone with a responsibility to ensure fidelity to the mission of L'Arche while also hoping core members saw him *"as a friend, somebody they can trust, rely on and approach for trash bags or whatever else they need."*

c. **Communal spirituality**

L'Arche Southown identifies as a faith community and Serenity House communal spiritual practices were part of the daily life of the house. Throughout observation, before dinner there usually was a short prayer to bless the food, generally led by a core member

or an assistant, followed by a post-dinner candle-lit prayer. During this evening prayer, lights were turned off, the candle (an electric candle as George had mentioned not liking flames in the house due to safety) was passed from person to person and each person could pray intentions out loud, or remain quiet. The prayer ritual then ended with the Our Father prayer, with people holding hands.

Post-dinner prayer, Alfred recalled, was a practice that started right from the beginning of Serenity House, and was then carried on as a tradition. At a certain point however, for unclear reasons, it stopped. It is believed someone had stopped it because Alfred was praying for too long, but Alfred was not aware as to why it had stopped: *"I don't know. I really don't know."* He mentioned how residents were not asked before stopping this practice and he felt *"hurt. 'Cuz we need that in the house. We need that."*

Ellen said she heard stories from core members *"that they did a lot more with spirituality as a community, uhm, and then it kinda just stopped."* She felt that now spirituality was coming back a little bit at the house *"mostly due to the core members themselves…they have been commenting a lot how they missed after dinner-prayer."* She still felt that spirituality played more of a private role with core members than communally as a house.

Considering the general talkativeness of the house residents and the hustle and bustle that can accompany ordinary afternoons, during prayer an atmosphere of quiet prevailed. People seemed to pray from deep places, mentioning family concerns, world issues, things they needed help with, but also being grateful for happenings, relationships and experiences. There seemed to be an atmosphere or relaxation.

All four core members, when speaking about house spirituality, mentioned prayer. Jenna said prayer is important at Serenity House. To Alfred the prayer practice at Serenity House is of

value as well: *"prayer keeps everybody together. You feel good, you see. You eat, you say a prayer first. You are done, (...) we say another prayer. We hold hands. That's nice."* To him spirituality has space and should have space at Serenity House, a space he described as *"no fight (...) peace."*

Matthew mentioned prayer as a spiritual house practice but also mentioned the work of the community Spiritual Life Committee, comprised of three staff and three core members: *"The one where we meet and talk on how to make spirituality better at L'Arche."* George instead spoke of house spirituality as *"saying grace and doing check in."* In some way he enlarged the idea of spirituality to encompass also personal sharing between core member and assistant.

Staff generally had various opinions on the place house spirituality had at Serenity House. Steve and Anna saw it as having a strong presence. Steve mentioned it as a foundation for Serenity House, believing faith and spirituality to be *"a way to ground ourselves in community, so it teaches us how we belong, where we belong, to whom we belong, and from there we engage in this idea of sharing life together."* Anna, too, emphasized the importance spirituality has for the house: *"It is big. Takes a big role in the house."* She mentioned it as being particularly important for people like Jenna and Alfred to feel they can have time to pray and to have the space to do it.

Jane, instead, believed spirituality to be something that was not talked about much at Serenity House. She said people go to church with core members on Sunday, prayer is shared at the dinner table, appreciation is shown and religious holidays are celebrated, *"but I don't see much discussion going on in the home."* Michelle, too, said spirituality at Serenity House is mostly going together at church and sharing prayer.

Assistants accompanied Jenna in going to weekly Mass. Jenna is well known by the congregation at her Catholic parish, often greeting and interacting with them when there. She spoke to me with pride whenever she had a reading to do. Over a period of some weeks Jenna would miss Sunday Mass. It seemed a cause for this was that she went to bed late and was tired in the morning. Assistants were not aware at what time she went to bed but encouraged her to go to bed earlier, which she eventually did. The practice of attending church on Sunday then resumed. Matthew often joined for Sunday Mass as well.

Alfred, instead, usually went alone to his church, but has invited assistants from time to time to join him. During data collection he invited Michelle to join him before she went back to Europe. In the past his church's pastor was also invited to visit Serenity House. George, instead, used to be an altar boy in years past while at Serenity House and even chose to get baptized, but as the years went by he decided not to go to church.

3. **Meaning of community**

Grounded on their experience in community, how did informants see community? What meaning did they give to it? During interviews, I partly explored this by asking for the difference between group and community. Considering L'Arche is different than group homes because of its community element, I was intrigued by how its residents viewed community in comparison to group.

Core members' responses varied from thinking that *"it doesn't matter either way, [group and community] are the same thing"* (Jenna) to not knowing if there was a difference (George). Matthew took community life "as a given," mentioning that a community is different than a group because in "*community you live together as a community. A group is just a group of*

people that might not even live together and a group is where you go out and hang out with a group of friends, but a community base is more community life."

Alfred emphasized quality of care as well as welcoming people and sharing specific activities with them as that that differentiates community from group. He said, *"us you meet people every day, and they have a home here, and we meet people every day, community night sometimes, we eat together, we pray together, people come over and we eat with them, they eat with us. That's how I see it."* Community talk, in fact, can sometimes be insular – focusing on what residents do in the homes and how they treat each other – yet Alfred's understanding of community as providing a home for visitors that might join as guests for dinner or come to one of the monthly community nights open to all broadened the horizons of community as something that far extended residents or community members to include people "outside" (friends, guests and visitors). In regards to care, Alfred was also aware of group living environments in which people with disabilities were treated badly. Alfred: *"Yeah, there is a difference. Here [L'Arche Southown] fine, but if somewhere else maybe the people don't treat the right way,"*

Assistants' responses as that which differentiated community and group emphasized commitment to a mission and emotional connection. In regards to mission, Steve mentioned not being interested in being the director of a group home as it is not as mission oriented as L'Arche is: "*I think we are doing something important very very quietly (…): witnessing to peace, recognizing the value of people (…). I think there is a certain element of growth in being together in diversity."* Paul noted that in a group *"you just meet with the people to meet up (…) but in community there's a foundation of life."*

Jane and Ellen shared an understanding that a group of people could have a goal, but that community added an emotional connection between members to that. Jane gave the example of

people in a group sharing common goals like cleaning city water, supporting feminism or feeding the poor, but lacking the emotional attachments that one could find in community. Ellen highlighted this too when she said that in social clubs/groups she was in people worked together for a certain goal but *"we don't all mourn together."*

Being a group and being a community are not necessarily opposites, according to some informants. Paul mentioned how the two realities might be combined but that ultimately they are separate. Jane mentioned that a group could become a community once emotions (and conflict!) became part of it, in a spirit of friendship. According to Ellen, instead, both groups and communities can have a certain individualization – or focus on the individual – but community sheds light on what is happening in a spirit of togetherness. She mentioned how a group could be symbolized as *"many bodies walking together to a common goal"* and community as *"one body made up of many parts."* Even if people did not physically live together in community, they could still live togetherness by the sharing of their experiences.

Michelle mentioned an understanding of community as a place of both choice and "non-choice," which differentiates it from a group: albeit you can choose community, Michelle mentioned, you don't necessarily get to choose the people in it. She said that *"you choose which group you are hanging out with…mostly people at your age (…) and, we are like, everybody just gets together pretty well but in the end of the day you just go home and you don't spend like all day with them."* In a community like L'Arche, however, Michelle mentioned that different people are *"mixed together in one house and then it's like 'ok, now we get along' and you somehow have to figure out how to get along with the differences."* To her this encounter of diversity can be great because people can learn from one another and be like a family. Jane too had used family imagery to describe independent selves and community.

Albeit these stances tackled the difference between group and community, I was interested in a thicker sense of what community meant for informants, so I inquired directly as to what community meant for them.

Alfred maintained his outlook of outreach towards others, describing community as *"friends, meeting people, I go places, I talk about L'Arche."* For George too community was about making friends and *"living with people my own age, with people with and without disabilities,"* while Matthew said that to him community meant *"where everybody lives together, and try to get along with everybody."* For Jenna community meant, *"to understand our feelings"* and spoke of having particular tasks (like cooking).

For Michelle community was about helping each other out and doing things together, while fighting for the same things. An example of this, she mentioned, was when Serenity House residents chose together what new furniture to buy for the house, all giving input on it so that, as she said, *"it wasn't only like one person that made the decision – 'ok, we are going to do this' – but the whole house really wanted to."*

Some informants spoke about the meaning of community using images. Paul was reminded about the meaning of community from a core member who mentioned to him that community was like a prayer. Paul saw prayer as coming in different shapes and forms: it can have different interconnected styles (silent, chanted, repeated, musical), tones (happy, angry) and results. Community too has that element of inter-related diversity. Paul also saw an orchestra as symbolizing community: composed of people in different roles playing different instruments, an orchestra can inspire people if all play together beautifully in synch. Jane, instead, pictured community as a family: different people comprising a single unit, solving problems together, and rejoicing together.

All informants emphasized a sense of togetherness in their understandings of community. All of this was matched by observation, as we have plentifully seen through this study. Jane, however, also specified challenges relevant to community: conflict between persons and challenges related to personal space.

In regards to conflict, we have seen in this study conflict situations involving food choice, presence at community gatherings and choosing activity options. Jane mentioned how when conflict happens in community, forgiveness can happen too. She said that in community *"by the end of the day everything was wrong, but we are sitting down having dinner together. That was a good dinner. That's soothing, comforting."* Most times, Jane mentioned, *"people would forgive you for mistakes made and conflicts created."*

In regards to space challenges, I noticed Jenna often replying *"I don't wanna talk about it"* to people asking her questions or I have seen George seeking places in the house where he could be quiet and alone because, as he often said, *"there is too much noise"* wherever people gathered. Matthew and Alfred complained multiple times about Jenna's screaming heard from their bedrooms and disrupting their sleep. These were all different ways of needing and/or asking for space. Jane mentioned how in community people share life together partially, not entirely, and how they can still feel lonely but not alone, as people do things together: "*sometimes when people live so closely, I want to be private about certain information. Not so much about my emotions, but my outer social life, how can I keep it to myself. Like, I am a private person, I don't always share everything about me with people, but when you live together it's like lady talk, or friends talk, and they wanna know about it and I sometimes don't tell people everything"* (laughs). Community, therefore, even if it had a meaningful sense of relational closeness and practical support, was not without its shares of challenges.

VI. DISCUSSION

Presented in this section will be a general summary of the results, together with conclusions and theoretical insights that have emerged through this study. These will be followed by study limitations, reflexive reflections on my role and suggestions for further practice/research.

A. Summary of Results

This ethnographic study examined the relationship between self-determination and community life in adults with ID living at Serenity House, a residence of L'Arche Southown, a community where core members with ID and assistants/staff are invited to live together in a spirit of friendship and belonging. It was clear in the study that core members' self-determination's was intertwined with their communal relations with assistants. I analyzed it through interviews, participant observation and material resources, with both core members and staff as informants.

In short, core members proudly reported making their own choices in community, with observation and interview data highlighting how their choice-making in community was often influenced by staff and other factors (personal spirituality, community practices, agency responsibilities, physical space).

Firstly, this study opened up the "self" of "self"-determination, and located core members' self decision-making and communal living experience in their personal historical contexts. It became apparent through the study that all core members reported experiencing some form of rejection, violence or oppression at some point in their younger years, whether through friends/acquaintances or family members (Alfred and George with family members, Jenna with people treating her the wrong way as a teen, Matthew with a bully who threatened to kill him).

Assistants/staff did not report such rejection or violence, but generally reported feelings of loneliness or a sense of "being different" than the surrounding population (Ellen not talking and not having many friends in high school, Steve feeling that he didn't fit in any specific mold, Paul reporting not feeling loved by his parents, Anna recalling being neglected as a little girl). Of course informants also reported happier family moments and positive peer relationships, but a feeling of rejection at some point in their early lives seemed to be shared by most. At the same time, informants also reported choosing community and wanting to be in it. Core members reported wanting to be core members in community, away from isolation or institutional-like settings, and assistants chose to be in community generally attracted by the relational richness and loving context it implied. It is not the place here to enter into an improvised psychological analysis of each informant to see if their choice for community was influenced by feelings of rejection at a younger age, but it is a reasonable assumption that these two realities may not be too separate after all.

Core members generally did not strongly identify as persons with disabilities and all mentioned making their choices in community. Staff, which had nuanced understandings of disability (mentioning social and cognitive components), generally viewed themselves as supporting core members to make their decisions. Thus, core-members self-understanding seemed to be one of being decision-makers, and staff to be one of support to their choice-making capacity. Within this, however, there emerged a multi-layered complexity in the decision-making process.

Two relevant decision-making elements emerged highlighting the multi-layered aspect of decision-making within community, namely that of option availability and that of finding compromise. In regards to the former, core members generally had options to choose from and

staff generally sought to support this availability. They generally did so in five ways: 1) asking core members to choose between two things, 2) trusting core members to find options from their own past experience, 3) providing core members with new options, 4) increasing options through external resources, but at rare times, and 5) focusing on one option only.

Choice-making out of an array of different options, however, was only part of the core members' decision-making process in community, which was not simply about an individual choosing one or more options that he/she liked and wanted but also about putting one's decisional process in dialogue with that of others, taking into account staff support limitations, other residents' needs and wishes, as well as community influences. Compromises, therefore, often needed to be found. This usually happened in four ways: 1) finding a happy medium amongst different options, 2) postponing option-gathering and decision-making, 3) catering to different options at different times, and 4) coming to clarity as to what options are feasible and to what options aren't.

Two of the core members considered assistants both staff and friends and two highlighted their staff role, while assistants viewed themselves as both friends and staff to the core members. It was clear that the shared living arrangement, the mutual sharing of life (time, space, family, inner experiences, spirituality, sorrow, and fun) as well as the emotional connections amongst core members and assistants, was not always easy to navigate but provided a rich communal context within which to locate core members' selves and their self-determination.

B. **Theoretical findings**

I will now present how this study's research findings, in dialogue with the existing literature on self-determination, challenge, deepen and expand current self-determination theory. I propose that: self-determination is not only about conscious volition but also about

unconscious dynamics and expression; the "self" in self-determination discourse might be better framed as "self/other"; the emphasis on the autonomous individual should be challenged by a focus on interdependence; the self-determination of persons with disabilities should encompass a study of the persons without disabilities they are in relationship with; having too many options to choose from is not necessarily a positive element of self-determination; and levels of privilege and power relations between persons with ID and staff need to be recognized so as to inform a more critical understanding of mutuality in community.

1. **The role of the unconscious**

Self-determination has been presented in research as a psychological construct that refers to people acting volitionally, basing themselves on personal will, with volition understood as the capacity of making a conscious intention, decision or choice (Loman et al., 2010; Wehmeyer, 2010). Data from my research, however, brings to question this emphasis on consciousness, expanding the understanding of volition to the unconscious, a place in choice-making that is active yet deep to the point of people not being aware of it.

Until recently science and philosophy have often emphasized mental life as an entirely or primarily conscious phenomena; suffice to remember here Cartesian “I think, therefore I am” and Lockian “mind first” cosmology (Bargh & Morsella, 2008). Within the realm of psychology, motivation theory has generally emphasized people’s actions being motivated by rewards/punishment (instrumentality), inner and external needs (content), as well as expectations, comparisons, and goals (process) (Armstrong & Taylor, 2014). Without discrediting conscious mental life and motivating factors, in recent years a large body of research has documented that much of mental life, including cognitive, affective and motivational processes, is unconscious and that this impacts judgments and behavior (Westen, 1999).

Bechara and Damasio (1997), for example, have concluded that people (without prefrontal brain damage/stable focal lesions) have a covert system in their brains that draws upon emotional memories. This, activated long before people are consciously aware that they have decided anything, suggests which decisions are advantageous and which are not. Most of the time, such emotional memories are covert and influence decision-making at an unconscious level. Some have even theorized that the conscious mind is not the source or origin of behavior, insofar as impulses to act are unconsciously activated and consciousness then acts as a gate-keeper (Gazzaniga, 1985; Libet, 1986; Wegner, 2002).

Unconscious processes may be defined in terms of their unintentional nature and inherent lack of awareness of triggering stimuli (Bargh & Morsella, 2008). Unconscious forces influencing behaviors may be various: organized mental products (phantasies, for example), derivatives of repressed drives, unconscious body images, infantile representations of parents, repetitions of early patterns of relationships, and defense mechanisms to name a few (Ward & Zarate, 2000)

In this study, data that brought to the forefront the need to take the unconscious into account was particularly the one related to George. Within community, George spoke often and clearly about wanting to be with people that didn't speak with angry voices, which reminded him of his father, whom he reported as having an angry voice and getting upset at times with him when he was little. George did not like that and to this day the memory seems to still influence whom he chooses to be with, and the approach he wants people to have – and not have – towards him. George, on the other hand, enjoys his mom's gentle approach and generally tends to be attracted to older comforting "mother-type" women, as he seems to consider them. This choice of being with certain people rather than others seems to mirror his parental images, their

projection on others and a repetition of early patterns of relationship. It is not surprising that when incidents happen George prefers to speak only to his mother and does not want to hear an angry voice. As much as George may consciously freely decide who to speak to or who to be with during his days in community, it seems that the unconscious influences that orient him towards certain people with particular characteristics, and away from others, cannot be underestimated if we seek a more complete and layered understanding of self-determination.

Another example is that of core member Matthew. When he was younger Matthew experienced bullying – even a death threat from someone. Today Matthew doesn't identify as someone with a disability. Matthew at times seemed to side/try to relate more to assistants than with core members. Whether it was about reminding people in the house of their routines and schedules (usually a staff task), emphasizing what he did as different from other core members (for example, taking the train or going abroad alone), or standing his ground if staff tried to encourage him to do something (as when he seemed irritated when I encouraged him to put a band-aid over his bloody after-shave neck stain), I wonder how much his experience of being bullied has unconsciously influenced him in detaching or distancing himself from those things that remind him of having a disability (receiving support, experiences shared with other core members, etc.).

If just seen from a conscious volitional lens George's opting to be with a certain typology of "mother-like" people may simply be seen as a personal preference, while Matthew's "distancing" himself from disability/core member identity an individual identity choice. However, George's past childhood experiences with family and Matthew's experiences with bullying, and their influence to their current so-called "self-caused actions" are missing in such framework, thus limiting the understanding of self and impoverishing that of determination.

Unconscious motivation does not mean that the person is always unaware of the sources of his/her behavior. In some instances, for example, George was vocal about not wanting to be in the company of people with angry voices and also reminiscing of his dad using an angry voice. These connections, however, sometimes did seem more "instinctual" and less consciously "connected" - at least in his verbalized thinking - when decision-making happened. This could be understood as a form of tacit knowledge motivating behavior, tacit knowledge being an element of unconscious motivation (Safran & Kriss, 2014).

There is another way in which this study's results pinpoint to the unconscious. The core member informant with the strongest disability identity was Jenna, who was also the core member who wanted to attend advocacy conferences. Might her strong disability identification, if not "disability pride," not only be an influence of her attendance at advocacy conferences but also an unconscious expression of a desire for more of that advocacy spirit in her own community experience/outside life? In other words, unconsciousness need not only be understood as a hidden motivating force in decision-making, but also as a way in which needs and wants are expressed (even if the person might not be fully aware of them) through the decision or behavior itself.

This study suggests framing self-determination not simply as stemming from a conscious choice, intention or decision, but also from unconscious dynamics, influences, needs and desires, often made manifest by the person's decision or behavior itself.

2. **From self to self/other**

Self-determination presupposes, as the name implies, the existence of a self that acts as a causal agent. What is the "self" self-determination refers to, however? This is not very clear in the self-determination literature, which generally seems to equate self with an

individual or a person. These concepts, which seem obvious, need to be problematized into a richer and more nuanced conceptual framework.

Historically the self has been subject of great philosophical inquiry. It is not the aim of this paper to summarize centuries of thinking about the self, but suffice to say that "selfhood" has been given different meanings across time and places. For example, there has been a Kantian way of seeing the self as an abstract transcendental pole of identity behind all experience; there has been a 20th century understanding of the self as the constantly changing result of a narrative construction of identity (see for example, the work of Paul Ricoeur); there has also been a phenomenological understanding of the self as a dimension that is already implied in any kind of experience (Engberg-Pedersen, 2008).

What is most relevant to this study, however, is the self as located in community. We have seen how in community selves are in constant relationship. Core members and staff come with different histories, experiences and understandings, bringing those to their interactions with others. Within their relationships, personal choices are made and compromised, some options are given and others are taken away, deep emotional connections are made and personal ties built…the influence people have on each other cannot be under-estimated. We have also seen how selves and personal decisions were influenced by other factors that shaped informants' lives: from spiritual beliefs to physical space, from community traditions built through time to outside networks. In other words, selves were influenced and shaped by otherness.

How much has the approach assistants employed in supporting George (for example, using or not using soft voices) influenced his decisions? How much has staff approach to soda intake influenced Jenna's understanding of a healthy/unhealthy self but also of herself as causal choice-making agent? How much has the freedom Matthew was given in traveling abroad alone

empowered him to make other similar choices? How much has Alfred's belief in what he calls *"the man above"* but also his troubled childhood family history shaped his outlook on living communally? I am pinpointing here to something that has emerged constantly through the study: the self as a causal agent is not isolated but is in a relational dynamic with others. It seems influenced and shaped by others; it is relational. This, of course, is even more obvious in the practical examples shown in this study: many core members' choices (going to the movies, going to buy soda, deciding what to cook, etc.) wouldn't have been possible if staff did not support them. At the same time, core members' choices influenced assistants too and their choices (whether to go to the movies, to accompany a core member to buy soda, to attend city events, etc.). Thus self-determination happened in a profoundly relational context, impacting both core members and assistants. The processes we have explored of option-making and compromise in core members' decisional process clearly exemplified this inter-personal aspect of self-determination within community.

Moving beyond individualistic understandings of the self, Battaglia (1995) discusses the self as a representational economy. Selfhood could thus be understood as a product of "mutual entanglements with other subject's histories, experiences, self-representations; with their texts, conduct, gestures (…)" (p. 3). On a similar note, Mead (1962) redefines the "self" as "self-other," presenting it as a product of social interaction and not as the precondition (logical or biological) of that interaction. Marcus (1995), instead, argues for the eccentric self as a performative and unself-conscious response to social conditions.

Battaglia, Mead, and Marcus might emphasize understandings of selves as social products to an extreme (in stark contrast with more essentialist understandings of it), but this study suggests that understanding the self by locating it, at least in part, in its social dynamic and

relational plasticity is important. It thus expands the individuated (differentiated) understanding of the "self" in self-determination, without denying its value, to a relational understanding of the self, almost to the point of speaking of a "self/other determination," emphasizing how mutual encounter impacts both single agents and their decisions.

3. **From self-autonomy to interdependence**

Closely related to expanding an understanding of the individuated self to a relational self, data challenges the concept of self-autonomy. Within self-determination theory, self-determined behavior has been related to the person acting autonomously (Wehmeyer & Bolding, 2001), with a functional focus on how personal actions enable the self to act independently (Wehmeyer et al., 2011). Such an individualistic understanding of autonomy needs to be problematized.

As exemplified by simple ordinary examples in life at Serenity House, for example in the support core members received from assistants (as when George compromised to go drink soda with others at McDonald's, driven by an assistant) and in the support core members gave to assistants (as when Jenna left the lights on in the stairwell for Michelle so she didn't have to do that when she got back home in the dark), autonomy was embedded in social relationships, which shaped choice. Thus, George chose to buy soda at McDonald's, but had to reach that choice through taking into account others' choices and compromising, coming up with a different choice than the initial one (going to buy soda at a store). Michelle came home and needed to turn the lights on so as not to walk in the dark, but she didn't even have the option to choose to do so as Jenna had already caringly left the lights on for her in the first place. In other words, informants' choice and actions did not exist in an autonomous vacuum, but were

relationally embedded, interdependent on others' influences (input and reactions), choices, supports, and needs.

The story of Matthew, who lived in an independent living setting and then chose community because he felt lonely there, as well as other informants' experiences of support and friendship in community, also brings to interdependence an element of emotional and relational quality. Vanier seems to touch on this when he wrote, "Today some people idealize people with disabilities when they find autonomy, live alone, look at television, and drink beer. Autonomy can be good to a certain extent, but in our community a number of people who wanted to live alone fell into loneliness and alcoholism. The problem was not that they lived alone but that they lacked a network of friends. It always comes back to belonging." (Hauerwas & Vanier, 2008, p. 37). Such a framework brings together autonomy - aimed for by the political advancements of the deinstitutionalization/disability rights movement - within a communal framework based on friendship. Friendship, however, should not be forced, and core members' responses in this study show that not all core members identified support persons as friends. Vanier wrote of how people can choose their friends, but "in our families, we do not choose our brothers and sisters; they are given to us. So it is in community life" (Vanier, 1989, p. 46). Such a vision seems to allow an understanding of staff that is not necessarily embedded in friendship discourse. Yet at other times, as noted before, the element of friendship is given greater emphasis within L'Arche. This "staff as friend" issue seems to be a gray area that, as informants' responses at times hinted at, can be a concrete struggle. In any case, whether the relationship between core members and assistants has the deeper emotional tones of friendship or the more professional tones of staff services, or a mix of the two, the inter-connection between the two agents remains.

Shifting from an autonomous understanding of self to a relational one is closely related to a feminist understanding of autonomy. Feminist theory has criticized Kantian and Rawlsian accounts of self-autonomy, deeming them "atomistic," abstracted from the social relations agents are embedded in. Such understandings are associated with claims that autonomous agents should be self-sufficient, a notion that is at the core of the "self-made man" (Stoljar, 2015). Feminist theory has re-conceptualized autonomy, to the point of calling it "relational autonomy": emphasizing care and interdependence but also highlighting agents as being socially and historically embedded and influenced rather than being isolated (Mackenzie & Stoljar 2000; Stoljar, 2015).

Loman et al. (2010) do bring in the idea of interdependence in self-determination specifically as related to proxy agency, but at the core of their analysis the understanding of the agent still seems to be individualistic. They emphasize how an individual agent can act to influence others and how this does not signify dependence on others. This understanding of interdependence, however, is very limited: it still focuses on the solo individual enacting choice and influencing others. This study has pinpointed to a more mutual influence between social actors, one in which decision-making is a process influenced by a to-and-fro dynamic that includes but goes beyond the individual. In short, an understanding of autonomy as interdependent and relational seems to greatly enrich and help contextualize self-determination of persons with disabilities beyond the emphasis on an individualist understanding of autonomy.

4. **From disability to dis/ability**

In this study persons with disabilities were studied together/in relationship to persons without disabilities. Both were equally important informants. After all, at the core of L'Arche are people with and without disabilities that are invited to live together in relationships

of belonging; if one seeks to study the thoughts, behaviors and actions of core members he/she might do well to study those of the assistants as well. This is simply because of core members' and assistants' shared life and the mutual influence they can exhort on each other.

This research choice is not far from the relational premise that some feminist philosophy has contributed to modern scholarship, helping to analyze social differences in relation with each other rather than as separate from each other. Strathern (1995), for example, speaks of the difficulty in understanding the lives of women without also understanding the lives of men, and vice versa. In this research, how could we study persons with disabilities/core members without studying the persons without disabilities/assistants they were in constant relation with?

This relational with/without disability dynamic was present into the very fabric of the study. Albeit the study focused on core members' self-determination I gave great attention to assistants' experiences and behaviors as well, observing how the two interacted together and what came out of the interactions. Assistants were therefore not just included in this study as a contextual background, but as agents, together with the core members, that influenced particular self-determination dynamics in the latter. In the above-mentioned instance of George compromising to buy soda at McDonald's, for example, both him, house coordinator Ellen and other core members were involved in the decision-making process, within particular power dynamics (George wanted something, core members had a wish different than George, Ellen was staff and could drive people). How to divorce George's choice from Ellen's?

We can also see, however, another way in which ability and disability are in relation to each other. Ellen, a staff with "the power of the keys," could hypothetically have chosen to go wherever to get soda (store, McDonald's, somewhere else). George, instead, relied on Ellen's

support and choice to enact his choice. He did not end up going to the market to buy soda, but did end up going to McDonald's to buy it with others. He was thus "disabled" from going to the market (not enough support for it), but was later "enabled" to go to McDonald's and get the soda.

This study not only showed that core members are welcomed in L'Arche because of their disability diagnostic status, but its findings also pinpointed to a broader contextual understanding of disability, a critical framework of disability social constructionism, by which disablement is a creation of ability. Such understanding of disability is historically sound – disability, in fact, may be understood as a social construction produced by ableist medical and statistical realms of power (Davis, 2006). Clinical IQ diagnostics, liberal self-made notions of personhood, inaccessible environments, ableist hegemonic cultural norms, and other socio-cultural elements have disabled people that, through time, didn't meet certain criteria of normalcy. These powers have thus created (or at least shaped, so as to avoid fundamentalisms) disability. May we say disability might best be written as dis/ability, if they are two sides of the same coin?

I propose that studying the self-determination of persons with disabilities should be done, as much as it is appropriate, by also exploring in depth the persons without disabilities (staff, employers, friends, family, etc.) that they are in relationship with as they make choices, noticing disabling and enabling influences the latter exert on the former, and how the two should be understood as being in relationship rather than as separate entities in the creation of personal choice.

5. **A plethora of options?**

Loman et al. (2010) suggest that one of the dimensions of self-determination consists in an enriched environment where a person is exposed to a range of opportunities that

encourage “a plethora of options” (p. 8) for him/her, rather than an other-prescribed range of opportunities. Matthew’s case, however, is exemplary of someone who, when facing many options, might feel anxious and “lost.” In the case of the menu-planning instance in which Ellen had to help direct or narrow the options for Matthew, he was speaking a long list of food specifics that seemed to stem from food anxieties and not simply from a free personal choice. George, too, who enjoys structures and order, seemed overwhelmed at times when too much was proposed to him. These instances seem to be confirmed by research.

A study on choice done by Iyengar and Lepper (2000) appears to challenge the notion that having more – rather than fewer – options or choices “is necessarily more desirable and intrinsically motivating” (p. 997). The researchers had two people dressed as store employees with two tables for display, one displaying 6 jams and the other 24. They switched the tables every hour so customers would encounter either one throughout the day, and be given the option to taste as many jams as they wished together with a coupon. The customers had to go to the jam aisle, where they’d be exposed to all varieties of jam, to select one for purchase. Albeit the large display table of jams attracted more customers than the smaller display, only 3% of the people who had gone to the larger display ended up purchasing a jar; 30% of the people who went to the smaller table picked out a jam jar and bought it. The researchers concluded that having unlimited options can lead people to be more dissatisfied with the choices they make (Iyengar & Lepper, 2000). What is more important, having more options to choose from but being dissatisfied or having less options but being satisfied?

Sweeney (2011) notes that having too much choice appears to impair decision-making possibly because extra choices force the decision-maker to put forth greater mental effort, which may be seen as not worth the gain. Albeit some choice is good, Sweeney claims, too much of it

isn't, as it causes psychological pain to the point that even the pleasure of making the best choice may not negate the stress, expenditure of mental and physical energy, and potential regret of decision-making.

The findings from this study, together with research on choice, suggest that, rather than being exposed to a plethora of options, self-determination can also happen (without unjust restriction, of course) with a limited number of options. This, with help in developing better options and receiving more information on specific options, may also be more satisfying, or at least less anxiety-provoking for the person making decisions.

6. **The shadow side: Privilege and power differences**

As much as the vision of L'Arche emphasizes mutuality and belonging (L'Arche USA, n.d.a), through the study it became apparent that community had a "shadow side" that unsurprisingly did not explicitly come up from informants' interviews, but was clear in observation and reflection. Staff and core members were on different privilege and power levels, both in their personal histories and in their community roles and relationships; this affected their life together. It is important to examine and recognize these imbalances so as to inform a more critical understanding of mutuality in community.

Lee (1991) notes that right at its inception L'Arche was founded by a man whose personal circumstances enabled him to choose for L'Arche: Vanier was the son of a wealthy Canadian diplomat, received college education, was a naval officer, and was part of different Catholic communities before founding L'Arche. Albeit I found Lee's criticism to be exaggerated and crass - "The wealth enabled him [Vanier] to decide that he ought to live with and like the poor (…) some might see it as the self indulgence of a 'poor little rich boy'" (Lee, 1991, p. 74) - he highlights elements that are relevant to critically analyze power differences within L'Arche.

In our study at Serenity House, staff seemed to have greater overall opportunities and options in their lives than core members did, possibly due to different privilege levels. Besides the difference in roles (assistants, with the support responsibilities the role implies, and core members), almost all staff had college education – if they didn't have one they were planning to have it after their L'Arche experience; core members, instead, had less educational options. Many assistants also had various opportunities for travel before deciding for L'Arche (some were assistants in other countries/states, one came from abroad through an international volunteer program); albeit core members had various travel experiences, they were less tied to living/professional opportunities. During their stay in L'Arche employed assistants received a stipend, which was modest but still higher than core members' work salaries. In addition, as much as core members were given the choice as to whether to continue living or not in L'Arche Southown, their living options as persons with disabilities seemed much more limited than those available to staff, which after a year of living at L'Arche could potentially find other living arrangements easily.

These differences also shaped informants' different power levels. It would be reductive to claim that at Serenity House shared life happened between equals. Although core members and staff did share a certain equality in their living environment and shared life qualities, there were clear power differences: assistants ultimately had a gatekeeping authority that core members did not have. Such power was not always overt, but was embedded in conversations and relationships between staff and core members.

The religious element, for example, has been very influential in the development of L'Arche. L'Arche has seen inter-religious and multi-cultural expansion through the years, and practices such as prayer before meals or religious celebration gatherings clearly denote how the

religious aspect is embedded in its communal life. Assistants do seem to have greater power than core members, though, in the implementation and continuation of such practices. Alfred mentioned how hurt he felt when a post-meal prayer tradition was stopped without him knowing why.

Data also shows that as assistants tried to support core members in their different life areas, at times they sought to influence core members' decision making to the point of persuasion (convincing them to take a particular action). This generally seemed to happen through negotiation - reaching an understanding between the parties (Taylor, 2013) - but such negotiation seemed to weigh more heavily on one side: facilitated by their role/position in the community, assistants could easily persuade core members to choose a particular option over another.

Let's take as an example Jenna's soda-related instances with Michelle and Paul. When Jenna and Michelle discussed going out to buy soda, Michelle clearly reminded Jenna of a promise Jenna made to buy a limited amount of soda (*"If we make promises we should stick to them,"* Michelle told her) and how she was *"afraid that in a few months you won't be able to get in car anymore if you gain weight."* In a similar instance, Paul reminded Jenna of health concerns over soda intake and that he needed to watch his own weight too. "*When I am with her I have this guilty pleasure of getting pop if she gets pop,"* Paul said. Both Michelle and Paul seemed to use persuasive tones to encourage her not to buy soda; their decision was not to accompany her to buy soda, and she didn't buy it. After all, she couldn't leave the house without support.

These episodes relate to findings from Antaki, Walton, and Finlay (2007) investigating how, in another residential home setting, staff proposed activities to residents. Albeit in our study

Jenna and staff's instances deal with health-related choices and Antaki et al. (2007) focus on outside social activities, the dynamics at play are similar. In their research they have noticed how staff generally introduced outside activities to residents minimally, possibly mentioning their intrinsic attractions, and at times associating the activities with a given individual. For example, one staff member asked a resident, *"...there's a concert next week (...) Do you want to go to the concert next week with Bill?"* (Antaki et al., 2007, p. 402). The staff member did not mention the type of music of the concert but only that Bill was going to the concert too. In another example, one staff member told a resident who did not want to go to a meeting: *"...what about the other people there that like you (...) they'll miss you"* (Antaki et al., 2007, p. 404). The authors suggest that such ways of asking questions and communicating with residents with ID emphasized activities' social aspects, mobilizing the residents' social obligations, sense of community and the feelings that go along with it. Might this considered persuasion (or subtle coercion)?

In the episodes involving Jenna, Michelle told her multiple times that Jenna had promised her to limit soda intake and Paul brought his own personal weight concerns and challenges in negotiating with Jenna. They both related Jenna's wanting to go buy soda not only to her own health, but to themselves, trying to discourage her from buying soda and buy something else instead. Such interactions could be seen as episodes in which staff had Jenna's interests in mind, encouraging her to be healthy and to keep her promises, or they could also be seen as episodic acts of domination or coercion, in which power is wielded by staff with the excuse of a "regime of truth" (in this case, the importance of health) to enforce on others (Foucault, 1998).

This is consistent with McDonald and Keys (2005) conclusions that "when core members make decisions that assistants consider to be poor decisions, the lack of power of core members relative to assistants may emerge and be used to limit core member's control over decisions […]

The seemingly good intentions of assistants grounded in a desire to share life and maintain the safety and well-being of core members, nonetheless reduce core member's opportunities to make 'risky decisions' (Perske, 1972) by using relationships with core members to control undesired activities" (p. 22 - 23). Interestingly, however, informants did not bring such issues up, even if they were very present in the life of the house, possibly because it is a shadow side challenging more idealistic notions of shared community life.

C. **Study limitations**

The study was performed over an extended period of time at a specific site (Serenity House) within a specific community (L'Arche Southown) and with a specific number of informants (N=10). It did not take into account influences on core members from other community members living in the other community house, with which Serenity House occasionally gets together. It also did not take into account influences from employers, family members, guardians and friends, unless informants specifically mentioned such external influences (even then, though, only their side was taken into consideration). As all these agents probably influence informants' self-determination in some ways, further study might be expanded to include them.

There are many understandings and ways of being community. This study focused on a specific way of being community, that of L'Arche Southown. Expanding the study to other communities, with different philosophies, could bring out different self-determination and communal dynamics.

My personal and professional involvement in the community, together with my previous intellectual formation, might have brought in bias – I sought to record that, as much as

reasonably possible, in my reflexive notes and to make that clear in this study. The following section will examine this in greater depth.

D. **Reflexive Comments on My Role**

As a person working at L'Arche Southown and as someone influenced by the vision of L'Arche, being the researcher/participant observer for this study had both benefits and challenges. I had an insider knowledge that was helpful in understanding traditions, terminology and dynamics present at Serenity House/L'Arche Southown. As I already knew informants and have participated in various Serenity House activities throughout the years I felt my presence in the house did not seem awkward nor imposing, but interwoven naturally in the life of the site. During the consent/assent process, however, I did emphasize to informants the confidentiality aspect of the research and how deciding not to participate in the study would not have influenced informants' relationship with Serenity House/L'Arche Southown. This was particularly important to me, as I worked at the site and wanted informants to feel as free and comfortable as possible in participating in the research.

I did experience challenges in being a participant observer with community ties, however, which I reported in my reflexivity journal from the beginning to the end of the research process. Such notes have helped me find an insightful self-awareness and reasonable detachment during data collection and analysis; they have helped me navigate the challenges. What these reflexive notes generally pinpointed to were two specific challenges: the challenge of coming to realize a personal bias towards a certain idea of community in my participation in the life of the house and the challenge of "holding back" from intervening in some interactions that were unfolding in front of me during my observation process.

As a community employee I often had the instinct to jump in situations and thus influence certain events. Sometimes I felt this was acceptable, insofar as a participant observer obviously participates in a culture and thus influences it. Thus, I was fine walking with George to The Irish restaurant and seeing how he made choices in that settings, encouraging Alfred to eat with the home, or suggesting Matthew to put on a band-aid over his shaving cut and seeing how he responded. I felt I would have done those things naturally in my role in the first place and that core members' response to those interactions with me could be relevant.

During such moments of participation in the life of the house and afterwards in the write-up, however, I was also able to realize how my own participatory approach was at times influenced by my own idea of "what community should be like." This idea was generally based on both previous experiences at L'Arche Southown but also on more "idealistic" conceptualizations of community, stemming from involvement in previous communities and on more general L'Arche discourses. This was my bias.

For example, when I mentioned to George that dinner was ready and he didn't want to join for it I wondered what he was expressing by his behavior – if he was simply testing boundaries or, as he says, *"feeling mischievous"* or if he was expressing his needs even if it meant challenging community traditions. In my written record of the situation, therefore, I wanted to make sure I kept that bias in check, recording it in my reflexivity journal as possibly informative but also ensuring it didn't bring imbalance to the the write-up.

On a similar note, in the instance of Alfred heading out to buy outside food for himself for the house dinner, I approached him encouraging him to share the same house food as everyone else. In so doing, I was aware that I had a particular idea of community in mind, one in which breaking and sharing the same bread was important and valuable. As I noted in my

reflexivity journal, *"Encouraging Alfred to eat the same food as the rest of the house seems to be 'normal' to me. In my previous L'Arche communities dinner food was always shared, as there was a tacit understanding that this was really the only way. I guess it was not questioned either (…). L'Arche discourses – in Jean Vanier's writings and in other L'Arche materials- emphasize the spirituality and humanness of eating at the same table. I agree with them. I also come from a family in which food was shared at the dinner table, so this has probably formed my vision, too.*

Sharing a meal has its beauty - it shows appreciation for another's cooking, it can also show a certain equality. We might have different abilities, disabilities, gifts and weaknesses, but when we eat we are the same, we share the same bread, lovingly provided to us. Plus, if someone enters community they make a choice for some things and say no to others. For example, saying yes to living together means saying no to living alone and isolated. A yes implies a no. Same thing with sharing a meal – if you choose to live communally then sharing bread implies choosing not to get your own food all the time.

However, I must admit that, differently from assistants, core members have less options…how much is their choice for community a 'one-size fit all' thing? Maybe Alfred is saying something through his behavior, but I still think sharing house food is important. If he buys his own food, I prefer he shares it with others, as he has done a couple of times (…). I realize I have a bias, and this has influenced my approach to him regarding food. I don't think the bias is good or bad; I find as a researcher I need to admit to this bias, bring it to light and be honest about it, without moralizing about its goodness or badness. After all, even Alfred has a bias. Don't we all?"

During the research I also wondered about my role as participant observer. As helpful and fitting as it was, I also felt that at some point I had to put a limit on the participatory part and

become more detached, focusing on simply being an observer. I wanted to make sure I had thick and rich data that focused on relationships I observed, together with data focusing on relationships I participated in (and observed). I thus included both in the study.

Simply being an observer, without participating much, was at times challenging, but I thought it was important for the integrity of the study. An episode is telling in this, namely the situation in which Jenna and Michelle discussed about whether or not to get soda. This episode tested me a bit. It happened in the dining room, as the two were standing and I was sitting by the dining room table. I watched the conversation enfold in front of me: Jenna wanting to go buy soda, at times rising her voice, and Michelle not wanting to support her in this due to health concerns. I wanted to intervene, but held back, observing and letting the situation unfold in front of my eyes. The situation brought alive the challenge Michelle and Ellen had to face in supporting Jenna' health (and helping her keep her word/promise) and the challenge Jenna had to face when wanting to buy something as simple as a soda and having such a limitation in doing so.

From the notes I took in my reflexivity journal right after the event: *"It wasn't the easiest thing witnessing to that conversation without intervening. I am used to help support the quality of life for both core members and assistants, but I had to sit and just watch. It would have been easier to get there and help de-escalate the situation, possibly help both sides communicate, or encourage a compromise or a decision over the other. If I had to encourage a decision it would probably have been that of helping Jenna see the health benefits of avoiding soda."*

Not only, however, did I admit to this bias, but I also sought to problematize it: *"I probably would have encouraged Jenna to take good care of her health, and remind her, considering she had already drunk a substantial amount of soda, of the possible health dangers*

of soda. This stance of mine is influenced by my professional role in community, which includes supporting core members' health in reasonable ways. I am aware, however, that people outside community, and assistants themselves, can go out whenever they want and choose to be healthy or unhealthy. Choose to drink as much or as little soda as they wish, without having too much "screening." My stance is therefore biased. I don't want to impose a regiment, and yet I'd like to support healthier choices rather than unhealthy ones that also have influence on the community. If Jenna drank more soda in fact, she could stay awake yelling in her room at late hours, preventing others from sleeping. What a challenging balance to find."

I performed my research as a student of Disability Studies. Through this study I maintained an understanding of core members as having ID, but also as being part of a system that in some way disables them, or enables them, depending on instance and context. I kept track of this in my notes. In my reflexive stance as expressed in my notes I therefore recorded my thoughts, deconstructed potential bias, and analyzed "where I stood" in relation to the research process, even to the point of problematizing that. This latter practice is a post-critical approach to ethnography (Madison, 2004) that I employed.

E. **Recommendations for Research and Practice**

Taking into account the results of this study and the existing literature, some suggestions for further research can be made. This research pointed to the role of the unconscious in self-determination. More research needs to be done on how the unconscious might influence choice-making in persons with ID. A qualitative study on this topic, for example, could potentially bring rich insight.

This study proposed framing self as self/other as well as studying persons with disability in relation to the persons without disability they interact with. Further self-determination

research can thus change the paradigm and include more intentionally persons with and without disabilities and study their interaction, framing selfhood and agency in more relational and interdependent tones.

This study focused on a community home setting. Further research might compare such a setting with a group home setting, where the boundary between professional staff and clients might be more emphasized. It would be interesting to see how self-determination is supported differently from staff, how persons with ID make choices and what their options availability is in the two different settings.

This study sought to explore self-determination dynamics in community, finding ethnographic insight from which to ground theoretical advancement. I believe such theoretical work is not only abstract but has the potential to influence reality. As critical pedagogue Paulo Freire presented in his work on people's growth in conscientization, critical awareness that is derived from reflection on one's personal and external situation leads one to break the cycle of casualty, thus transforming reality (Taylor, 1993). What may be seen as an "abstract" growth in consciousness and understanding, therefore, can actually influence praxis/informs action. Freire constructed this understanding specifically as related to oppression: action against oppression cannot be imposed from without but must be generated by a person's perception of his or her situation (Freire, 1970).

This study does not claim that its insights are generalizable to all community realities where people with and without ID share life together, however, there are ways in which awareness of these theoretical findings can be translated into practical action within communities where persons with and without ID live together and/or are in support relationships. Some examples:

- Helping persons get in touch with the motives that influence their decision-making, not only of a conscious nature, but also of an unconscious one. For example, person with ID and staff can be asked to find the picture of an important person in their childhood they liked (might be good to keep a positive focus without eliciting negative memories). They can then come together, with as much confidentiality precautions as needed, and share about how their chosen person lived and how they made decisions. People can then be invited to see if there are any similarities or connections between their own current life preferences and decisions and their chosen person. This, of course, is not meant to be exact science, but a concrete way to bring to awareness how unconscious elements can be of impact in people's present lives and choices.
- Finding ways to celebrate interdependent relationships between persons with and without ID, highlighting how these relationships can be supporting and emotionally enriching. A special dinner, the creation of a song, an article written in a newspaper…there can be many ways of emphasizing how valuable relationships between persons with and without ID can be. McDonald, Keys, and Balcazar (2007) found that it is often a friend, a teacher or a service provider that provides encouragement and belief in a person's potential. On a more mutual level, mutual enrichment between persons with and without ID can thus be celebrated as well.
- Providing persons with/without ID with tools to develop critical awareness of power dynamics at play in their relationships. This could be done by the creation of an accessible workshop on power dynamics or by an advocacy club or committee where such dynamics can be focused on. Such projects can help keep power imbalances between persons with and without ID in a community/agency in check.

- Having persons with ID create a lifeline or story book on their lives (in L'Arche these are called "sacred stories") by bringing together their autobiographical memories and experiences, narrating them through words and visuals, and creating a physical book (or poster, video, recording, computer project) to record them. Such a lifeline would be focused on persons with ID's self-journey within their relational and decision-making histories, potentially helping them visualize and claim their self-determination and relational history. Caldwell (2010) and Bolding and Wehmeyer (1999) gave lifeline examples that could be adapted for such a project.

F. Conclusion

This research studied a site where persons with and without ID share life together in community. It presented the relationship between self-determination and community by highlighting and exploring the ways and dynamics in which persons with ID engaged in choice-making within community, influenced by others and by various external factors. The study framed its results in the larger theoretical self-determination framework, which lacks substantial research on self-determination and community, suggesting that awareness of unconscious motives/expression, acceptance of interdependence, a relational understanding of the autonomous self, and a recognition of power differences in mutuality community discourses, can expand current understanding of self-determination and inform action in the field.

APPENDIX

APPENDIX A

UNIVERSITY OF ILLINOIS
AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice
Initial Review (Response To Modifications)

December 2, 2014

Luca Badetti
Disability and Human Development
1640 W Roosevelt Rd
Disability and Human Development, M/C 626
Chicago, IL 60612
Phone: (312) 996-7988

RE: **Protocol # 2014-0774**
"Self-Determination and Community Living of Persons with Intellectual Disabilities"

Dear Mr. Badetti:

Your Initial Review application (Response To Modifications) was reviewed and approved by the Expedited review process on November 24, 2014. You may now begin your research.

Please note the following information about your approved research protocol:

Protocol Approval Period: November 24, 2014 - November 24, 2015
Approved Subject Enrollment #: 9
Additional Determinations for Research Involving Minors: These determinations have not been made for this study since it has not been approved for enrollment of minors.
Performance Sites: UIC, L'Arche Chicago
Sponsor: None
Research Protocol:

a) Examining the Relationship between the Self-determination of Persons with Intellectual Disabilities and Community Living in L'Arche; Version 2; 10/20/2014

Recruitment Materials:

a) Recruitment Flyer; Version 1; 10/17/2014
b) Recruitment Script PWD Own Guardian; Version 1; 10/23/2014
c) Recruitment Script Staff; Version 1; 10/23/2014
d) Recruitment Script for Guardians; Version 1; 10/23/2014
e) Recruitment Script PWD with Other Guardians; Version 1; 10/23/2014

Informed Consents:

a) Consent Form Person with Disability (4 page); Version 2; 10/13/2014
b) Consent Form Person with Disability (2 page); Version 2; 10/13/2014

APPENDIX A (continued)

c) Consent Form Staff; Version 3; 11/17/2014
d) A waiver of consent has been granted for recruitment purposes for the release of guardian contact information only under 45 CFR 46.116(d) (minimal risk; could not otherwise identify or contact guardians)
e) A waiver of the signature on a consent document (documentation) has been granted for subjects with I/DD who cannot write but whose assent/dissent will be ascertained by a qualified professional under 45 CFR 46.117(c)(2) (minimal risk)

Assents:

a) Assent Form Person with Disability (4 page); Version 1; 10/13/2014
b) Assent Form Person with Disability (1 page); Version 1; 10/13/2014

Guardian Permission:

a) Consent Form Guardian; Version 2; 11/03/2014

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes., (7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
08/13/2014	Initial Review	Expedited	08/17/2014	Modifications Required
10/29/2014	Response To Modifications	Expedited	11/03/2014	Modifications Required
11/05/2014	Response To Modifications	Expedited	11/10/2014	Modifications Required
11/18/2014	Response To Modifications	Expedited	11/24/2014	Approved

Please remember to:

→ Use your **research protocol number** (2014-0774) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the enclosure,
"**UIC Investigator Responsibilities, Protection of Human Research Subjects**"
(http://tigger.uic.edu/depts/ovcr/research/protocolreview/irb/policies/0924.pdf)

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

APPENDIX A (continued)

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 996-2014. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Sandra Costello
Assistant Director, IRB # 2
Office for the Protection of Research Subjects

Enclosures:

1. **UIC Investigator Responsibilities, Protection of Human Research Subjects**
2. **Informed Consent Documents:**
   a) Consent Form Person with Disability (4 page); Version 2; 10/13/2014
   b) Consent Form Person with Disability (2 page); Version 2; 10/13/2014
   c) Consent Form Staff; Version 3; 11/17/2014
3. **Assent Documents:**
   a) Assent Form Person with Disability (4 page); Version 1; 10/13/2014
   b) Assent Form Person with Disability (1 page); Version 1; 10/13/2014
4. **Guardian Permission:**
   a) Consent Form Guardian; Version 2; 11/03/2014
5. **Recruiting Materials:**
   a) Recruitment Flyer; Version 1; 10/17/2014
   b) Recruitment Script PWD Own Guardian; Version 1; 10/23/2014
   c) Recruitment Script Staff; Version 1; 10/23/2014
   d) Recruitment Script for Guardians; Version 1; 10/23/2014
   e) Recruitment Script PWD with Other Guardians; Version 1; 10/23/2014

cc: Tamar Heller (faculty advisor), Disability and Human Development, M/C 626

APPENDIX A (continued)

UNIVERSITY OF ILLINOIS
AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice
Amendment to Research Protocol – Expedited Review
UIC Amendment # 1

May 20, 2015

Luca Badetti
Disability and Human Development
1640 W Roosevelt Rd
Disability and Human Development, M/C 626
Chicago, IL 60612
Phone: (312) 996-7988

RE: **Protocol # 2014-0774**
"Self-Determination and Community Living of Persons with Intellectual Disabilities"

Dear Mr. Badetti:

Members of Institutional Review Board (IRB) #2 have reviewed this amendment to your research under expedited procedures for minor changes to previously approved research allowed by Federal regulations [45 CFR 46.110(b)(2)]. The amendment to your research was determined to be acceptable and may now be implemented.

Please note the following information about your approved amendment:

Amendment Approval Date: May 14, 2015
Amendment:
Summary: UIC Amendment #1, dated 5 May 2015 and submitted to OPRS 11 May 2015, is an investigator-initiated amendment increasing the total sample size from 4 to 5 subjects due to the hiring of new personnel at the research site (Initial Review application, pp 6, 13-14; Protocol, v3, p33).
Approved Subject Enrollment #: 10
Performance Sites: UIC, L'Arche Chicago
Sponsor: None
Research Protocol:
a) Examining the Relationship between the Self-determination of Persons with Intellectual Disabilities and Community Living in L'Arche, p33; Version 3; 05/05/2015

APPENDIX A (continued)

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
05/11/2015	Amendment	Expedited	05/14/2015	Approved

Please be sure to:

→ Use your research protocol number (2014-0774) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the OPRS website under:
"**UIC Investigator Responsibilities, Protection of Human Research Subjects**"
(*http://tigger.uic.edu/depts/ovcr/research/protocolreview/irb/policies/0924.pdf*)

Please note that the UIC IRB #2 has the right to ask further questions, seek additional information, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact the OPRS at (312) 996-1711 or me at (312) 996-2014. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Sandra Costello
Assistant Director, IRB # 2
Office for the Protection of Research Subjects

cc: Tamar Heller (faculty advisor), Disability and Human Development, M/C 626

APPENDIX A (continued)

UNIVERSITY OF ILLINOIS
AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice
Amendment to Research Protocol and/or Consent Document – Expedited Review
UIC Amendment # 2

September 16, 2015

Luca Badetti
Disability and Human Development
1640 W Roosevelt Rd
Disability and Human Development, M/C 626
Chicago, IL 60612
Phone: (312) 996-7988

RE: **Protocol # 2014-0774**
"Self-Determination and Community Living of Persons with Intellectual Disabilities"

Dear Mr. Badetti:

Members of Institutional Review Board (IRB) #2 have reviewed this amendment to your research and/or consent form under expedited procedures for minor changes to previously approved research allowed by Federal regulations 45 CFR 46.110(b)(2). The amendment to your research was determined to be acceptable and may now be implemented.

Please note the following information about your approved amendment:

Amendment Approval Date: September 16, 2015
Amendment:
Summary: UIC Amendment #2, dated 27 August 2015 and submitted to OPRS 11 September 2015, is an investigator-initiated amendment adding Lieke van Heumen as key research personnel (Appendix P).
Approved Subject Enrollment #: 10
Performance Sites: UIC, L'Arche Chicago
Sponsor: None
PAF#: Not applicable

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
09/11/2015	Amendment	Expedited	09/16/2015	Approved

APPENDIX A (continued)

Please be sure to:

→ Use your research protocol number (2014-0774) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the OPRS website under:
"UIC Investigator Responsibilities, Protection of Human Research Subjects"
(http://tigger.uic.edu/depts/ovcr/research/protocolreview/irb/policies/0924.pdf)

Please note that the UIC IRB #2 has the right to ask further questions, seek additional information, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact the OPRS at (312) 996-1711 or me at (312) 996-9299. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Anna Bernadska, M.A.
IRB Coordinator, IRB # 2
Office for the Protection of Research Subjects

Enclosure: None

cc: Tamar Heller, Disability and Human Development, M/C 626

APPENDIX A (continued)

UNIVERSITY OF ILLINOIS
AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice
Continuing Review

October 27, 2015

Luca Badetti
1640 W Roosevelt Rd
Disability and Human Development, M/C 626
Chicago, IL 60612
Phone: (312) 996-7988

RE: **Protocol # 2014-0774**
"Self-Determination and Community Living of Persons with Intellectual Disabilities"

Dear Mr. Badetti:

Your Continuing Review application was reviewed and approved by the Expedited review process on October 22, 2015. You may now continue your research.

Please note the following information about your approved research protocol:

Protocol Approval Period: October 22, 2015 - October 21, 2016
Approved Subject Enrollment #: 10 (limited to data analysis for 10 enrolled subjects)
Additional Determinations for Research Involving Minors: These determinations have not been made for this study since it has not been approved for enrollment of minors.
Performance Sites: UIC, L'Arche Chicago
Sponsor: None
Research Protocol:

a) Examining the Relationship between the Self-determination of Persons with Intellectual Disabilities and Community Living in L'Arche, p33; Version 3; 05/05/2015

Recruitment Material:

a) N/A – research limited to data analysis only

Informed Consent:

a) N/A – research limited to data analysis only

Your research continues to meet the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

APPENDIX A (continued)

2014-0774 Page 2 of 2 10/27/2015

(7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
10/21/2015	Continuing Review	Expedited	10/22/2015	Approved

Please remember to:

→ Use your **research protocol number** (2014-0774) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the OPRS website under:
"UIC Investigator Responsibilities, Protection of Human Research Subjects"
(http://tigger.uic.edu/depts/ovcr/research/protocolreview/irb/policies/0924.pdf)

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 996-2014. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Sandra Costello
Assistant Director, IRB # 2
Office for the Protection of Research Subjects

cc: Tamar Heller (faculty advisor), Disability and Human Development, M/C 626

CITED LITERATURE

Abery, B. H., Elkin, S., Smith, J. G., Stancliffe, R. J., Lewis, R., Scholin, S., & Paris, K. (2008). *Enhancing self-determination of adults with intellectual disability: A training program for direct service professionals.* Minneapolis, MN: University of Minnesota, Institute on Community Integration.

Abery, B. H., Scholin, S., Paris, K., & Smith, J. G. (2009). *The impact of person-centered planning, consumer directed community supports, and staff training on the self-determination of adults with intellectual disabilities – an ecological analysis* (manuscript under preparation).

Altheide, D. L., & Johnson, J. M. (1994). Criteria for assessing interpretive validity in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 485-499). Thousand Oaks, CA: Sage.

Anderson, G. (1989). Critical ethnography in education: Origins, current status and new Directions. *Review of Educational Research,* 59(3), 249-270.

Angrosino, M. V. (2005). *Projects in Ethnographic Research.* Long Grove, IL: Waveland Press.

Antaki, C., Walton, C., & Finlay, W. M. L. (2007). How proposing an activity to a person with an intellectual disability can imply a limited identity. *Discourse & Society, 18*(4), 393-410.

American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: American Psychiatric Association.

Armstrong M., & Taylor, S. (2014). *Armstrong's handbook of human resource management practice*. Philadelphia, PA: Kogan Page Ltd.

Ary, D., Jacobs, L. C., & Razavieh, A. (1996). *Introduction to research in education* (5th ed.). Orlando, FL: Harcourt Brace College Publishers.

Babchuk, W. A., & Hitchcock, R.K. (2013). Grounded theory ethnography: Merging methodologies for advancing naturalistic inquiry. In E. P. Isaac-Savage (Ed.), *Proceedings of the 54st annual adult education research conference* (pp. 27-34). St. Louis, MO: The University of Missouri-St. Louis.

Bachrach, L. L. (1976). *Deinstitutionalization: An analytical review and sociological review*. Rockville, MD: National Institute of Mental Health.

Bargh, J. A., & Morsella, E. (2008). The unconscious mind. *Perspectives on Psychological Science*, 3, 73-79.

Barnes, C. (1997). A legacy of oppression: A history of disability in western culture. In L. Barton & M. Oliver (Eds.), *Disability studies: Past, present and future* (pp. 3-24). Leeds, UK: The Disability Press.

Barton, L. (1996). *Inclusion: An emancipatory project or a counter-productive discourse?* Paper presented at Culture, Difference and Inclusion, Sheffield, UK.

Battaglia, D. (1995). On problematizing the self: A thematic introduction. In D. Battaglia (Ed.), *Rethorics of self-making* (pp. 1-15). Berkeley, CA: University of California Press.

Battersby, D. (1981). The use of ethnography and grounded theory in educational research. *McGill Journal of Education*, *16*(1), 91-98.

Bechara, A., & Damasio, H. (1997). Deciding advantageously before knowing the advantageous strategy. *Science*, *275*(5304), 1293-1295.

Bernard, H. R. (1994). *Research methods in anthropology: Qualitative and quantitative approaches* (2nd ed.). Walnut Creek, CA: AltaMira Press.

Bolding, N. L., & Wehmeyer, M. L. (1999). *It's my future!: Planning for what I want in my life.* Silver Spring, MD: The Arc of the United States.

Butler, N.S. (2000). "In the most appropriate setting": The rights of mentally disabled individuals under the Americans With Disabilities Act in the wake of Olmstead. *Catholic University Law Review, 49*(4), 1021-1052.

Caldwell, J. (2010). Leadership development of individuals with developmental disabilities in the self-advocacy movement. *Journal of Intellectual Disability Research*, *54*(11), 1004-1014.

Carter, J. (2004). Research notes: Reflections on interviewing across the ethnic divide. *International Journal of Social Research Methodology*, *7*(4), 345-353.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis.* London, UK: Sage.

Charmaz, K., & Mitchell, R. (2001). Grounded theory in ethnography. In P. Atkinson, A. Coffey, S. Delamont, J. Lofland, & L. Lofland (Eds.), *Handbook of ethnography* (pp. 160-175). London, England: Sage.

Coffey, A., & Atkinson, P. (1996). *Making sense of qualitative data: Complementary research strategies.* Thousand Oaks, CA: Sage.

Corbin Dwyer, S., & Buckle, J. (2009). The space between: On being an insider-outsider in qualitative research. *International Journal of Qualitative Methods, 8*(1), 54-63.

Costley, C., & Armsby, A. (2007). Methodologies for undergraduates doing practitioner investigations at work. *Journal of Workplace Learning*, *19*(3), 131-145.

Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions.* Thousand Oaks, CA: Sage.

Crichton, J. (1998). Balancing restriction and freedom in the care of people with intellectual disability. *Journal of Intellectual Disability Research, 42*(2), 189-195.

D'Alessio, S. (2011). *Inclusive Education in Italy: a critical analysis of the policy of integrazione scolastica*. Rotterdam, Netherlands: Sense Publishers.

Dalton, J., Elias, M., & Wandersman, A. (2001). *Community psychology: Linking individuals and communities*. Belmont, CA: Wadsworth/Thomson Learning.

Davis, J. (2000). Disability studies as ethnographic research and text: Research strategies and roles for promoting social change? *Disability & Society*, *15*(2), 191-206.

Davis, L. J. (2006). Constructing normalcy. The bell curve, the novel, and the invention of the disabled body in the nineteenth century. In L. J. Davis (Ed.), *The disability studies reader* (2nd ed., pp. 3-16). New York, NY: Routledge.

Deci, E., & Ryan, R. (2002). *Handbook of self-determination research*. Rochester, NY: University of Rochester Press.

Department of Health (2001). *Seeking consent: Working with people with learning disabilities.* London, UK: The Stationery Office.

Dunne, C. (2011). The place of the literature review in grounded theory research. *International Journal of Social Research Methodology, 14*(2), 111-124.

Dybwad, G., & Bersani, H. (1996). *New voices: Self-advocacy by people with disabilities*. Cambridge, MA: Brookline Books.

Emerson, R. M., Fretz, R. I., & Shaw, L. L. (1995). *Writing ethnographic fieldnotes.* Chicago, IL: University of Chicago Press.

Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., Knapp, M., Järbrink, K., & Netten, A. (1999). *Quality and costs of residential supports for people*

with learning disabilities: a comparative analysis of quality and costs in group homes and supported living schemes. University of Manchester, Manchester: Hester Adrian Research Centre.

Engberg-Pedersen, T. (2008). Philosophy of the self in the apostle Paul. In P. Remes & J. Sihvola (Eds.), *Ancient philosophy of the self* (pp. 179-194). Netherlands: Springer.

Felce, D. (1998). The determinants of staff and resident activity in residential services for people with severe intellectual disability: Moving beyond size, building design, location and number of staff. *Journal of Intellectual and Developmental Disability*, *23*, 103-119.

Fetterman, D. M. (2010). *Ethnography: Step-by-step* (3rd ed.). Thousand Oaks, CA: Sage.

Finlay, W. M. L., Walton, C., & Antaki, C. (2008). Promoting choice and control in residential services for people with learning disabilities. *Disability & Society, 23*(4), 349-360.

Flynn, M. (1989). *Independent living for adults with mental handicap: A place of my own.* London, UK: Cassell Educational.

Foucault, M. (1965). *Madness and civilization: A history of insanity in the age of reason*. New York, NY: Pantheon Books.

Foucault, M. (1998). *The history of sexuality: The will to knowledge*. London, UK: Penguin.

Freire, P. (1970). *Pedagogy of the Oppressed.* New York: Herder and Herder.

Galea, A. (2009). Breaking the barriers of insider research in occupational health and safety. *Journal of Health and Safety Research and Practice*, *1*(1), 3-12.

Gaventa, W. (2005). A place for ALL of me and ALL of us: Rekindling the spirit in services and supports. *Mental Retardation, 43*(1), 48-54.

Gaventa, W. C. (2010). Learning from people with disabilities: How to ask the right questions. In H. S. Reinders (Ed.), *The paradox of disability* (pp. 103-112). Grand Rapids, MI: Wm. B. Eerdmans Publishing Co.

Gazzaniga, M. (1985). *The social brain.* New York, NY: Basic Books.

Genzuk, M. (2003). *A Synthesis of Ethnographic Research*. Occasional Papers Series. Center for Multilingual, Multicultural Research, Rossier School of Education, University of Southern California, Los Angeles.

Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory.* Chicago, IL: Aldine.

Goldingay, J. (1997). Being human. In F. Young (Ed.), *Encounter the mystery: Reflections on L'Arche and living with disability* (pp. 133-151). London, UK: Darton, Longman and Todd.

Goodley, D. (1999). Disability research and the 'researcher template': Reflections on grounded subjectivity in ethnographic research. *Qualitative Inquiry, 5*(1), 24-46.

Gusfield, J. R. (1975). *The community: A critical response*. New York, NY: Harper Colophon.

Hall, E. (1981). *Beyond culture.* New York, NY: Doubleday.

Hammel, J., Lai, J., & Heller, T. (2002). The impact of assistive technology and environmental interventions on function and living situation status with people who are ageing with developmental disabilities. *Disability & Rehabilitation, 24*, 93-105.

Hammersley, M. (1992). *What's wrong with ethnography? Methodological explorations.* London, UK: Routledge.

Harris, M., & Johnson, O. (2000). *Cultural anthropology* (5th ed.). Needham Heights, MA: Allyn and Bacon.

Hatton, C. C., Emerson, E. E., Robertson, J. J., Gregory, N. N., Kessissoglou, S. S., & Walsh, P. N. (2004). The resident choice scale: A measure to assess opportunities for self-determination in residential settings. *Journal of Intellectual Disability Research*, *48*(2), 103-113.

Hawley, H. H. (1986). *Human ecology: A theoretical essay.* Chicago, IL: University of Chicago Press.

Heller, T. (1978). Group decision-making by mentally retarded adults. *American Journal of Mental Deficiency, 82*(5), 480-486.

Heller, T., & Berkson, G. (1982). *Friendship and residential relocation.* Paper presented at the Gatlinburg Conference on Research in Mental Retardation, Gatlinburg, Tennessee.

Heller, T., Miller, A. B., & Factor, A. (1999). Autonomy in residential facilities and community functioning of adults with mental retardation. *Mental Retardation*, *37*, 449-457.

Heller, T., Miller, A. B., Hsieh, K., & Sterns, H. (2000). Later-life planning: Promoting knowledge of options and choice-making. *Mental Retardation,* 38*,* 395-406.

Heller, T., Schindler, A., Palmer, S., Wehmeyer, M., Parent, W., …O'Hara, D. (2011). Self-determination across the life span: Issues and gaps. *Exceptionality, 19*(1), 31-45.

Henwood, K., & Pidgeon, N. (2006). Grounded theory. In G. M. Breakwell, S. Hammond, C. Fife-Shaw, & J.A. Smith (Eds.), *Research methods in psychology* (3rd ed., pp. 342-365). Thousand Oaks, CA: Sage.

Hillary, G. (1955). Definitions of community: Areas of agreement. *Rural Sociology, 20*, 111-123.

Hutchison, E. D., & Lee, S. M. (2011). Communities. In E. D. Hutchison (Ed.), *Dimensions of human behavior* (4th ed., pp. 441-472). Los Angeles, CA: Sage.

Hytten, K. (2004). Post-critical ethnography: Research as a pedagogical encounter. In G. W. Noblit, S. Y., Flores, & E. G. Murillo, Jr. (Eds.), *Postcritical ethnography: Reinscribing critique* (pp. 95-105). Cresskill, NJ: Hampton Press.

Iyengar, S. S., & Lepper, M. R. (2000). When choice is demotivating: Can one desire too much of a good thing? *Journal of Personality and Social Psychology*, *79*(6), 995-1006.

Jackson, R. (1999). The case for village communities for adults with learning disabilities: An exploration of the concept. *Journal of Learning Disabilities for Nursing, Health and Social Care, 3*, 110-117.

Kieffer, C. H. (1984). Citizen empowerment: A developmental perspective. *Prevention in Human Services, 3(2),* 9-36.

L'Arche USA. (n.d.a). Identity and mission. Retrieved September 27, 2015, from http://www.larcheusa.org/who-we-are/identity-and-mission/

L'Arche USA. (n.d.b). Jean Vanier – L'Arche founder. Retrieved October 30, 2015, from http://www.larcheusa.org/who-we-are/jean-vanier/

Labaree, R. V. (2002). The risk of 'going observationalist': Negotiating the hidden dilemmas of being an insider participant observer. *Qualitative Research*, *2*, 97-122.

Lee, J. (1991). Jean Vanier & L'Arche: A communion of love. *Disability & Society*, *6*(1), 73-74.

Libet, B. (1986). Unconscious cerebral initiative and the role of conscious will in voluntary action. *Behavioral and Brain Sciences*, *8*, 529-566.

Lindemann, H. (2010). Holding one another (well, wrongly, clumsily) in a time of dementia. In E. F. Kittay, & L. Carlson (Eds.), *Cognitive disability and its challenge to moral philosophy* (pp. 161-169). Oxford, UK: Wiley-Blackwell.

Loman, S., Vatland, C., Strickland-Cohen, K., Horner, R., & Walker, H. (2010). Promoting self-determination: A practical guide. A National Gateway to Self-Determination. Retrieved March 1, 2015, from http://ngsd.org/sites/default/files/promoting_selfdetermination_a_practice_guide.pdf

Mackenzie, C., & Stoljar, N. (2000). Introduction: Refiguring autonomy. In C. Mackenzie & N. Stoljar (Eds.), *Relational autonomy feminist perspectives on autonomy, agency and the social self* (pp. 3-34). New York, NY: Oxford University Press.

MacQueen, K. M., McLellan, E., Metzger, D. S., Kegeles, S., Strauss, R. P., Scotti, R., … Trotter, R. T. (2001). What is community? An evidence-based definition for participatory public health. *American Journal of Public Health*, *91*(12), 1929-1938.

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

Madison, D. S. (2004). *Critical ethnography: Method, ethics, and performance.* Thousand Oaks, CA: Sage.

Marcus, G. E. (1995). On Eccentricity. In D. Battaglia (Ed.), *Rethorics of self-making* (pp. 43-59). Berkeley, CA: University of California Press.

Maykut, P., & Morehouse, R. (1994). *Beginning qualitative research: A philosophical and practical guide* (Vol. 6). London, UK: Routledge.

McConkey, R. R. (2007). Variations in the social inclusion of people with intellectual disabilities in supported living schemes and residential settings. *Journal of Intellectual Disability Research*, *51*(3), 207-217.

McDermid, F., Peters, K., Jackson, D., & Daly, J. (2014). Conducting qualitative research in the context of pre-existing peer and collegial relationships. *Nurse Researcher*, *21*(5), 28-33.

McDonald, K. E., & Keys, C. B. (2005). L'Arche: the success of community, the challenges of empowerment in a faith-centered setting. *Journal of Religion, Disability & Health, 9*(4), 5-28.

McDonald, K. E., Keys, C. B., & Balcazar, F. E. (2007). Disability, race/ethnicity and gender: Themes of cultural oppression, acts of individual resistance. *American Journal of Community Psychology*, *39*, 145-161.

McDonald, K. E., Kidney, C. A., & Patka, M. M. (2013). 'You need to let your voice be heard': Research participants' views on research. *Journal Of Intellectual Disability Research, 57*(3), 216-225.

McConkey, R. R., & Collins, S. S. (2010). The role of support staff in promoting the social inclusion of persons with an intellectual disability. *Journal Of Intellectual Disability Research*, *54*(8), 691-700.

Mcllfatrick, S., Sullivan, K., & McKenna, H. (2006). Exploring the ethical issues of the research interview in the cancer context. *European Journal of Oncology Nursing*, *10*(1), 39-47.

McMillan, D. W., & Chavis, D. M. (1986). Sense of community: A definition and theory. *Journal of Community Psychology*, *14*(1), 6-23.

Mead, G. H. (1962). *Mind, self, and society from the standpoint of a social behaviorist.* Chicago, IL: University of Chicago Press.

Merriam, S. B. (1998). *Qualitative research and case study applications in education*. San Francisco, CA: Jossey-Bass Publishers.

Merriam, S. B., & Tisdell, E. J. (2009). *Qualitative research: A guide to design and implementation.* San Francisco, CA: Jossey-Bass.

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd Ed.). Thousand Oaks, CA: Sage.

Mithaug, D. (1996). *Equal opportunity theory.* Thousand Oaks, CA: Sage.

Mosteller, S. (1998). *A place to hold my shaky heart: Reflections from life in a community.* New York, NY: Crossroad.

Murchison, J. M. (2010). *Ethnography essentials: Designing, conducting, and presenting your research.* San Francisco, CA: Jossey-Bass.

Nieswiadomy, R. M. (1987). *Foundations of nursing research.* Norwalk, CT: Appleton and Lange.

Nouwen, H. J. M. (1997). *Adam: God's beloved.* Maryknoll, NY: Orbis Books.

O'Brien, J. (1984). *A guide to personal futures planning.* Lithonia, GA: Responsive Systems Associates.

Ogilvie, L. D., Burgess-Pinto, E., & Caufield, C. (2008). Challenges and approaches to newcomer health research. *Journal of Transcultural Nursing, 19*(1), 64-73.

O'Reilly, K. (2009). *Key concepts in ethnography*. Thousand Oaks, CA: Sage.

Patton, M. Q. (2002). *Qualitative research & evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.

Perske, R. (1972). The dignity of risk and the mentally retarded. *Mental Retardation*, *10*, 24-27.

Priestley, M. (1997). Who's research? A personal audit. In C. Barnes & G. Mercer (Eds.), *Doing disability research* (pp. 89-106). Leeds, UK: Disability Press.

Prime Minister's Strategy Unit (2005). *Improving the life chances of disabled people: final report.* London, UK: Cabinet Office.

Randell, M. & Cumella, S. (2009). People with an intellectual disability living in an intentional community. *Journal of Intellectual Disability Research*, *53*, 716-726.

Rappaport, J. (1987). Terms of empowerment/exemplars of prevention: Toward a theory for community psychology. *American Journal of Community Psychology*, *15*(2), 121-148.

Reeves, S., Kuper, A., & Hodges, B. D. (2008). Qualitative research methodologies: Ethnography. *British Medical Journal, 337*, a1020.

Romer, D., & Heller, T. (1983). Social adaptation of mentally retarded adults in community settings: A social-ecological approach. *Applied Research in Mental Retardation, 4*, 303-314.

Safran, J. D., & Kriss, A. (2014). Psychoanalytic psychotherapies. In D. Wedding & R. J. Corsini (Eds.), *Current psychotherapies* (pp. 19-54). Belmont, CA: Cengage Learning.

Sangasubana, N. (2009). How to conduct ethnographic research. *The Qualitative Report*, *16*(2), 567-573. Retrieved January 5, 2015 from http://nova.edu/ssss/QR/QR16-2/sangasubana.pdf

Schalock, R., Verdugo, M., Jenaro, C., Wang, M., Wehmeyer, M., Xu, J., & Lachapelle, Y. (2005). Cross-cultural study of core quality of life indicators. *American Journal on Mental Retardation, 110*, 298-311.

Schensul, S. L., Schensul, J. J., & LeCompte, M. D. (1999). Ethnographic sampling. In S. L. Schensul, J. J. Schensul, & M. D. LeCompte (Eds.), *Essential ethnographic methods* (pp. 231-269). Walnut Creek, CA: Altamira Press.

Scotch, R. K. (2000). Models of disability and the Americans with Disabilities Act. *Berkeley Journal of Employment & Labor Law*, *21*, 213-222.

Shakespeare, T. (1997). Researching disabled sexuality. In C. Barnes & G. Mercer (Eds.), *Doing disability research* (pp. 177-189). Leeds, UK: Disability Press.

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

Shogren, K. A., & Broussard, R. (2011). Exploring the perceptions of self-determination of individuals with intellectual disability. *Intellectual and Developmental Disabilities, 49*(2), 86-102.

Spradley, J. P. (1979). *The ethnographic interview.* New York, NY: Harcourt Brace Jovanich College Publisher.

Spradley, J. P. (1980). *Participant observation*. New York, NY: Holt, Rinehart and Winston.

Spink, K. (2006). *The miracle, the message, the story: Jean Vanier and L'Arche*. London, UK: Darton, Longman & Todd.

Stancliffe, R. J. (2001). Living with support in the community: Predictors of choice and self-determination. *Mental Retardation and Developmental Disabilities Research Reviews, 7*(2), 91-98.

Stoljar, Natalie (2015). Feminist perspectives on autonomy. In E.N. Zalta (Ed.) *The Stanford encyclopedia of philosophy*. Retrieved October 1, 2015 from http://plato.stanford.edu/archives/fall2015/entries/feminism-autonomy.

Stone, E., & Priestley, M. (1996). Parasites, pawns and partners: Disability research and the role of non-disabled researchers. *British Journal of Sociology*, *47*, 699-716.

Strathern, M. (1995). Nostalgia and the new genetics. In D. Battaglia (Ed.), *Rethorics of self-making* (pp. 97-120). Berkeley, CA: University of California Press.

Sweeney, M. S. (2011). *Brainworks: The mind-bending science of how you see, what you think, and who you are.* Washington, D. C: National Geographic.

Taylor, P. V. (1993). *The texts of Paulo Freire.* Philadelphia, PA: Open University Press.

Taylor, V. (2013). *Leading for health and well-being.* London, UK: Learning Matters/Sage.

Timmermans, S., & Tavory, I. (2007). Advancing ethnographic research through grounded theory practice. In A. Bryant & K. Charmaz (Eds.), *The SAGE handbook of grounded theory* (pp. 493-513). London, England: Sage.

Tossebro J. (1995). Impact of size revisited: Relation of number of residents to self-determination and deprivatization. *American Journal on Mental Retardation, 100*, 59-67.

Van, M. J. (2011). *Tales of the field: On writing ethnography*. Chicago, IL: University of Chicago Press.

Vanier, J. (1975). *Be not afraid.* New York: Paulist Press.

Vanier, J. (1989). *Community and growth*. New York: Paulist Press.

Vanier, J. (1998). *Becoming human*. New York: Paulist Press.

Vanier, J. (2012a). *An ark for the poor: The story of L'Arche.* Toronto, Canada: Novalis.

Vanier, J. (2012b). *The heart of L'Arche.* Toronto, Canada: Novalis.

Walker, H. M., Calkins, C., Wehmeyer, M. L., Walker, L., Bacon, A., Palmer, S. B., & Johnson, D. R. (2011). *A social-ecological approach to promote self-determination. Exceptionality, 19*(1), 6-18.

Ward, I., & Zarate, O. (2000). *Introducing psychoanalysis.* London, UK: Icon Books.

Wegner, D. M. (2002). *The illusion of conscious will.* Cambridge, MA: MIT Press.

Wehmeyer, M. L. (1996). Self-determination as an educational outcome: How does it relate to the educational needs of our children and youth? In D. J. Sands & M. L. Wehmeyer (Eds.), *Self determination across the life span: Independence and choice for people with disabilities* (pp. 15-34). Baltimore, MD: Brookes.

Wehmeyer, M.L. (2010). Self determination. In J.H. Sonte & M. Blouin (Eds.), *International encyclopedia of rehabilitation*. Retrieved October 1, 2015 from http://cirrie.buffalo.edu/encyclopedia/en/article/34.

Wehmeyer, M. L., & Bolding, N. (2001). Enhanced self-determination of adults with intellectual disability as an outcome of moving to community-based work or living environments. *Journal of Intellectual Disability Research*, *45*(5), 371-383.

Wehmeyer, M. L., & Garner, N. W. (2003). The impact of personal characteristics of people with intellectual and developmental disability on self-determination and autonomous functioning. *Journal of Applied Research in Intellectual Disabilities*, *16*(4), 255-265.

Wehmeyer, M. L. (2005). Self-determination and individuals with severe disabilities: Re-examining meanings and misinterpretations. *Research & Practice for Persons with Severe Disabilities*, *30*(3), 113-120.

Wehmeyer, M. L., Buntinx, W. H., Lachapelle, Y., Luckasson, R. A., Schalock, R. L., Verdugo, M. A., & Yeager, M. H. (2008). The intellectual disability construct and its relation to human functioning. *Intellectual & Developmental Disabilities, 46*(4), 311-318.

Wehmeyer, M. L., Abery, B. H., Zhang, D., Ward, K., Willis, D., Hossain, W., & Walker, H. M. (2011). Personal self-determination and moderating variables that impact efforts to promote self-determination. *Exceptionality*, *19*(1), 19-30.

Westen, D. (1999). The scientific status of unconscious processes: Is Freud really dead? *Journal of the American Psychoanalytic Association*, *47*(4), 1061-1106.

Whitehead, T.L. (2005). Basic Classical Ethnographic Research Methods. Retrieved January 1, 2015, from http://www.cusag.umd.edu/documents/WorkingPapers/ClassicalEthnoMethods.pdf

Wolcott, H. (1999). *Ethnography: A Way of Seeing*. Lanham, MD: Altamira Press.

VITA
Luca Badetti

EDUCATION

2016	Ph.D. in Disability Studies University of Illinois at Chicago, Chicago, IL
2009	M.S. in Clinical Psychology The Institute for the Psychological Sciences, Arlington, VA
2006	B.A. in Communication Arts; Theology Franciscan University of Steubenville, Steubenville, OH

FELLOWSHIP

2011-2012	Leadership Education in Neurodevelopmental and Related Disabilities (LEND)

TEACHING

2014	Teaching Assistant/Instructor of Foundations of Disability and Human Development, University of Illinois at Chicago, Chicago, IL

RESEARCH

2010-2014	Research Assistant for various research projects (The Autism Program; Support Service Teams; Aging and Disability Resource Centers; LEND; Special Olympics), University of Illinois at Chicago, Chicago, IL

PUBLICATIONS

Heller, T., Hsieh, K., Owen, R., & **Badetti, L.** (2012). *Evaluation of the Illinois Services and Support Program.* IDHD, Chicago, IL.

Heller, T., Hsieh, K., & **Badetti, L.** (2012). *The Special Olympics Community-based Health Promotion Programs: Program Evaluation Report*. Special Olympics International, Washington D.C.; IDHD, Chicago, IL.

CONFERENCES AND PRESENTATIONS

Disability at the Center: Becoming Human, Transforming Society (2015). Axis, University of Chicago, Chicago, IL.

From the Asylum to the Heights: Disablement, Folly, Love, Mysticism in the Poetry of Alda Merini (2015). University of Illinois at Chicago, Chicago, IL.

Community, Peace and Justice: Relationships of Belonging as an Answer to Violence (2015). Chicago Disability Studies Conference, Chicago, IL.

Becoming Community (2012). Society for Disability Studies Conference, Denver, CO.

CLINICAL EXPERIENCE

2012-2013	Therapist intern, Developmental Disabilities Family Clinics, Chicago, IL

COMMUNITY EXPERIENCE

2013-present	Community Coordinator (role name changed to Director of Community Life in 2016), L'Arche Chicago, Chicago, IL
2013-2016	Co-Chair, L'Arche USA National Inclusion Team
2007-2013	Assistant in L'Arche communities (Chicago, IL; Trosly-Breuil, France; Rome, Italy; Arlington, VA; Haverhill, MA)

SCIENTIFIC COMMITTEES

2013-present	Scientific Committee Member, *Disability Studies* book series, Ed. Erickson, Trento, Italy
2013-present	Advisory Committee Member, *Italian Journal of Disability Studies*

AWARDS AND HONORS

2016	*Luca Badetti. Finding Similarities in Differences* (Wisby, G., 1/13/2016, UIC News)
2015	*This week's Chicagoan: Luca Badetti* (Ford, A., 6/4/2015, Chicago Reader)
2008-2009	AmeriCorps Education Award
2004	Dean's List, Franciscan University of Steubenville, Steubenville, OH
2003	Dean's List, University of Connecticut, Storrs, CT