Friendship and Inclusion of People with Intellectual Disabilities and Immigrant Care Workers

by

Deanna Neri

A thesis submitted in partial fulfillment of the requirements for the degree of

Master of Arts

Department of Anthropology
University of Alberta

Abstract

Friendship plays an integral part in modern life. Apart from families and romantic partners, friends are one of the most important sources of fulfillment and foundation for a well-lived life. However, studies have shown that people with intellectual disabilities face more challenges forming and maintaining friendships compared to people without disabilities. This research pays close analytic attention to friendship, an understudied domain relative to kinship in the extant anthropological literature. I am particularly interested in how disability support workers facilitate the inclusion of adults with intellectual disabilities. For this population, supported community participation and increased community presence are crucial in opening opportunities for socialization and friendship formation. Front-line care workers are overwhelmingly women and disproportionately immigrant women. As they facilitate the inclusion of their clients, they too experience social isolation. Data gathered from 20 in-depth interviews with front-line care workers in Edmonton, Canada show four key points; (1) staff develop an affectionate relationship with clients but some do not call it "friendship" to maintain professional boundaries, (2) genuine relationships help staff understand clients better and gives them a deeper sense of purpose in life, (3) context, environment, and frequency of meetings are essential for the development of friendships, (4) friendships among people with and without disabilities are crucial for community development. Through this research, I intend to contribute to the growing anthropological discussion on friendship and its importance in binding contemporary societies. This study will shed light on the importance of friendship for people with intellectual disabilities and disability support workers.

Preface

This thesis is an original work by Deanna Joyce Neri. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name "Friendship and Inclusion in Contemporary Canada: Immigrant Disability Support Workers and the Nurturing of Amity.", Pro00090805, May 13, 2019.

Some parts of Chapter 3 and Chapter 4 of this thesis has been accepted for publication as "Interdependence: The Pathway to Inclusion of People with Intellectual Disabilities and Migrant Care Workers" in *Anthropologica* 2021.

Acknowledgement

I cannot begin to express my deepest gratitude to my supervisor, Dr. Kathleen Lowrey who had been so patient and supportive since I started my graduate studies. Her immense knowledge and practical advice from data gathering to thesis writing had been really helpful. I am sincerely grateful for her patience, invaluable support, and motivation during my study. I could not have imagined having a better supervisor and mentor for my graduate studies.

I wish to thank Dr. Joseph Hill for acting as the chair of my thesis committee along with Dr. Helen Vallianatos and Dr. Bukola Salami for their insightful comments and questions, and for taking the time to critically engage with this research.

I would like to acknowledge my professors and colleagues at the University of Alberta whose expertise and experience have greatly shaped my perspective in my research. To Dr. Danielle Peers, Dr. Donna Goodwin, and my colleagues, I will be forever grateful for our thoughtful discussions on Critical Disability course. As well, I would like to express my special thanks to Dr. Andie Palmer, Dr. Helen Vallianatos, and my cohort for the stimulating conversations in class and their inputs that proved to be very helpful in my writing process.

I am also indebted to the University of Alberta and the Department of Anthropology for funding my studies. Special thanks to Ms. Heather Cook for the administrative support. My sincere thanks also go to Dr. Marko Zivkovic for his support and guidance throughout my program and Dr. Ruth Gruhn for her generosity in supporting my research.

I must also thank Dr. Ethel Tungohan, Cynthia Palmaria, and Whitney Haynes for imparting their knowledge and community work with migrant caregivers in Canada.

I am sincerely grateful to Kevin Laxamana for being a mentor, a friend, and a brother to me. I would not have survived graduate school without his helpful tips and constant support. My heartfelt appreciation also goes to Incy Aranas, Kris Soliven, and Nicole Salvador for the friendship and company. Thank you so much for making my graduate school life more bearable and fun.

Special words of gratitude go to my best friends too, Kim Reina, Sache, and Sharmaine who have always been a major source of support when things get rough. To the friends turned family, ate Arianne, ate Jovy, Shadrach, Allin, Charlene, and Chuckie, thank you for your constant encouragement. My sincere thanks to Eden Florendo as well for helping me with my interview transcripts.

A huge thanks to Hansel, Jun, Jayken, Psyche, Damian, Dannah, Jenny, and Jodan as well. Thank you so much for being my support system and family here in Edmonton.

The completion of this thesis would not have been possible without the love and nurturing of my family. To Mama, Papa, Chim, Kuya, Daryll, and Bilal, thank you for constantly giving me strength and motivation to achieve my goals. Special thanks to my sister, Ana for her unconditional love, and for the emotional and financial support that allowed me to focus on my studies. To the two most important people in my life, Andres and Ares, you have always been my greatest source of inspiration and happiness.

The last words of gratitude go to the organizations for welcoming me to their community and helping me reach out to their employees. Finally, I must express my deepest respect and appreciation for the care workers whose lives and work truly inspired me to finish this thesis. Thank you so much for being very generous with your time and insights during the interviews.

List of Abbreviations

ACDS- Alberta Council of Disability Services

CDSP- Community Disability Services Practitioner

DATS- Disabled Adult Transit Service

DSW- Disability Support Workers/ Developmental Support Workers

HCA- Health Care Aide

IDD- Intellectual and Developmental Disabilities

ILO- International Labour Organization

PSW- Personal Support Worker

PWID- People with Intellectual Disabilities

UNICEF- United Nations International Children's Emergency Fund

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Prologue

As an international student and a newcomer to Canada, I had difficulties adjusting to the new environment and finding a social circle where I feel a sense of belonging. As an anthropology student who has carried out at least three short-term stints of fieldwork and managed to quickly adapt to each community's way of living, I thought overcoming culture shock would be easier for me this time. However, after almost two years, I still find myself grappling with the social cues and socializing with people in this new country. Currently, I have three friends in Edmonton, all of them Filipino as I find it easier to relate and socialize with them.

This thesis is about friendship and inclusion of people with intellectual and disabilities and migrant care workers. My interest in disability studies started with the project I had with the United Nations International Children's Emergency Fund (UNICEF) on the health-seeking behavior of parents who have children with disabilities. Initially, I planned to do a comparative study on the treatment and perception of disability in Canada and the Philippines. However, prior to the start of my first year in graduate school, I had a few reflections while accompanying my nephew who has physical disabilities to his recreational activities. As well, my brief encounters with Filipino care workers led me to shift my research focus. While it is vital to support one's physical function, an individual's emotional and social well-being is equally important, yet often neglected. This led me to consider questions about what makes a life well-lived in various cultural contexts and what it means to belong to a community.

Introduction

Friendship plays a significant role in any individual's life. Aside from families and romantic partners, friends serve as a strong support system. They provide security and a sense of belonging. In times of trouble, people seek refuge in and comfort from their friends. In times of triumph, people celebrate in the company of their friends. However, research shows that adults with intellectual disabilities often have few friends and experience loneliness, thus, greatly affecting their physical and emotional well-being. The success of deinstitutionalization and normalization movements led to the integration of people with intellectual disabilities into mainstream society (Brown and Radford 2015). However, despite this progress, social inclusion remains elusive for this population. Adults with intellectual disabilities still experience isolation as they have difficulties forming and maintaining friendships. This research explores the development of friendship by adults with intellectual disabilities and the work of disability support workers in helping to make this form of inclusion happen.

Research questions and objectives

Considering the indispensable role and unique situation of disability support workers in facilitating social inclusion for people with intellectual disabilities, this project aims to address the following research questions:

1. What is the role of friendship in modern contemporary societies?
2. What kind of care work and social activities do support workers engage in to foster friendship and social inclusion for people with intellectual disabilities?
3. Given the demanding and isolating nature of care work, how do support workers in turn develop friendship for themselves?

The general objective of this research is to elucidate the kind of care work disability support workers do to make inclusion happen. Intimate and personal care is widely documented in the existing literature, while this “amity” work is not. By doing so, my specific research objectives are:

1. To document and analyze the specific activities that foster friendship and inclusion.
2. To document the paths and barriers to social inclusion both for people with intellectual disabilities and disability support workers.
3. To understand the importance of friendship in modern contemporary societies.

Through the first and second objectives, this study aims to shed light on the concrete work of disability support workers in facilitating social inclusion which is often neglected in the extant literature on care work. Recognizing the paths and barriers to social inclusion will help policymakers come up with better measures to improve the quality of life of people with disabilities. Moreover, this will also help understand the actual work of disability support workers and provide assistance in areas where they need it most. In turn, this will have an impact on the quality of care provided and ensure the sustainability of the care economy. Finally, as scholars have paid less attention to friendship than to other forms of relationship, the third objective will illuminate the importance of friendship both in a theoretical and practical manner.

Overview of the problem

Friends are one of the most important sources of fulfillment and measures of an individual's quality of life (Fulford and Cobigo 2018). However, in contrast to their non-disabled peers, people with intellectual disabilities face more challenges developing and maintaining friendships and are more prone to loneliness and social isolation (Fulford and Cobigo 2018; Petrina et al. 2014; Petrina et al. 2017).

Despite significant changes and progress in disability policies, social inclusion and friendship formation still remain a serious challenge for people with intellectual disabilities (Van Asselt et al. 2015). For people with intellectual disabilities, facilitators of social inclusion include the development of friendships through supported community participation, community presence, and activities involving other people that open possibilities for friendships to form and flourish (Van Asselt et al. 2015).

In Canada, care work is highly feminized, a job often taken up by migrant and racialized women (Hanley et al. 2017; Kelly et al. 2011; Spitzer and Torres 2008). While these workers facilitate the inclusion of intellectually disabled individuals, they too face problems of isolation and loneliness. Care work remains undervalued due to the presumption that it is unpaid, and a less skillful 'female job' despite the significant skills, professionalism, and physical strength involved (Armstrong and Armstrong 2001).

It is also worthwhile to note that the rates of staff turnover in this field are quite high (ACDS 2020) which greatly affects the quality of care and well-being of the clients. As well, disability support workers who are often highly-educated immigrants experience job mismatch and face difficulties transitioning into the Canadian labour market (Hawthorne 2008; Tungohan et al. 2015; Wilkinson et al. 2014, 2016).

Significance of the study

This project will contribute to the growing anthropological and sociological literature on friendship and care work. Much of existing literature focuses on physically intimate labour: bathing, dressing, and feeding, whether of children, the elderly, or people with disabilities. This attention to *intimacy* has neglected *amity*: friendly tasks of disability support workers which include helping people find friends or simply accompanying them in leisure activities. This research will shed light on the importance of friendship and how it promotes a sense of belonging, especially among people with loosening family ties. As well, this research will show how people with intellectual disabilities and migrant care workers navigate their way through diversity and inclusivity. Canada is an appropriate site for this study because it is one of the exemplars of inclusivity for both people with disabilities and immigrants worldwide (Hennebry 2014; Hennebry and Preibisch 2012). The paths and barriers to social inclusion and how these affect the quality of life of every individual will be highlighted in this study. Results from this research will help inform policies and practices to make a truly inclusive society and ensure the future of the Canadian care economy.

Literature Review

Friendship

Friendship plays a central role in many people's lives across cultures (Beer and Gardner 2015), yet scholars have paid little attention to this concept in the extant anthropological literature until recently (Killick and Desai 2010; Miller 2017; Pitt-Rivers [1983] 2016). Scholars have linked this relative lack of attention to friendship to anthropology's emphasis on kinship and its role in structuring traditional societies. Additionally, the fluidity and scope of the definition of friendship in various cultural contexts made it more difficult for scholars to explore this concept (Killick and Desai 2010).

In an extensive literature review on friendship, Pakaluck (1991) noted that Greek philosophers like Aristotle and Plato were among the earliest proponents of theoretical conceptions of friendship. These theories have been neatly summarized by Adam and Blieszner (1992) in their influential book on *Adult friendship*. According to Plato, the innate human desire to achieve goodness and realize self-actualization through human connection lay the foundation for a true friendship to develop and flourish (Adam and Blieszner 1992; Bolotin 1979; LaBranche 1975, 1976; Price 1989; Synder and Smith 1986). Similarly, Aristotle describes the ideal friendship as a mutually beneficial relationship where both individuals appreciate each other's good qualities, values the friendship, and cherish each other's presence. In contrast, he also discussed the illusory friendship where people establish a relationship for the sake of utility and pleasure, with the ultimate goal of gaining something from the other person (Adam and Blieszner 1992; Bukowski et al. 1987; Synder and Smith 1986).

Generally, friendship studies in this era were characterized by philosophical questions about the connection between social justice and happiness, and the development of moral character (Blieszner and Adams 1992; Sahakian 1974).

Meanwhile, contemporary scholars have provided a different view on friendships based on the changes in its representation and function across time. Lopata (1991) believed that early human societies were collective in nature and provided numerous opportunities for friendships to develop among individuals. People interacted with other members of the community daily and were more likely to maintain social relations. The onset of industrialization allowed individuals to expand their social network through their interactions in public places with other people. These social activities paved the way for all kinds of friendships to flourish, transcending gender, age, and class distinctions. As industrialization continues, people are slowly becoming more individualistic and have begun having fewer social interactions outside the nuclear family (Adam and Blieszner 1991; Lopata 1991). However, in the modern age, Lopata argued that people have struck a balance between these two extremes by maintaining friendly relations with spouses and colleagues (1991).

This view has been contested by scholars who believed that industrialization enabled contemporary friendships to flourish. The economic transformations which placed the nuclear family as the norm in Western societies increased the importance of friendship ties in binding contemporary societies (Adams and Allan 1998; Giddens 1992, 1999; Oliker 1998). However, in an introductory chapter of *Ways of friendship*, editors Desai and Killick (2010) challenged this assumption and argued that friendship is not a product of modernity. Early research on the perceived importance of friendship in European societies pre-industrial revolution shows otherwise (Bell and Coleman 1999; Brain 1977; Spencer and Pahl 2006;

Hanawalt 1986). Further, the editors argued that friendship is not peculiar to Western societies and has varying definitions across time and cultures (Killick and Desai 2010).

This lack of consensus on the definition of friendship in anthropological studies created difficulties for scholars to do continued and cross-cultural research (Killick and Desai 2010). However, to date, there have been two significant theoretical and methodological distinctions in the existing literature. The first proposition as identified by Torresan (2011) is held by authors who conceptualize friendship as a kind of relationship deeply embedded in Western notions of individual autonomy. Conversely, the second proposition views friendship as a form of social relatedness present in all societies (Torresan 2011), and a social process that occurs within particular historical and cultural contexts (Aguilar 1999). This definition allows for a more contextual and nuanced understanding of friendship in contrast to the narrow, private relationship characteristic of the western model. (Torresan 2011).

Several authors who follow the first definition, describe friendship as a product of capitalist transformations that brought about the changes in social and moral codes that separate individuals from society and the divide between private and public spheres (see Allan 1989; Carrier 1999; Paine 1999; Pitt-Rivers 1973). In his chapter, '*People who can be friends',* Carrier (1999) argues that friendship is a voluntary relationship based on spontaneous and unconstrained sentiment between two autonomous individuals in a private domain. Following this argument, western scholars believe that friendship can only develop between two social equals who can reciprocate each other without material interference (Carrier 1999; Winkler-Reid 2016).

Meanwhile, scholars who hold the opposite views on the westernized model have put emphasis on friendship as a social process and defined by friends themselves in different contexts. Friendship can have different models and practices, thus, ‘making it difficult to offer a single, all-encompassing definition of Friendship with a capital F’ (Santos-Granero 2007, 9; Winkler-Reid 2016). Similarly, Killick and Desai (2010) suggested that an efficient way to explore this concept is to allow an expansive definition of friendship. This proposition is built on Carsten’s (2000) invitation to allow open and multiple definitions of friendship rather than restricting it to the existing social categories since “relationships of friendship do not necessarily map neatly on to local conceptions of kin and non-kin” (Killick and Desai 2010, 1). This is also supported by Firth in his preface to *The Anthropology of Friendship,* “the concept of friendship can vary greatly in intensity, from simple well-wishers to familiar, close, dear, intimate, bosom, boon-companion friend, each with its own subtle quality” (Firth 1999, xiv). Thus, it would be impossible to come up with a clear-cut definition of friendship that will capture its cross-cultural variations. This was anticipated by a prescient essay by Pitt-Rivers who encouraged scholars to understand friendship in specific contexts for “there is no such thing as friendship, but only friendships” ([1983] 2016, 451).

Following this approach, I am also putting emphasis on the social context and dynamics of relations to minimize the risk of masking important local distinctions by lumping it all together under the category of *friends* (Killick and Desai 2010). By putting *friendships in context*, I acknowledge the conditions that affect the formation, maintenance, and disintegration of friendships (Adams and Allan 1998). This means putting a more nuanced understanding of friendship-- one that is embedded in a wider, complex network and interplay of relations (Policarpo 2015).

In this thesis, I follow this proposition to allow an open definition to include various kinds of relationships and elicit the social importance and functions of these relationships (Killick and Desai 2010; Pitt-Rivers [1983] 2016).

Friendship among people with intellectual disabilities

Scholars argued that people who have established intimate relationships have reported higher emotional well-being (Arias et al. 2009; Fulford and Cobigo 2018). Strong social support that can be derived from friendships is pivotal to increased community participation, positive engagement, and conflict resolution (Fulford and Cobigo 2018; Lafferty et al. 2013; Petrina et al. 2014). Despite the deinstitutionalization movement and drive for social inclusion, people with intellectual disabilities still have limited friendships (DaWalt et al. 2019; Emerson and McVilly 2004; Tipton et al. 2013). Thus, it is not unusual that most people with intellectual disabilities consider their paid staff as their friends (Asselt-Goverts et al. 2015; Friedman and Rizzolo 2017; Pottie and Sumarah 2004). While the friendship between staff and clients has considerable mutual benefits, some scholars argue that “paid relationships” are inappropriate and cannot be considered as real friendships. This argument is built on the premise that friendships cannot be paid or bought as it distorts the “private” arrangement of the relationship and converts it into “business” (De Freitas-Cardoso 1987; Lutfiyya 1993; Reiss and Daly 1989; Rubin 1985). Additionally, this is problematic since this field has quite high level of staff turnover and friendships with staff are most likely temporary (Bigby 2008).

Studies indicated that poor social networks are a result of limited opportunities for developing and maintaining friendships (Friedman and Rizzolo 2017; Pottie and Sumarah, 2004). For people with intellectual disabilities, social inclusion rely heavily on support of staff to facilitate friendship formation through supported community participation, community presence, and activities involving other people that open possibilities for social interaction (Van Asselt et al. 2015). According to Bogenschutz et al., "focusing on the benefits of social inclusion for both people with IDD and for people without disabilities is a necessary endeavor and important framework that emphasizes inclusion as having reciprocal benefits for the entire community" (2015, 212).

As evidenced in previous research concerning people with physical disabilities, removing physical barriers will most likely improve participation in meaningful social activities (see Law et al. 2015). However, for people with intellectual disabilities, restrictions are not only limited to environmental barriers as they need adequate support in planning, organizing, traveling, and communicating to participate in a particular activity (Lante et al. 2014). As Wilson et al., aptly puts it "finding novel interventions to increase the activity, social inclusion, social contacts and friendships for people with intellectual disability is urgently needed" (2016, 848).

Social inclusion

Just like *friendship,* scholars also face difficulty finding a clear definition of inclusion (Wilson et al. 2016). Some have opted to use terms such as integration, community participation, and belonging interchangeably which compounded this confusion (e.g., Amado et al. 2013).

The United Nations Convention on the Rights of Persons with Disabilities (2006) states in Article 19 that people with disabilities have the right to live and be fully included in the community. The treaty stipulates that persons with disabilities should have the freedom to choose where and with whom to live and should have an opportunity to choose a range of in-home, residential and other community support services to make inclusion happen. Scholars noted that this ambiguity creates challenges in assessing whether this goal was achieved (Wilson et al. 2016). Thus, making it harder to measure outcomes and influence research, policy, and practice in general. This ambiguity is best illustrated in the scenario described in O'Brien and O'Brien (1993) where there is a disagreement between a special education teacher and a mother who advocated for her child's inclusion. While the teacher takes pride in expressing that everybody in school knows the child's name and says hi to him, the mother believes that people are friendly to him but they do not involve him in their social activities outside of school. She later asks that people should be more supportive and focused on assisting her child to have more friends which the teacher cannot understand (O'Brien and O'Brien 1993).

Inclusion does not simply mean presence in the community. More than any declaration of their rights, people with disabilities need a genuine social network to ensure they get access to opportunities to form friendships and participate in meaningful social activities. As Reindeer (2002) argued, it is not only citizenship but *friendship* that matters. For this population, inclusion will remain elusive and problematic without supported social networks (Reindeers 2002).

Simplican et al. (2015) came up with an ecological model of social inclusion by focusing on two domains: *interpersonal relationships* and *community participation.* Each domain covers categories that overlap and support each other to make social inclusion happen. On the one hand, the framework captures categories of relationships such as family and friends among others, including its structure and functions. On the other hand, community participation is expounded by presenting different types and degrees of participation such as employment, religious activities, etc., and defining its structures whether it is segregated or mainstream. While some relationships are used to explain this model, it is important to note that this model does not exclude other types of relationships such as those with paid staff. Rather, as the authors argued, "social inclusion is for all of us: an individual with an intellectual or developmental disability; for people with intellectual and developmental disabilities as a group; for members of society who will benefit from their inclusion; and for nation-states who can benefit from the participation of people with all levels of abilities" (Simplican et al. 2015, 22). Increased community involvement will most likely strengthen an individual's social network and vice versa (Petry, Maes, and Vlaskamp 2005).

The discussion of inclusion above specifically pertains to people with intellectual disabilities. However, I believe this concept of inclusion that emphasizes interpersonal relationships and community participation is also crucial to the situation of disability support workers, especially migrants. They, like the people they support also experience social exclusion and loneliness.

Social exclusion and loneliness among disability support workers

Interviews with people with intellectual disabilities show that their inclusion heavily relies on supported social networks (Wilson et al. 2016). Disability support workers play a significant role in facilitating friendship formation and increasing their clients' community participation. However, as they support the inclusion of people with intellectual disabilities, they too face social isolation.

It has been widely recognized that immigrant care workers form the backbone of the Canadian care industry (Hanley, Larios and Koo 2017). Despite the significant skills, professionalism, and physical strength required by care work, it remains undervalued due to the presumption that it is unpaid, and a less skillful 'female job'(Armstrong and Armstrong 2001).

While Canada is renowned for its best practice model on labour migration management (see Basok 2003; Hennebry and Preibisch 2012) and for its promotion of multiculturalism, several studies on immigrant settlement and integration show that the majority of immigrants experience social isolation and loneliness (Hanley, Larios and Koo 2017; Ihejirikaa, Salami and Karimi 2016).

For immigrant live-in caregivers, the isolating nature in the private sphere, the low wages, and under-recognition of the legitimacy of their work presents a great challenge for their integration after the live-in program (Spitzer and Torres 2008). Similarly, in a sweeping review of literature on African immigrant women's experience in western societies, one of the most common problems was isolation and the absence of family members and social networks (Hyman et al. 2008; Ogunsiji et al. 2011; Tilbery and Rapley 2004). This lack of social support greatly affected immigrant women's well-being as they struggled to secure jobs in gendered and racialized job markets (Ihejirikaa, Salami and Karimi 2016).

While there is a growing scholarly literature on the supported inclusion of people with intellectual disability, disability support workers have tended to be eclipsed in both the activist and scholarly discussions. I believe that capturing narratives from people who make inclusion possible for people with intellectual disability is equally important to ensure quality care services and the sustainability of the care economy.

Research Methodology

Framework

In this research, I draw on Joel Robbins' "anthropology of the good" (2013) in exploring how immigrant disability support workers facilitate friendship formation and inclusion for people with intellectual disabilities. In this framework, Robbins highlighted how contemporary anthropological studies represent suffering to build an empathetic connection to the readers hoping it will be an impetus to social change. While these stories of struggle are important in raising awareness and achieving social justice, he argued that this also creates risks of flattening multi-faceted experiences as mere stories of suffering. As Robbins puts it:

> It is my hope that an anthropology of the good can take up that project, helping us do justice to the different ways people live for the good, and finding ways to let their efforts inform our own...The point of developing this new kind of anthropology would not be to displace the anthropology of suffering, which will continue for the foreseeable future to address problems we need to face. It would be to help realize in a distinctively anthropological way the promise suffering slot anthropology always at least implicitly makes: that there must be better ways to live than the ones it documents (2013, 458-459).

I find this approach relevant to my thesis mainly because immigrant disability support workers and adults with intellectual disabilities are among the population who belong to the "suffering slot" in anthropology (Robbins, 2013). I believe that the stories of marginalized communities I have worked with are not just stories of struggles and sufferings. Their experiences are intricately intertwined with stories of success, joy, resilience, and resistance as well. Within this framework, instead of approaching disability as an attribute attached only to what Robbins wryly calls "suffering subjects" (2013), I use it to look at the dynamics of the relationship between immigrant disability support workers and people with intellectual disabilities as an inevitable element in complex community-building.

Methods

For this research, I conducted 20 semi-structured interviews with disability support workers across Edmonton. I chose to conduct the study in Edmonton for practical reasons; first, I am an international student and getting funding for my fieldwork outside the city is quite challenging. Second, since I am a newcomer, I am more familiar with the city and could easily go around and meet potential interviewees within my limited timeframe.

Initially, I planned to interview live-in migrant care workers for people with intellectual disabilities as they present an interesting case. Migrant care workers enter the country with a temporary work visa and are tied to a specific employer. As evidenced in previous studies, the precarious status and the live-in component of their contract make them vulnerable to different types of labour abuse such as non-payment of wages, long working hours, and unsafe working environments to name a few (Maher and Cawley 2016; Peixoto 2009; Tungohan 2018). Additionally, while they facilitate the inclusion of people with intellectual disabilities, they too, face problems of isolation and loneliness. I am interested in how these workers navigate their way through diversity and inclusivity despite the challenges attached to being temporary workers. However, due to the isolating nature of this work, I had difficulty reaching out to this population especially those who are working with people with intellectual disabilities.

My supervisor had previous engagement with a non-profit organization offering residential services to people with developmental disabilities and their families in Edmonton.

It was part of the Community Service Learning component of the two undergraduate courses she taught. I was able to draw my first set of interviewees from this organization. I sent out emails and flyers to the organization and asked if they could forward it to their employees and post it in bulletin boards. I sent out a call for participants twice and was able to get six responses out of the 500+ employees. During the course of my interviews, some staff referred me to other service organizations offering day programs, employment programs, and respite services. We contacted at least five more service organizations in Edmonton and we were able to get responses from two of them. These are medium-sized and large-sized organizations with an average of 80 to 500 employees. Yet, even with this network, I still had difficulty getting enough participants.

Some of the participants preferred to hold the interviewees in recreation centers after their shift. It had been beneficial for me since they were also able to refer me to other support workers who were there at the same time. I was able to get seven immigrant interviewees by visiting recreation centers. These contacts also recommended two more. Unfortunately, while some service organizations are willing to collaborate on our research project, others were rather disinclined to participate. Thus, by the end of the summer break, two of the participants requested to withdraw their interviews, and the other two canceled their interview schedules fearing it might affect their jobs. Their employer disapproved of their participation in the research due to image management concerns. The employer emphasized that they did not want anything negative written against their organization since government funding is contingent on their performance.

In conducting research, we often intend to do good, create a positive impact, and inspire social change in a specific field (Clark and Sharf 2007). However, despite the richness of data in some interviews, protecting the interviewees' identity and welfare is a top priority for me. In the beginning of our interviews, I emphasized that their participation is completely voluntary and they can withdraw from the research anytime they wish without any repercussions. I see to it that I maintain open communication with all my interviewees before and after fieldwork. As a researcher, I ought to seek consent as I progress and always remind my informants that they are free to withdraw or eliminate the data they have shared anytime (Clark and Sharf 2007). And so in these instances, I immediately deleted their files according to the research protocol I have designed in my ethics application. As much as the informants wanted to publicize their stories, I believe it is my task to ensure that the possibility of harm to my informants is kept at a minimum.

Laura Nader discussed this dilemma in her influential 1972 essay "Up the Anthropologist — Perspectives Gained from Studying Up." In this essay, Nader cautioned researchers that in turning the ethnographic eye *up* to the people who wielded power, one may encounter problems of access, which actually happened in my fieldwork. It is also worthwhile to note that although there are organizations that agreed to collaborate with us, some have also carefully screened the potential interviewees. When my supervisor and I explained the purpose of my research, we were given a master list of people we should contact and interview. I believe this is not surprising in conducting social research just as what a business professor discussed in his essay, "Interviewing Important People in Big Companies":

> Large corporations... have gates, guards, and security devices... Even welcome visitors encounter inner lines of defense: public relations departments, "official spokespeople," and whole levels of management trained in how to represent the company to the outside world (Thomas 1993, 82).

Although the initial purpose of my study was to interview support workers, I believe looking at these service organizations which have a direct impact on the employees merits further anthropological study.

The usual participant-observation which has defined most anthropological fieldwork was not carried out for this project since it requires a sensitive human subjects research protocol. At this stage, I do not feel prepared to design a robust informed consent protocol in conducting interviews with adults with intellectual disabilities. Further, as awareness has grown about disability and disability rights, support workers have tended to be eclipsed in both the activist and scholarly literature on disability. However, I would like to clarify that it is not my intention to create a hierarchy of oppression by foregrounding the accounts of disability support workers. Rather, I believe that incorporating the accounts of disability support workers is essential in understanding the complexity of the lived experiences of people with disabilities. Additionally, as contemporary scholars argue, with regard to people with intellectual disabilities, we need to recognize the role of guardians as people who are sometimes well-positioned to represent and speak for them (Berube 2010). This challenges the notions of personal autonomy which emphasizes the individual's capacity for self-determination and self-government (Davy 2015).

The concept of individual autonomy has become central in campaigns for achieving inclusion and full citizenship for people with disabilities. This westernized notion of autonomy emphasizes individual's rationality and ability to decide for every aspect in their lives free from the imposition of external forces (Davy 2015, 133). Considering the long history of oppression and dehumanization of people with disabilities in institutions, personal autonomy has been at the core of disability advocacy (Barnes 2012; Davy 2015). However, this emphasis on personal autonomy has been criticized by feminist theorists for neglecting to consider that people regardless of ability are inherently social and relational. Even able-bodied adults are not fully autonomous as they have basic dependencies in the course of life, whether it be in childhood, old age, temporary limitations, or in the case of illness (Kittay 1999; Pickering and Silvers 2007).

Similarly, disability scholars also challenge this notion for its cognitive bias that further marginalizes people with intellectual disabilities (Davy 2015). Scholars argue that no individual is ever fully autonomous as we all have basic human dependencies. Throughout our lives, we seek support whether it be emotional, financial, or practical support from family, friends, or even the government (Davy 2015; Kittay 1999; Withers 2012).

Consequently, Davy (2015) suggests a reconfigured view of autonomy that recognizes every individual’s vulnerability and basic dependencies and the need for an ongoing support and caring environment to be autonomous agents in the society. This was built on Nedelsky’s relational model of autonomy that discards the view of autonomy as a human attribute but rather enabled through supportive relationships and network (1989, 2011). In this model, autonomy is not an individual attribute but a collective responsibility, as Davy puts it, “the “I” is only autonomous with or through “we” or “them” (2015, 140). Through this model, the role of carers whether members of the family or paid carers, are highlighted as they are the ones providing direct support and care to people with intellectual disabilities.

Research participants

For this research, I interviewed 16 female care workers; 10 of them were migrant caregivers who came to Canada from Southeast Asia and Africa with a temporary visa; five (5) were white females, born and raised in Canada; and one (1) was an Indigenous woman. I also interviewed six (6) male interviewees; two (2) were from Africa; one (1) from an Indigenous community, one (1) from Europe with Canadian citizenship; two (2) were white male, and citizens of Canada.

Research data was based mainly on individual in-depth interviews I conducted from June to October 2019 in Edmonton. I also attended orientation and facility tours by different service organizations, went to one organization's general assembly, and participated in panel discussions concerning the caregivers in Alberta.

Since most of my interviewees were migrant women care workers, the vast majority of my detailed analyses were centred around on their accounts. I put more emphasis on their experiences as these migrant women were the ones providing direct personal care and taking out the individuals to the community. Whereas, the Canadian women and men interviewees were more involved in administrative tasks, planning, and recreation activities for people with intellectual disabilities.

Interview questions focused on the practices and strategies that disability support workers use to foster friendships for people with intellectual disabilities. Factors that either support or impede the development of social relationships for both clients and support workers were also discussed. For the most part, interviewees focused the discussion around the most challenging and rewarding aspects of this work. While I have prepared a set of questions (see Appendix), during the actual interviews these questions were slightly modified based on what the interviewee wishes to share. For instance, immigrant support workers were more inclined to talk about their previous profession in their home countries and the process of integration in Canada. Whereas, support workers who were citizens in this country talked more about their motivations for working in this industry. I tried to keep our interviews as open and free-flowing as possible to capture the myriad experiences of disability support workers.

To protect the identity of research participants and maintain confidentiality, all identifying information are removed from this thesis and all names are replaced with pseudonyms.

Trustworthiness and Truth Value

In an effort to be as objective as possible, researchers often try to eliminate personal reflections in the process of writing fearing it will dominate the discussion and supersede the actual research topic. However, in doing so, scholars are actually leaving a substantial gap in the research process which is crucial for the readers to understand what influenced the research and their interpretation (Yow 2006). These subjectivities are actually beneficial when researchers become more aware of their motivations in choosing the topic and recognize how their class, gender, age, race, and other aspects of one's identities affect the relationship with the interviewees as well as the entire research process (Yow 2006). In my case, I initially chose the anthropology of disability because of my nephew who has physical disabilities. My interests in migrant care workers arose from my undergraduate thesis and my previous engagement with vulnerable women in my home country, the Philippines.

Another aspect of the researcher's identity that may influence the interview process is *age.* Considering that I come from a younger generation, the way I think and the kinds of information I seek differ from what my interviewees consider as important (Yow 2006). The fact that I am also a single woman affects the types of stories and information the participants usually share. For instance, the struggles of being a breadwinner and a mother separated from her kids are often seen by my interviewees as less relevant to me. Often, interviewees start their statements with, *"you may not fully understand this because you don't have children yet",* when explaining the challenges of being a mother.

Status can also influence conversations. Throughout the course of my fieldwork, I realized that migrant workers in Canada have the assumption that individuals on a student visa are rich and therefore do not share the same experiences with them. Some of my Filipino interviewees say that we do not have the same struggles and I have no idea how difficult it is to make ends meet and send money back home. Sometimes this creates a barrier for more open communication between me and my interviewees. However, as we continue with our conversations and exchanged experiences of culture shock, we were able to negotiate this presumed class differences and agree that we are similar in a way that we have precarious immigration status in this country.

Another important factor that constantly arises in informal conversations with interviewees is the concept of *transference*. Transference happens when past feelings are redirected to a person in a present situation (Figlio 1988). Yow expounded this concept by providing an example which I find very relevant to me; "a narrator may be consciously or unconsciously relating to a younger interviewer as a daughter or son. Not only may transference be influencing narrator's attitudes in the interview but there may be transference as the interviewer responds to this" (2006, 65). I often have these encounters with female interviewees. Every time I introduce myself, most of the older women I interviewed would relate to me in the most affectionate way and say "I see my daughter in you, or you are the same age as my son." Researchers argue that transference is beneficial and often leads to positive relationship between researchers and narrators. However, at some point, this will also cause some hesitations in asking questions that may be uncomfortable for the interviewees who have become too close to the researcher. As for my experience, I did not have too much difficulty asking certain questions since most of my interviewees openly shared their experiences to me as if I were their child. At times, when I had difficulty rephrasing sensitive questions especially about family life, the majority of my interviewees would finish my sentence even before I spoke it.

Transcription and translation

In this research, I did a lot of transcribing and translating especially in my interviews with Filipino support workers. On one hand, I am grateful for interviews done in Tagalog since my interviewees were able to provide a more elaborate and detailed story of their experiences in Canada. On the other hand, I find the process of transcribing and translating to English quite challenging. Unlike printed documents from which we can easily quote and cite original sources, oral sources present a dilemma on the level of accuracy of the transcript in contrast to the actual conversation (Ives 1995). As much as I want to transcribe everything from the tape, Ives (1995) argued that transcription will only serve as the best representation of our own interpretation of the actual dialogue recorded. Ives (1995) suggested that before transcribing, the researcher should decide the level of accuracy one wishes to achieve. In my research, I prefer the clean transcriptions in which all the "uhh", false starts, tag questions, and the like are omitted. I choose clean transcriptions because these conversations will be translated into English afterward.

Just like the transcribing process, translating also requires the identification of goals and priorities in processing the recorded interviews. In this project, I draw on Langen's (1992) idea of glossed versions of translations. Translating does not necessarily mean faithfulness to the original text. As Nida puts it, "...all translating involves differing degrees of paraphrase, since there is no way in which one can successfully translate word for word and structure for structure" (1993, 2). Literal translations will be most likely misleading and impossible to achieve and so in these glossed versions (Langen 1992), I will provide interlinear texts which will show the connection between the original text and the translated version which is very important and helpful to the readers.

Notes on language

Friendship and friends

In this study, *friendship* and *friends* often come up as a core concept, yet these words lack a clear-cut definition. This ambiguity has been noted by Raymond Firth in the preface of *The Anthropology of Friendship: "*the concept of friendship can vary greatly in intensity, from simple well-wishers to familiar, close, dear, intimate, bosom, boon-companion friend, each with its own subtle quality" (Firth 1999, xiv). Thus, in this research, I explore the concept of friendship in the broadest sense, *i.e.*, it is not primarily considered as kinship (Killick and Desai 2010). Instead of exploring this term through the lens of existing categories, I rely on my interviewees' definitions of friendship in different social contexts. Allowing an open definition of the concept will reveal various kinds of relationships and elicit the social importance and functions of these relationships (Carsten 2000; Killick and Desai 2010).

Disabled people vs people with disabilities

There has been an enduring debate about the "identity-first" and "person-first" language in the disability community (Vaughn 1997). The Person-first language is built on the premise that we should recognize the person as a whole rather than reducing their identity to their disability. Thus, it is more preferable to say "person with disability" than "disabled person". By contrast, the identity-first argument asserts that disability is not something that is simply added unto one's identity, a negative characteristic that can be separated from the person. By using the term "disabled person", we recognize that their disability is integral to their person; impairments can put some limitations, but ultimately, it is the inaccessibility of society that disables them. Ideally, I would have asked the people directly how they identify themselves. However, I find that it is not possible to do so in this research for two reasons.

First, I am interviewing disability support staff. Second, many of their clients are non-verbal. Thus, I decided to use the default language commonly used by members of the community, which is the people-first language. People with intellectual disabilities often identify with this language. Moreover, there has been an advocacy group that dates back to 1970s called *People First,* an organization run by and for people with intellectual disabilities.

Intellectual disability, developmental disability, cognitive disability

According to the American Association on Intellectual and Developmental Disabilities (n.d.), *intellectual disability* refers to the significant limitations in both intellectual functioning and in adaptive behavior which originates before the age of 18. *Cognitive disability* can be categorized under this term as it broadly relates to the thought process. Meanwhile, *developmental disabilities* refer to severe chronic disabilities that can be cognitive or physical or both. These are usually lifelong disabilities that appear before the age of 22. Initially, I used the term *people with intellectual disabilities.* However, throughout the course of my research, I found out that most of my interviewees are working with clients who both have physical and intellectual disabilities. Thus, for this research, I use both *people with intellectual and developmental disabilities* and *people with intellectual disabilities*.

Immigrant vs. migrant

According to Statistics Canada (2016), an *immigrant* is a person who is, or who has ever been, a landed immigrant or permanent resident. Such a person has been granted the right to live in Canada permanently by immigration authorities. Whereas, *migrant worker* is defined by the International Labour Organization (ILO) as those who cross international boundaries for employment. In this thesis, I have used the terms *immigrant* and *migrant* interchangeably since some of my interviewees started with the Live-in Caregiver Program (LCP). Live-in caregivers hold a temporary status within a specific period. Upon completing the program and meeting the requirements set by Immigration, Refugees and Citizenship Canada (IRCC), they are then eligible to apply for permanent residency. Most of them are already immigrants but the experiences shared during the interviews go back to when they were still temporary workers. For this research, I use migrants and immigrants interchangeably to describe care workers who move from their country of origin for employment.

Caregiver, care worker, support worker

In Canada, there are numerous titles used to describe a worker who provides personal care and support services. According to Sorrentino, Remmert, and Wilk (2018), each province and territory in Canada adopt different titles for care workers such as patient care assistant, resident care attendant, health care aide, home support worker, nursing aide, community health worker among others. In Alberta, Health Care Aide (HCA) is the commonly used term to describe workers who provide direct care, personal assistance and support to patients who are ill, elderly or disabled. They assist in daily personal care such as bathing, grooming, dressing, and toileting (Alberta Health Services n.d.). While this is part of the job description of my interviewees, most of them also perform tasks beyond personal care. They also accompany their clients in their day-programs, help them seek employment, arrange medical appointments, and facilitate community participation to name a few. Some of them describe themselves as *caregivers,* others as *disability support worker,* and few of them identify as *community disability services practitioner*. In this thesis, I decided to use the general title *support worker, care worker,* or *carer* to encompass all kinds of support services that they provide.

Support

I am aware that the term *support* is quite broad and problematic as it is used too often in various contexts. Even during interviews, research participants refer to all the services they provide as *support*, this includes personal care, household chores, social support, companionship, and even being a friend is considered as a form of support. For the purpose of this paper, I will use it to describe all the activities, services, and strategies that disability support workers do to meet the needs and ensure the safety of their clients, as well as facilitate their meaningful integration to the community.

RESULTS

Friendships of people with intellectual and developmental disabilities

When asked whether their clients have friends, participants always refer to their client's physical disabilities and communication abilities. People who have limited mobility also have limited chances of going out to meet people. Most of their activities depend on the support worker's initiative and planned activities for the day, outlined by either the family or the organization and program of which they partake. According to the interviewees, people who are capable of doing self-care have more time to go out and participate in day programs. Whereas, clients who need support on feeding, bathing, taking medications rarely or sometimes do not have enough time left for socialization. On top of the personal care activities, support workers also have to clean the house. Care workers employed by an agency sometimes do this voluntarily. However, care workers directly employed by families often find themselves obliged to do this 'extra' work as demanded by their employers. Another factor affecting friendship formation is the individual's *communication abilities***.** Care workers observed it is difficult for their clients to find friends when they cannot communicate directly in a conventional way with other people. Some support workers also refer to their client's short-term memory as another barrier in forming and maintaining friendships.

> Like Travis and Mary, every activity they see each other and that's how they became friends. Tomorrow, Travis will have another set of friends from a different program. As the time goes by, Travis gets to know a lot of acquaintances who will later become his friends.
> *~Amelia*
>
> It's not really… I guess because I mean considering the fact that she's non-verbal, there isn't really much communication but between me and her, yes, because I've gotten to know her quite a bit.
> *~Briana*

> Because even sometimes, you know, some people come in and they don't even want to interact with the person. Then it's like they feel, you know, even though they are non-verbal, they can still understand, right? Because even sometimes I say *"today we're doing this*" and then you can see her nodding her head.
> *~Chesca*

Staff-client friendship

Some participants identify themselves as their clients' friends. Some also say, they are acting like a friend to show clients how to make friends. They are modelling friendships by being one. Others also say clients make friends through the support workers' network. While waiting for the clients to finish their regular programs, support workers start talking with each other and share information that may be helpful to one another's client. Sometimes they also plan to go to the same activities or share a table with one another, introduce their clients to each other and eventually become a little community. There are times when clients become friends with each other first, so the staff often see each other and become friends eventually.

> Yeah we're always in a group. Like everywhere we go, the clients themselves are friends that's how we also develop friendship. So it becomes like a community of its own.
> *~ Dorothy*
>
> …then the friendship kind of gets there because the clients will ask "let's hang out again" or the staff will say "Let's do this again, it was fun" just to have that company with each other even if the clients are non-verbal, they enjoy being around with other people.
> *~Esther*

Staff find it very helpful to have a community where everyone feels safe and comfortable with each other. Aside from sharing information with one another, staff also share simple responsibilities over their clients when needed, like taking turns in their washroom breaks. One participant shared how she became the favorite of another care worker's client and how she is able to calm down or cheer that person when she is not feeling so good.

> Yeah. So I myself know the individuals as well and they all know Elena. For example, if I need to use the washroom, I feel comfortable leaving her there because you know, because sometimes it's just hard when you're at the mall and stuff like that happens. I always take Elena with me even in the washroom. It's just difficult sometimes but you know you have support staff who will watch out for your client.
> *~Fiona*

In contrast to previous studies indicating the negative effect of friendships between staff and clients, the disability support workers I have talked to claimed that these affectionate relationships if they may call it as friendship is the major reason why they don't want to leave their jobs easily.

> I only work 6 hours for him since I only accompany him in his day programs. I've been getting a lot of offers with full-time hours even from the agency managing his group home, but I did not accept it. I can't just leave him. I thought of working in his group home but I realized I have the tendency to be unfair with the other clients. Of course, I will be unconsciously giving him more attention because we've been together for a while. So I didn't take it. Instead, I continued working for him and took another part-time job to make up for the 8 hours I need.
> *~Esther*

Facilitating friendships

Care workers who work with clients who have limited mobility and communication capabilities do most of the work in facilitating inclusion and friendship formation. Data showed that people who are able to express their desires and needs can work directly with program coordinators and support workers in planning their activities. Whereas, for non-verbal clients, support staff do most of the effort in researching activities that might be interesting and appropriate for the client. Most of the time, this is a trial and error scenario where the support worker introduce the activity or place to the client and observe through their non-verbal cues and behavior whether they like it or not. In some cases, the staff work hand in hand with the family and organizations in planning the activities for the individual. However, there are also instances where the staff has to do almost everything, especially for people who have less involved families or no family members anymore. Support workers then have to rely on their networks in finding activities and helpful information on programs that are appropriate for their clients. Interviewees also mention other organizations that have programs which actually help determine and set the goals of each individual at the beginning of the year. This serves as a helpful guide for the staff to find activities that will meet the needs and goals of their clients throughout the year. For those who do not have this program and are directly employed by the family, some support workers try to be more innovative by planning out activities with other staff they meet in the community. Some staff also tried talking to people in the community and share about their client who might be interested in joining their local groups.

> Yeah, we look for things that they're interested in. we seek out groups, we get a little bit more information. So we do our background research. We call them and we ask, "What do you guys do?" "What are you part of?" "What are the costs?' "How often do you get together?" – these basic facts that you wanna find out and then you ask, "Is it wheelchair accessible?" because I know my individual. So I went to the center to see what it's like.
> *~Georgie*

> I'll start giving suggestions like why don't we look on the internet and see what movies are playing? When street performers are in Edmonton or whatever. And it is kind of hard when it's always up to you to kind of think of new ideas and then they will go to something and like totally hate it.
> *~Hyacinth*

> In the case of the church, I personally went and spoke to the pastor and I said, "you know, this individual comes here and nobody really reaches out to him". I told the pastor one of the things we'd like to do whenever possible, if you can have tea with them and that is all. And I said not only that but when he comes to church, can you reach out to him? He said, "Oh! you know, I've seen him here but he always leaves right away. I'll make sure that when he comes though I'll reach out to him."
> *~Irvine*

Barriers to friendships

Interviewees express the first challenge that their clients face when making friends is the ability to communicate and socialize. Most of the participants' clients are non-verbal, some have behavioral problems which make it difficult for them to communicate and establish new connections. There are individuals who are not used to being around new people or huge crowds, sometimes an unfamiliar setting becomes a trigger for people with intellectual disabilities. Thus, care workers have to make sure that the place is accessible, safe, and appropriate for their clients. Moreover, as part of the safety protocol, interviewees shared the bureaucratic processes and tons of paperwork they have to complete which make it harder for them to take the individuals out in the community. Activities have to be planned out ahead of time, thus, care workers prefer to stick to a routine for a couple of months. One interviewee said there's a new program for her client but it was not included in their original transportation arrangement so they have to wait for a couple of months.

> It's very difficult to change or add activities for my client because we have to consider the DATS ride. We have to book a new subscription to be able to go to that activity because without DATS, my client cannot go. That's one of the things that hinder us from changing schedules.
> *~Jessica*

Disability support workers also mentioned that parents who are overprotective can also limit their clients' social involvement. Some parents prefer that their children stay at home and disapprove of the support worker's suggested social activities.

Participants acknowledged that most public places are now physically accessible, however, they also emphasized that there are still spaces where they feel that their clients are not safe and welcome. Interviewees cited examples where people are being rude to their clients, shouting at them, continuously staring at them, or intentionally ignoring them. This has been a great challenge for disability support workers, especially those who are working with clients who prefer to be left alone. They said they wanted to give them space but cannot entirely leave their clients fearing some people might not be very understanding and accommodating to them.

> Sometimes I prefer to give her space so that she can do things on her own and interact with other people so like if I'm not there maybe she'll do a little bit better, right? Sometimes she does.
> *~Kyla*

Another challenge faced by disability support workers is language barrier, there are clients who do not communicate in English. Thus, it is difficult for them to make friends in the community.

> He's with elderly parents and they weren't able to take him out as much. Him and his parents, English is their second language, they were born and raised in Italy. They weren't really able to access services as much.
> *~Lilac*

An individual's financial capability is also one of the things that disability support workers have to consider. One care worker shared an experience where the client really loves to join his friends' weekly gathering at Boston Pizza restaurant, the client orders food but does not have enough money. Thus, the support worker has to constantly watch and remind him.

Maintaining friendships

Making friends is one thing, maintaining friendships is another. Disability support workers have enumerated factors that determine whether a friendship will last or not. For most non-verbal individuals, the major facilitating factor that make friendships possible is the environment and frequency of meeting with other people. When two people go to the same program regularly, they see each other frequently and start hanging out while completing the program. However, when that specific program ends, these two people will most likely not see each other again, especially with the limited transportation arrangements.

Disability support workers also worry that they might be the only person that's holding that friendship together. Most of the time, care workers initiate conversations with other individuals and introduce their client hoping it will foster friendship between two individuals. However, they later realized that when they do not initiate anything, none of the individuals would make the first move or keep the conversation going.

> …for me, sitting here with someone with a disability, you know we're talking because I'm asking them questions about their life. But then sometimes I find when I'm sitting here with two people and I'm trying to foster friendship, I'm asking questions so that they're responding and sharing information but they might not be asking those reciprocal questions back to the person. So, then when you remove the staff, the conversation is kind of harder for them to start and sustain.
> *~Mary*

This is problematic since the rate of staff turnover is high in this industry. When the staff no longer works for the individual, that person does not only lose staff support but also the network that they have established together with that support worker.

> I think staff turnover is the big one and new staff coming in and not necessarily knowing who's people's friends are and like people who are maybe less… like the one guy I worked for, he wouldn't remember someone's phone number or necessarily like initiate the call so as I was saying before, if a new staff were to come in and all this information wasn't very clear, they would not be able to foster new friendships as well.
> *~Nancy*

> But then if I leave, if I were to no longer work there, they might not be hanging out as much because I also know Marco's friends and I can be like "*Hey Marco, why don't we call this friend to hang out this weekend?*" but when I am not there and the staff doesn't know Marco's friends, they might not be "*Hey Marco, why don't you call Adrian to hang out this weekend or Liza*?" because I know all his friends I'm saying their names to him and he was like "*Yeah, that's a good idea*". But when a new staff comes in, they might not be saying these things to him.
> *~Nancy*

> Yeah, I think it's been a little easier for me because I know so many people from ABC and XYZ. Like I could be walking along the road and I see so many people and I think, "*oh this person will be a good match*". But I think for people coming into this field, new, or even new to Edmonton, it's a lot harder for them coz they don't know as many people.
> *~Olga*

Another challenge for disability support workers, especially among newcomers and immigrants are the familiarity with the environment and cultural adjustments. For carers who are born and raised in Canada, it is easier for them to find activities that might be of interest to the clients apart from the regular day programs. However, for immigrants who are still adjusting to the new culture, they might have limited knowledge on existing activities and places to take their clients to.

One factor that also strengthens friendship is common interests. For some people, communicating one's interests and hobbies are easy. For people with intellectual disabilities and non-verbal individuals, they need more support in relaying their likes and dislikes. Participants shared that they figured out their clients' preferences through their day to day activities, clients communicate through their non-verbal cues and body language whether they are interested or not. Disability support workers use different strategies to understand their clients better, some use boards and pictures, others try to act out or just observe keenly.

> All these picture graphs, picture boards. They'll show us, they'll point out. You know, it's visual cues. Body languages also because you know when someone's smiling and happy, people have facial expressions if you get to know somebody, you know what makes them irk or sad, what they like and what they enjoy so you could kinda gauge that to some extent. If you know them, you know the level of their competencies, essentially what they are able to tolerate, like if they can sit through a movie, do they have that capacity? If they can, there's a way that you can gauge it.
> *~Sasha*

When participants feel they know their clients better, they try to connect them to other individuals who they think might have similar interests. They work with other support workers and plan things together, or they introduce individuals directly to each other. While some are successful in connecting these people, others also find the opposite.

> And just like finding commonalities for people. I think someone may be a great fit for someone else because they really like video games but then when I get them together, I realize they like totally different video games. They aren't really connecting that much.
> *~Nancy*

Challenges in care work

Participants also shared their personal struggles as care workers dealing with colleagues, employers, families of clients, and the community in general. There are three types of care workers I have interviewed. The first ones are the care workers working at group homes responsible in doing personal care for people with intellectual disabilities. Next are those who identify as disability support workers who meet and accompany individuals in their community activities and day programs. The third ones are those who do both, they take care of individuals and take them out to the community.

During the interviews, some staff shared how they get in conflict with other workers at group homes due to the division of labor. Often, disability support workers who are supposed to accompany individuals in day programs end up doing personal care even if it is not part of their job description. Some staff also expressed that they were not satisfied with how the personal care workers in group homes take care of their individuals so they initiate to do things by themselves, such as cleaning the room or preparing the individual's food before going to day programs. While some staff react negatively, others also understand saying group homes are always understaffed. There is just so much work for one care worker, thus, one cannot expect high standards of care.

> When you're in a company and you're in a group home, you're not always around the family, right? You're around the support staff. The other support staff we support them and we work together, right?
> ~*Fiona*

Participants also mention that different agencies sometimes have different and conflicting rules imposed on the care workers, thus, they often get in conflict with one another. While some clash with each other, there are also staff who have established good relationship with each other and worked hand in hand for the best interest of their client.

> Sometimes a lot of support staff, depending if you work in a group home, you may have challenges with other co-workers because you don't see eye-to-eye so you'll be butting heads kind of thing. But then if you talk to them and maybe just be open… but I work alone with Florence so I don't have a lot of problems.
> *~Kyla*

> There are instances when the manager of the group home assign tasks to me even when I'm not under their supervision, I'm employed in a different agency and it pisses me off. Sometimes when I can't take it anymore, I try to vent out to my client because I'm just so stressed out.
> *~Dorothy*

Meanwhile, care workers who are employed directly by family often do both—personal care and social activities. Participants share how families can be so demanding and expect them to do household chores on top of the personal care they provide for the individual.

> I don't think I'll be able to stay because the mom is so demanding and the mom is just never happy with anything so that's frustrating.
> *~Fiona*

> Yeah and that's not fair, right? Like you're doing the best you can but some families don't understand that. They take it for granted and they expect you to do this and this and this. Like you know all the cleaning, all the housework, all the cooking. You're only one person, right? You only have so much time in a day just to support these guys.
> *~Irvine*

> This young man was intellectually challenged but the mom wanted him to get a job. Everyday she's demanding "when are you gonna find him a job"? So I explored Safeway. This was in Spruce Grove and I went to several offices and I explained to them and they said they'll look into it but they never really got a chance to give him a job. And then I'm sure the mother looked back and that was a failure in my part, not being able to secure a job for him but I tried.
> *~Trisha*

> You know, I can't really say myself but it's really difficult. Sometimes within that group home, they were there for about like 30 years and then the mom decided she wanted to move to Edmonton to be closer to the son. And so she asked the landlord if he had a place close to her son and he said, "well she can move in to the basement". And when mom moved in to the basement, that's when all the problems arise because the mom will always complain there's too much noise in the house. She said she's not getting enough sleep. She's also like "what are you feeding my son? It doesn't smell appetizing" but like the staff will always cook healthy food. Also the gentleman had a lot of health issues, too. He was in and out of the hospital so the mom maybe felt that the staff weren't supporting as best as they can but the gentleman was just not well.
> *~Mary*

Another challenging aspect of working directly with families is the lack of clear job description and fixed working hours. Unlike those employed by service agencies, care workers employed by families often do more than what their job description entail and work beyond the agreed working hours, especially when there is no alternate care worker.

> On Fridays, I don't have a specific time off because sometimes the wife has to meet colleagues or friends and I have to stay until she gets home. Then every other weekend, I work from 10 am to 6pm. When I'm off, the wife takes care of him.
> *~Brianna*

> So another thing that I have to do is basically helping with things to do around The house. Basically the parents have their own requirements for what needs to be done.
> *~Georgie*

Participants also shared how they try to make people in the community understand and accept the people they support. Often, disability support workers defend and advocate for people with intellectual disabilities. They become the buffer between their clients and people who are not very welcoming of this population in mainstream society. One care worker shared an experience where they took out their clients for a picnic and other people came and wanted them out.

> And we just got the clients to finish their lunches there and those people were still being really rude and ignorant. They're just staring at us and giving us dirty looks. And then they're just making comments like*, you know, we have a hundred people here and you guys kind of need to move.* But at that point, I just felt we weren't in the tarmac where the tables where reserved. You can't reserve the park area, you can't reserve all the park, right? So I just felt like they're being really rude and ignorant, right?
> *~Trisha*

> I find that on this field, you'll find a lot of ignorant people who will just give dirty looks and make rude comments and you just wish they wouldn't do that, right? Because sometimes I don't think they really understand. All these people wanna be out and about, right? And they're telling us not to be out and about and this is their enjoyment. This is how they enjoy with friends and stuff like that.
> *~Perrina*

> I think the challenge is to break down stereotypes, really, because a lot of people don't wanna get involved. And so these people with disabilities, one form or the other, they have behavioural issues. They're socially awkward and then people are not very open to allow this so we basically have to break down some of those barriers.You know, they've never been exposed to somebody with this level of disability like the people I work with.
> *~Hyacinth*

Hypervisibility and responsibility of care workers

Disability support workers feel that they are constantly being watched out in the community. One participant shared how she cannot even look at her phone for a bit fearing people might see her and think she is on her phone the whole time.

> And other people see…like when you're outside in the community, I always have eyes on me. So I've always known that if someone comes and complain, they may ask me or they may ask another support staff like "do you know where this lady works?" and then they'll get back to your employer. So sometimes you just have to be careful of what you do.
> *~Nancy*
>
> It's difficult for me because sometimes he has behavioral issues and start hitting his head against the wall. That's why he is on a one-on-one care because of that. You can't leave him even just for a second because what if he hits his head and gets bruises? He's under my care and I will be entirely responsible for that.
> *~Kyla*

This is quite challenging for support workers especially those who are working with individuals who prefer to be left alone. Care workers share how they want to support their clients' independence but at the same time they are always extra mindful of keeping a safe distance, in case they are needed. Disability support workers also shared how they feel that people are expecting too much from them and making them wholly responsible for the individuals they are supporting.

> We get that kind of experience… But one example, I was crossing the street with this one individual and he's got a pain in his leg and he walks with a limp kind of thing. I couldn't get him to cross the street fast enough and this individual came and got really upset and it's me he's yelling at. So yeah, there are those kinds of situations where you find people expect more from [you].
> *~ Georgie*
>
> Every day, you have to report every single detail. You don't want to miss even the smallest detail otherwise, if something happens to your client even if it's not your fault, you might end up being accused and responsible for it.
> *~Olga*

Participants also share how they have to deal with people in the community who are rude to them and their clients. They said it is easier to let things pass when people are rude towards them but when people are attacking their clients, care workers often get really affected. Sometimes, they just talk it through with the person or make their client understand, other times they get upset and become confrontational.

> Yeah, so many. But we just keep calm, keep cool. Some people you explain stuff to them and they listen, they understand. Some people you explain to them but they won't even bother. I just try to chill my individual like you know, you understand if somebody says something mean, it's not you. It's the person's issue.
> *~Dorothy*

> If you would be mean, be mean at a distance. Don't do it in front of my client because I will fight for my client.
> *~Irvine*

Aside from the challenges they face in these social settings, disability support workers also share that their job requires intensive physical labor. One care worker said she is really having difficulty lifting her client who is almost twice bigger than she is.

> That's why I really don't like the swimming activity. Not because I'm lazy but because it is very difficult for me to lift him out of the wheelchair to the pool. He is twice bigger than I am. For me, that's the most difficult part of my job. Other than that, I have no problem taking care of him, I can manage his behavior.
> *~Lilac*

> The most challenging part for me is the uncertainty, I'm so scared that something might happen to him under my care. His recent hospitalization required him to have G-tube feeding. Now, they told me that I need to be trained to do it. I am so scared since I've never done that and that's not my field, only nurses do that, it's not part of my job anymore. But they said they will train me, I just took it as a challenge then. But these additional tasks, even administering medicines, scares me a lot because I've never done this before.
> *~Mary*

Most care workers express dismay that people assume that it is an easy job. Some also express how they feel neglected and get the assumption that people think of care work as a low-skilled and unproductive job.

> People have less appreciation for our work. They think it is very easy, like a walk in the park but it's not. We have to undergo rigorous training especially in dealing with certain behaviors. We spend so much time trying to understand our individual and making sure they are safe and happy.
> *~Jessica*

Another participant shared how delighted he was to have somebody ask him about how he feels about his job. Most interviewees feel that they are "invisible" and less appreciated in the community.

> It's my first time to see people and ask me about my job because I love my job. Sometimes I talk about my job to my friends but here, as you see everybody are busy. We can help them but to think about "okay I want to see my colleague then talk about our jobs" it's something that never happened. We have a meeting every Wednesday but we're talking about what we need to do and never about how we feel towards the job.
> *~Georgie*

One participant emphasized how this job does not only entail physical work but a great amount of emotional labor as well. They expressed how their emotions can greatly affect their daily interaction with people with intellectual disabilities and vice versa.

> Yeah, but the turnover is really hard because I think it's very demanding. I don't think people understand what it is to be support worker. I think people, looking in, they think "oh wow, it's just they're gonna go to malls. They're gonna go out and about and movies" and stuff like that but they don't understand they're emotional. The emotional stress behind it, right? Because when you're working with the individuals, you're with them all day. You kind of rub off on each other. Like when she's stressed, I can feel the stress. When I'm stressed, she can feel the stress. You know the emotions and stuff like that.
> *~Esther*

Another participant also shared the importance of the support worker's emotional stability and well-being as these will have a direct impact on their client's experience too.

> And because of that it's like, you can teach me about the individual but how about the way that I feel, right? How does it make me feel to walk into that house to know that today I'm the only person that she's going to see for the next 6 hours and it's up to me to make it a good day or a bad day. I don't know but for me it becomes very personal becomes even though you go into that room, some of these clients, you're probably the only person that they will get to see throughout that whole shift because some people don't have visitors, some people don't have family, some people don't have friends.
> *~Jessica*

Disability support workers expressed that they are undercompensated and actually do more than their job descriptions suggest. While some care workers have broader scope of work and actually understand that personal care and community involvement is part of their job, others think they are doing it as an extra work. Some also felt that they are being taken advantage of by their employers and using their emotional attachment to their clients to get them to do the extra work. Others also expressed that they still worry about their clients even when they are taking the day off.

> And the longer you work with that person too they think, I understand the pay, the job, how much we get paid and like the benefits and stuff like that, sometimes it's not good. You're overworked basically. They make you work really hard, right? Like if there's people who's sick and they'll ask you to work, they'll kind of guilt-trip you sometimes so then you feel like you actually have to work and then you'll feel like "Oh my Lord, I'm just strained", right?
> *~Lilac*
>
> Yeah, so we have to do that every morning and as the day goes by we have to stop it at some point either in here or showers or bath or wherever it may be. So we're almost like an all-rounder work for her. We have to make sure that she is comfortable.
> *~Dorothy*
>
> Aside from personal care, We go out. We go to the mall sometimes, doctor visits. Pretty much I'm like everywhere with her.
> *~Brianna*
>
> So you would learn, right? But you get hired to one house to work at that home for those individuals. So you're essentially put to work at one home to work with all those individuals whether it's one, three, or nine, you work with those individuals, right?
> *~Perrina*

Finally, care workers shared how cultural differences and personal preferences of both the worker and client can pose a challenge in this type of job. While some agencies carefully match their employees to their clients, some also do not. Thus, care workers find themselves caught in a difficult situation where they are expected to do things that they are not comfortable with, because their priority is their client's welfare and satisfaction.

> One example was we went to the haunted house that they had in October, the Deadmonton. Yeah and he took a staff years ago and that staff freaked out coz it was scary for him so nobody wanted to go with him because it was personal choice, you know. For some people it's a religious thing like I don't wanna deal with that because of my spirituality. But he wanted to go so why should he miss out? And so I ended up taking him because I can go.
> *~Russel*

> Now you may gravitate towards certain individuals because of the needs so. At the seniors home that I work at, I'm the only male that works there. It's possible there may be another one now but at the time when I started, there was only myself as the male so a lot of these female staff who are there, it was difficult for them to do thing with some of the male individuals we are supporting because they wanna do the things that maybe women couldn't feel comfortable doing or had a hard time connecting with so they brought me in and they were able to do things that guys would like to do. So we've gone to car shows, you know. We've gone for beers and things like that because some of the staff don't feel comfortable or don't know how to do that.
> *~Russel*

Some agencies are consciously making the effort to match their employees to the client's needs and preferences. Staff from this company shared how they go through different screening processes to make sure they are the closest fit to the individual.

> So we try to match them, like when I first started, the team was all women working for 3 guys and one of the guys expressed to me that he wish there are more men so now there's 3 women and 4 men so it's a lot more even.
> *~Russel*

Staff expressed how this is an often overlooked factor yet very important as this will help the staff and client connect with each other better.

Perceptions and motivations in care work

Despite the challenges, staff also expressed the rewarding aspects of their job which made them stay in this profession. For staff who had challenges dealing with parents, getting the parents approval and appreciation for their job meant a lot to them. Some took pride in eventually gaining the parents' trust and establishing a positive relationship with the entire family through time.

> I hate to bring up the parents again but you know it's so hard for like parents to see change, a new individual coming in and trying to take care of their child but the most rewarding part was when I actually saw the mom step back and say "*you're doing an awesome job with my daughter*". It's really one of those things that, for the kind of parent that she was, it was really tough but I kept doing the best that I could until she was "*you know what I know that when she's with you, she's fine*". It's like yeah okay we're good now. So that was the most rewarding part.
> *~Chesca*

> The most rewarding part is being able to make a difference and see tangible results. When I started working with this one individual, basically the worker who was working with him will come in and make his lunch, supper, or whatever and put it down and he eats and that was the extent of the interaction. So I went it and with this individual, I got him involved in making up his own grocery list of what he wants. He writes up his grocery list and he goes to the store…He gets involved… even the parents recognize the difference so those things are quite rewarding and even if I'm not there, those things are happening. So you built that rapport…that's very rewarding, especially when the parents recognize that things are different.
> *~Olga*

Some staff also find it fulfilling when they see their clients clean, healthy and happy. They said it makes them feel that they are performing their job really well.

> This is what I do everyday, right? When I see him clean, I tell him he looks handsome and he says thank you and smiles. It really makes me happy when I see that he's healthy and happy. Knowing that he's doing okay, when he's clean and he smells good, that's already a reward for me.
> *~Mary*

Other participants also find it rewarding when their clients actually remember them and look for them when they are not working, especially for clients who have short-term memory. Care workers share they feel more inspired and motivated to work when they see that their clients' mood changes when they arrive and express it through non-verbal cues.

> The most rewarding part for me is when my client looks for me during my day off, it's the positive relationship I had with my client and not material things.
> *~Esther*

Some carers find a sense of fulfillment in the long-term impact they have made to their clients' lives and the community in general. They believe that they are not only working for the individual but for the larger community as well. Most of them expressed that working with people with disabilities have significantly changed their perspectives in life.

> So I like to get everything set up like you know…even if I'm not working with her anymore, she'll have a support system. You know wherever she goes, people will know her, right?
> *~Jessica*

> For me, the most rewarding part is knowing that I'm helping, I'm making a difference not only with him but with the community, the society as a whole. I'm paid to work with him but I'm not really helping just him, I'm helping other people too. I also help people with disabilities who come here alone.
> *~Amelia*

> The people are just incredible, you know, some really unique and cool people. It's really fun. And you get to do cool things, you get to go into the community a lot, you get to go to events in the city. I do a lot and it's nice…You get to know the city a little bit in a different perspective.
> *~Fiona*

Care workers also cited several examples where they succeeded in facilitating the inclusion of their clients in the community. Some were able to form groups that meet regularly outside of their individual day programs. Others were also able to find new groups in mainstream community which were not really directly involved with disability service agencies, such as advocacy groups and music communities.

> We've got enough people involved, we got one individual we supported for a while who was really into wrestling and heavy metal and we've been able to take him to a concert in Calgary for like a heavy metal show. He's in a wheelchair,and he was crowd-surfing. He crowd-surfed at the concert. He got involved at the wrestling mania group that's here, the local wrestling fanatics on Alberta avenue. There's a group that gets together there because they have weekly shows of wrestling. He's gotten involved in that.
> *~Kyla*

> We had another individual who wanted to get involved in the LGBTQ Community and we got him involved in that. He goes to the pride events. We've involved people into the self-advocacy federation because they want to represent and advocate for themselves and for other people.
> *~Russel*

Most people with intellectual disabilities find their social groups within their regular programs and activities. Unfortunately, some of these activities discontinue eventually, thus, people stop meeting each other too. However, there are instances, where care workers initiate to continue these activities on their own, one of which is the cooking program which now have around 15 people involved.

> We started off at Superstore, so there was a group there with like cerebral palsy and few of our friends are in that cooking class. But then I'm not sure why Superstore closed that cooking school. We had to find a new cooking school so we just decided

> to do it at one of her friend's home because it was accessible…and that's kind of where we tried to put the word out like we're doing a cooking class. When we take pictures and post things online, people see it and get interested…So like they pay $5, they get to choose what they wanna make and then we support them. We have a lot of adapted equipment, we have choppers that aren't really sharp but they can hold it and then they'll chop and stuff like that…So it's all adapted. We make it all for these guys.
> *~Nancy*

Some were also able to establish social groups where they meet regularly for coffee and just talk about anything. People with or without disabilities are welcome to join the conversation group which is held weekly at any public location where they are able to get together.

When asked how did they get into this type of work and what are their motivations in working in this field, most migrant care workers say this is the only path they see to acquire citizenship and reunite with their families. Others also say this is one of their stepping stones to be able to upgrade and eventually work in their desired profession. For Canadian care workers, their motivations come from their sense of fulfillment and purpose knowing they were able to help other people and the community in general.

DISCUSSION

Bridging friendships and social connections

Most friendships develop when two individuals find similar interests and connect with one another. For people with intellectual and developmental disabilities, communicating their interests may be quite challenging. My interviewees expressed that most of their clients have limited communication abilities and express themselves through non-verbal cues. Finding ways to effectively communicate with them takes time even for the care workers themselves, one needs to know them better to understand their likes and dislikes. Care workers shared that hanging out with their clients frequently allowed them to understand their clients' preferences and communication cues.

When asked whether their clients have friends, care workers said their clients made friends only through their daily activities. Contrary to the western notion of *friendship* as spontaneous and voluntary (Carrier 1999), for these individuals, friendships require planning. Their social network was formed as a result of agency social programming and their daily activities. In assessing the frequency of social activities of adults with intellectual disabilities, DaWalt et al. presumed that adult service models may have contributed to the increased social participation of adults with intellectual disabilities by allowing them to hang out with their peers at work and recreation centres (2019). While these may not reflect the individual's personal preference, it is still noteworthy that there is a need to create more opportunities for people with intellectual and developmental disabilities to socialize with others in the community (DaWalt et al. 2019).

Adam and Allan emphasized the importance of context in the development of friendships (1998). In the introductory chapter of their edited book *Placing Friendships in*

Context, the authors used the example of Duneier's account of the frequent yet unplanned interaction of customers who visit the same restaurant in Chicago which enabled them to foster connections with one another (1992). While agency social programs provide an avenue for friendships to develop, the downside is that should an individual switch to a new program, the friendship they have established may or may not continue, unless the care workers exert conscious effort to meet old friends outside of their programmed activities. However, for people who need more support and cannot take the public transportation, this may not be easily achieved since they are using the pre-arranged transport system.

For disability support workers whose job is to accompany clients to agency day programs, time management is not much of an issue. This type of employment has a specific schedule of activities that is solely focused on getting clients out to the community. They have fixed working hours, they pick up their clients in the morning and the client goes home in the afternoon through pre-arranged transportation. At the group home, another caregiver will take care of the clients. However, for care workers directly employed by families, especially those who live with their employers, sometimes the job description and working hours are not definite. While their main job is to look after their clients and facilitate their social activities, most care workers find themselves doing additional housework. Care workers are vulnerable to employers' abuse and exploitation due to their precarious immigration status (Parrenas 2008; Salami and Nelson 2014).

Scholars noted a striking difference between individuals living in staffed housing versus those living with their families. The former have more social participation and community engagement than the latter (Casey 2011). This bears an important implication not just for the well-being of the individual but for their families and caregivers as well. Just like people with intellectual and developmental disabilities, research shows that parents were also vulnerable to social isolation (DaWalt et al. 2019). During the interviews, care workers shared the same experience, especially those working for individuals living with their families and have lesser community engagement.

I am fortunate enough to have interviewed both live-in caregivers and live-out caregivers. There is a contrast between the experiences of those who live with employers and those who do not. Apart from the heavier workload of live-in caregivers, these workers also reported higher incidences of isolation and loneliness. Whereas, support workers accompanying clients to day programs shared that they adjusted easily to their work since they met a lot of other support workers and clients in community programs and recreational activities.

Furthermore, support workers expressed that their clients' behavioural problems also contributed to their isolation (DaWalt et al. 2019), especially those individuals who are not used to being around huge crowds of unfamiliar people. In cases like this, disability support workers focus on improving the individuals' social skills so that they will slowly become comfortable with other people in the community. One interviewee took pride in sharing that her client is a lot more sociable now than when they first started together, the client even got a favorite pal, one of the support workers they met at the recreation centre too. Care workers constantly emphasized the importance of having social networks and friends. Aside from the emotional support they are getting since they share the same experiences with one another, these networks prove to be very helpful on the practical side of their work too. Support workers help one another when one's client is having behavioral issues, they also offer to look after one another's client when one has to take a washroom break. These are small yet important things that care workers liked about having a supportive community.

All of this demonstrates that the inclusion of people with intellectual disabilities relies heavily on supported community participation, community presence, and activities involving other people that open possibilities for friendships to form and flourish (Van Asselt et al. 2015). However, community presence alone does not directly translate to inclusion. Lippold and Burns (2009) noted that not all community involvement and recreational activities develop into friendships. Most friendships are formed through the intervention and help of support workers and family members (Emerson and Mcvilly 2004; Orsmond et al. 2004 in DaWalt et al 2019). This was echoed by my interviewees when they shared how they constantly act as a bridge between individuals and make the first move to establish the connection among the two. While most of them had been successful in facilitating this connection, some were also worried about maintaining this relationship. Some support workers believed that they were the only ones keeping the friendship going by maintaining communication and arranging the meetings for the two individuals. This posed a challenge considering that there is high staff turnover among disability support workers.

Rethinking autonomy and interdependence

Considering the existing literature and the findings of my current research, I have argued in this thesis that the western notion of friendship anchored to individualism and autonomy is problematic. Previous research proved that friendship was not unique to modernity and did not specifically emerge from western societies (Desai and Killick 2010). This notion of individualism and spontaneous affection in friendships aligned with what Mauss noted as ‘formulated only for us, among us’ (1985 [1938], 22; Desai and Killick 2010). In her study in southeast London, Evans (2010) questioned the western individualistic view of a person and proposed:

> Rather than thinking about human relations in terms of a dichotomy between those societies characterized by situated persons engaged in personalized relations of exchange and those typified by autonomous individuals participating in the impersonalized relations of the market (Carrier 1999), we might more usefully think of a continuum of situatedness… Along this continuum, it becomes clear that due to particular historical circumstances, some people have more choice than others, both within any one society and when comparing one society with another, about whom they are able to bring themselves into being in relation to. (Evans 2010, 183).

In the same way, scholars problematizing the western notion of autonomy argued that the concept failed to recognize the nature of humans as relational beings, whose perception of the good were developed in relation with other people (Davy 2015, 138; Nedelsky 1989; Taylor 1989). The liberal theory that centred on autonomy and reason as the basis of personhood has been questioned by feminists and disability scholars alike for neglecting the relational nature of human beings and stigmatizing people with intellectual disabilities (Carslon and Kittay 2010; Davy 2015).

According to Davy, *autonomy* is commonly defined as “the capacity for self-determination and self-government: the ability or the condition of living in accordance with reasons, motives, and goals that are one’s own rather than imposed by external forces (2015, 133).” While some people with intellectual disabilities are capable of expressing themselves, others need assistance in communicating their thoughts and judgments. However, this concept of autonomy and independent individuals marginalize people with intellectual disabilities who are not capable of expressing their thoughts alone. For this reason, Davy (2015) proposed a relational model of autonomy that recognizes the importance of support and advocacy to enable certain individuals to exercise autonomy. This is analogous to the critiques of feminist scholars like Kittay who believed that there are no fully autonomous individuals. Every person has basic dependencies across their life course, from childhood to old age, or in the instance of temporary incapacity and chronic illness (1999). People are all dependent and need a certain degree of support to exercise autonomy and practice independence.

Within this revised concept of autonomy, scholars argued that those who have limited capacity to communicate their thoughts should not be denied the support and advocacy of the people close to them, people who understand them the most (Davy 2015). In this thesis, people with intellectual and developmental disabilities who were not capable of expressing themselves and had difficulty establishing a social network were actively supported by care workers.

Of affection, emotion, and responsibility

One aspect of friendship that distinguishes it from other relationships is the concept of equality. Paine argued that unlike other social relationships where there may be a hierarchical arrangement of opposite pairs such as father-son, employer-employee, husband-wife, friendships involve "persons paired in the same role" (1969, 507). In the same manner, Allan pointed out that "friendship is a bond in which issues of hierarchy and authority have no bearing" (Allan 1989, 20).

These claims raised questions about equality in friendship because according to my interviewees, most of them consider their clients as their friends or family and not just employers. They said treating their clients as a friend or a family paved the way for a more genuine connection to emerge which allowed them to give the best quality of care. While friendship and affection are present, one cannot deny the hierarchy in the relationship as well.

> I have to listen to my individual. I have to listen to what he wants. It's not about me, it's about him. It's all about what he wants.
> *~Esther*

This has been consistent with other care workers' sentiments where they end up doing things and going to places that they do not want because their clients want to. On the contrary, some support workers believe that they are completely responsible for their clients and make the decision on their behalf most of the time.

> For me, both individuals that I worked with are non-verbal so pretty much it's like I am responsible for making sure that the day is really smooth starting with coming in…
> *~Brianna*

While both care workers treat their clients as friends, they never see one another as equals. The former believes that the client has the authority as the employer, while the latter believes she has the authority as the carer. Nonetheless, the end goal of both the care workers regardless of who is in power is the same, that is to give the best quality of service to their individuals which was enabled through their friendly relationship.

Care workers believe that without friendship and genuine affection, they would be indifferent towards their clients and would not care so much about the clients' happiness as long as they have performed their daily tasks. This echoed the major findings of Salami and Meherali in their study on the perspectives of employers and family members on familial and professional relationships with caregivers (2018). As authors pointed out, employers have three types of relationships with caregivers, namely, "a professional employer/employee relationship that lacks any emotional attachment and is marked by a clearly identified boundary between live-in caregivers and employers; a familial relationship, which often starts with friendship between live-in caregivers and employers, where employers view live-in caregivers as a member of the family; and a relationship somewhere in-between the professional and friendly or familial relationships, which involves some elements of both"

(Salami and Meherali 2018, 178). It is evident that the importance of friendships and friendly relationships were emphasized in the last two types of relationships that employers described.

In contrast to Carrier's (1999) claims that an employee and employer cannot be friends, I will argue that friendships can emerge within employee-employer relationships even with the existing power imbalance. Killick (2010) pointed out that despite the presumed universality of equality in friendships, his work in an Amazonian community showed otherwise where hierarchical differences are still present within their practice of *compadrazgo* (ritual co-parenthood).

These examples demonstrated that there are many ways friendships can develop. Even within the same society, people may have diverse definitions and views on friendship. As Desai & Killick put it, "even participants in the same relationship can have a diversity of views as to its implications and importance (2010, 13).

In her book, "Unexpected Community", Hochschild described three trends that contributed to the problems of isolation in old-age; "the decline in work for old people, the development of age-stratification, and the relative weakening of kinship ties which leads the old to seek supplementary friendships outside the family" (1973, 18). Similarly, Salami and Meherali (2018) reported that elder care recipients called their caregivers son or daughter and the employee regarded them as mother or father due to the absence of family members. While both studies refer to the loosening kinship ties among the elderly, I believe people with intellectual disabilities in group homes and migrant care workers had the same experiences.

Considering that both populations experience isolation and weakening family ties, *could we assume that the absence of support system and social networks made them interdependent with one another and paved the way for their friendship to flourish?* While this is a possibility, it is still uncertain that the understanding between care workers and care receivers is mutual since I have only interviewed the former. I believe that the perspectives of clients themselves merit further studies to get a more nuanced understanding of this relationship and how both parties view one another and negotiate unequal power relations.

During the course of my research, I have encountered differing views on friendship among care workers. While most of my interviewees are straightforward in claiming that they are friends with their clients, others are more reluctant to use the term 'friends' saying it is against their agency's mandate to maintain professional detachment. As one interviewee shared, *"I treat her as a friend but I won't say we're friends because at ABC organization, we uphold professionalism"*.

This suppression of feelings can be categorized under Hochschild's types of *acting* in her work on the emotional labour of service workers (1983). According to Hochschild, there is *surface acting* where the person regulates her emotional expressions in a way that is acceptable to organizations, this could prove helpful since some organizations prefer to suppress certain feelings such as concern towards clients. There is also *deep acting* where the person does a conscious effort to manage and replace their emotions with an appropriate expression in a certain setting and situation (Hochschild 1983). This deep acting was evident in Casey's (2011) work among developmental service workers in Ontario when dealing with their daily tasks of bathing and toileting clients. As she put it, "this may be the most undesirable aspect of their job but they need to act as though it is not a problem" (Casey 2011, 43). While most service agencies emphasize professional detachment, other employers, especially family employers believe that the absence of emotional attachment by live-in caregivers reflects the lack of competence and dedication to one's work (Salami and Meherali 2018).

"This is what we do": Modeling friendship for PWID

Research shows that younger individuals with intellectual disabilities have greater community engagement than adults considering the number of programmed activities available for younger people in school and communities (DaWalt et al. 2019). For adults with intellectual disabilities, social activities are lesser and more personalized. Schalock argued that meaningful social participation includes community integration, participation in social activities, having a role in the community, and access to support networks (2004), all of which are crucial to improve the quality of life of people with intellectual disabilities.

For adults with intellectual disabilities who can communicate conventionally, the opportunities to develop friendships are higher since they can communicate with their peers with lesser intervention from disability support workers. However, for some individuals, disability support workers have to do most of the job. Interviewees expressed that they have to get to know the individuals better to get an idea of their likes and dislikes. Through time, they discovered things and events that interested their clients. For instance, music, one care worker found out that music makes her client calm when she is exhibiting violent behaviour. Thus, she makes sure to put on some relaxing music before bed just in case the client wakes up in the middle of the night and throws tantrums. Another care worker shared she accidentally discovered that her client likes Zumba when they passed a group of people doing Zumba and the client started clapping and nodding to the beat of the music. As they discover these things, they seek similar activities to meet people who share the same interests. From there, care workers start making friends with other care workers too so they can share tips and activities for their clients.

For individuals who are capable of expressing their thoughts, care workers seek and check the venues where their clients could meet other people with the same hobby. Sometimes, they also approach organizations or informal groups to see whether they are willing to accommodate the client and if it is safe for them to go there.

However, for some individuals, social gatherings are not very appealing as they are not used to being around a lot of unfamiliar people. This becomes a challenge for the support worker since they cannot take their clients anywhere easily. Sometimes, when they go to recreational activities, they look for a secluded place that is not too crowded to make sure their clients will not be triggered. While some care workers do this to protect their clients and the other individuals, other workers try to slowly introduce their clients to group gatherings too. Disability support workers believed that the best way to teach their clients how to make friends in the community is to demonstrate how it is done. Thus, some days, they will act and talk to their clients like friends.

This is also helpful in teaching individuals some social etiquettes and appropriate behaviour in a group setting. Once in a coloring activity, one individual was used to hoarding all the materials to himself and the others would get mad eventually. So the care worker did the same activity with the client and asked if they could share the coloring materials, the care worker also shared her materials in return. Another strategy that care workers use to help clients who can communicate conventionally is to practice conversations with them. They found out that practicing even the simple way of asking questions in return during the conversation and sharing one’s interests made a big difference in improving their client’s social and communication skills.

What is so difficult about facilitating friendships?

It has been established that social inclusion and communication are crucial to the quality of life of people with intellectual disabilities. While there have been several programs that open opportunities for social interaction, Murphy noted that this may not be an easy feat for adults with intellectual disabilities due to some conditions that result in challenging behaviours (2009).

As mentioned in the earlier section, another challenging aspect of facilitating the inclusion of people with intellectual disabilities is communication skills. This has been documented in the research by DaWalt and associates on the social participation of people with autism spectrum disorder and Fragile X Syndrome. They found out that people with intellectual disabilities have difficulties communicating and dealing with social reciprocity due to their condition (2019). The communication barrier does not only mean the inability to speak but also includes the language differences. Some clients were reported to be non-English speakers and they were paired with a care worker who did not speak the same language as them. The care worker shared that she is trying to help an individual connect with other people in the community but the client speaks a different language as well as the parents. While most of the interviewees are migrants, they are well-versed in English and can communicate effectively.

Disability support workers shared that finding the right community for their clients involve several trial and error experiments. There were instances when they thought the client liked a particular activity but when they tried it, the client was not happy or they realized that the environment was not too welcoming of them. While some can easily switch to a different activity, others have to wait for a specific period and undergo a lot of paperwork.

Care workers employed by families can easily go from one activity to another because they do not have agency programming. This arrangement had both advantages and disadvantages, on the positive side, the care worker can explore as many activities and places as possible for the client. The downside is the lack of consistency, it all depends on the care worker whether or not they will be very dedicated to find and join activities that their client likes. Another limitation is that when someone comes in to temporarily relieve the regular care worker, the new carer does not have any idea or may not feel compelled to take the client to the community. This happened to one of the interviewees where she shared that when she got pregnant, she cannot work as much as she used to before. Thus, the family had to get another care worker to fill in during her days off. However, she noticed that the new care worker did not make any effort to take the client outside. Even though she tried to tell her, the new carer refused to follow her advice saying she was only there to take care of the client in the form of bathing, dressing, and feeding which she said she already did.

When it comes to agency-employed care workers, switching to a different activity cannot be easily done. Care workers shared that one of the best practices in their organization is the regular planning and assessment of the individual’s life goals and social participation. At the beginning of the year, the care worker will sit with the client if the client is capable of communicating their thoughts, together with the family and other staff to plan the activities and potential programs they can join in the next few months. At the end of the specific period, there will be an assessment of whether the client was able to do all that and if there were any progress or concerns. Considering this structure, the care worker cannot easily change their activities or add a new activity until the next planning. Apart from the regular planning, transportation is an important consideration too since most of the clients are using a specialized and pre-arranged transportation system.

Care workers employed by families may have more flexibility with their activities but they too shared their struggle with getting the parent's approval. Sometimes they would suggest a specific activity that they think the client likes but the parents simply dismiss the idea. Perhaps, it is also the cost or for those who do not take the public transportation, this means the parents will have to take them there. Another concern of parents is the safety, some parents are not just very open and comfortable with the fact that their children are outside especially with care workers who just started working with them. Thus, one of the most rewarding aspects for some caregivers which I will discuss further in the later section is gaining the parents' trust and approval.

Disability support workers also shared some success stories in facilitating community connections for their clients. There was one client who got really involved in a social group that meets at a restaurant weekly and this client would end up ordering a lot of food in one meeting. However, with the frequency of their client's social activities, they worry about the finances too. Aside from ensuring the client's social integration, care workers also need to guide their clients on how to do basic budgeting, especially those who live alone or who live independently from their parents. One care worker shared that she was hired by the family on a part-time basis to do one specific thing: train the client how to properly allocate the monthly budget-- pay the rent, do the grocery shopping, and get other necessities.

This is not "just" a job: Challenges and rewarding aspects of care work

Care work can mean a wide range of tasks and this often comes up as one of the challenges that care workers face. My interviewees pointed out the difference between being employed by service agencies and directly hired by families. Working for service agencies meant having a more fixed working schedule and a clear job description. Whereas, being employed by families comes with a lot of ambiguity in tasks and responsibilities.

Disability support workers in service agencies follow an organizational structure where they can bring up their concerns at work. For those working in group homes, every group of care workers has team leaders who take charge of the administrative tasks and basic leadership roles. When care workers needed to bring up something about their work, they can present it to their team leader and the team leader would either resolve it or relay the message to the manager or supervisor. However, this is only limited to concerns like scheduling, clients' well-being, or conflict with colleagues. Issues like wage increases or unsafe working conditions were never brought up for the fear of reprisal from their employers. One interviewee shared how she felt bad that she is still receiving the same salary for the past 10 years but never really approached the management. However, some of them actively participate in community and rights-based organizations to negotiate with policy makers and employers.

Meanwhile, care workers directly employed by families shared how they had lesser autonomy and voice regarding their work. Aside from the lack of clear job description, these workers worked round the clock, especially those living with their employers. When they had concerns about their work, they did not complain to their employer for the fear of termination. Salami and Meherali claimed that a "much more restricted right to permanent resident status has the potential to further impede migrant caregivers' ability to challenge their employers or negotiate the employer/employee relationship" (Salami and Meherali 2018, 175). Some interviewees looked back at their experiences living with employers and shared how they endured those years and kept their mouths shut until they got their permanent residency and had more employment options.

Most of their concerns were being overloaded with work, aside from taking care of their client they also had to do the household chores. While some found this unjust, others were also more positive about it saying they were the ones who volunteered to do it since the caregiving tasks were already done. However, not all family employers were unfair to their employees, some had built a positive relationship with the care workers too. Salami and colleagues found out in their research on the care recipients' perception of care workers that both parties are mutually giving and receiving emotional support (2016). One interviewee shared how her employer was being very considerate and supportive when she was undergoing a tough family problem. This helped her get through those hard times and knowing she was supported by her employer made her more dedicated to her work.

Conflicts were not only common between employers and employees but among colleagues as well. Conflicts between care workers occur at group homes where there is more than one care worker looking after the client. One is in charge of doing the personal care work at home, the other is responsible for making sure the client gets involved in the community. I have interviewed both workers at home and in the community, data showed that conflicts arise when there is a lack of communication between the two workers and there is no clear division of labour. There are instances when the two workers follow conflicting rules from their respective employers and encounter problems with who should do the specific task. One scenario that the interviewee shared was when she came to pick up the client from the group home but found out the client was not ready yet. At first, she got upset but eventually understood that there was only one care worker at that time taking care of three individuals. She mentioned that this group home was always understaffed, so she just took the initiative to prepare the client even if it was not part of her job.

Aside from colleagues and families, care workers also had to deal with their clients. Despite the presumed monotonous job of care workers, in reality, every single day is unpredictable for them. Although the tasks are similar, the mood and behaviour of their clients are not. Care workers said some days were good, some days were bad. But this did not apply to the clients' mood only but to the care workers' as well. As much as they tried hard to keep their boundaries between work and personal life, there were times when their personal problems would affect their mood at work. Although none of them experienced lashing out at their clients due to their problems, they were aware that their mood significantly affected their clients. Most care workers shared that their job does not only include physical labour but a great amount of emotional labour as well (Hochschild 1983).

In her study among developmental service workers (DSW) in Ontario, Casey reported the danger that comes with working with people with developmental disabilities, "both the worker and the person being supported might have a bad day which can lead to challenging situations" (2011, 49). This is analogous to my interviewees' experiences especially in the first few weeks of their employment when they were still getting to know the client. One care worker shared because of her client's behaviour, no care worker lasts nor wants to relieve her. She said she was the only person who endured the difficulties and stayed with the client. She admitted that it was very difficult at first and sometimes she would end up getting beaten.

However, she got to know the client better and understood that some things trigger him, especially when he is with new people and unfamiliar places. The interviewee eventually got attached to the client since she was the only one who could make the client feel comfortable and calm. It is also important to note that while these experiences are common and present dangers to care workers, care recipients are also vulnerable to abuse. There are also instances where caregivers have abused, neglected, or abandoned their care recipients (Ayalon 2010, 2011).

Emotional attachment to clients is strongly discouraged by some employers, especially service agencies, thus, care workers do a great amount of emotional labour to hide this affection towards their charges. Casey (2011) believed that strong attachment towards the client may or may not be beneficial in providing the best quality of care for people with developmental disabilities. Familial and close relationships with employers can be a double-edged sword. While it gives a comforting and fulfilling feeling for care workers that they are being treated as part of the family, some employers might also use this to exploit these workers by making them work beyond normal working hours without being paid under the guise of familial obligation (Constable 2007; Salami and Meherali 2018; Stacey 2011; Stasiulis and Bakan 1997).

While most of the interviewees understood the need to detach themselves from their clients, others also expressed that being affectionate towards their clients helped lessen their guilt and emotional stress for being away from their families. Most of them felt guilty for taking care of another family instead of their own which is common among migrant workers, especially in domestic service. This inability to take care of one's own family due to physical distance has been termed by Parrenas as *displaced mothering* or *displaced caretaking* seen as a "social consequence of the international division of reproductive labor" (2000, 59). For this reason, care workers find themselves into *diverted mothering* which happens when "the time and energy available for mothering are diverted from those who, by kinship or communal ties, are the more rightful recipients" (Wong 1994, 69). This had also been justified by several studies that showed how migrant women are finding emotional rewards for pouring their love to another family (Parrenas 2000, 2004; Tungohan 2013). Further, in the absence of family and close friends, care workers find comfort in the company of their clients. One of the participants shared that when she had problems and got no one else to talk to, she shared it with her client. Even though the client was not talking, she felt that the client was trying to comfort her. Knowing that someone was there to listen to her made her feel a lot better.

Interviewees reported that while there have been major strides to promote inclusion of people with disabilities, there are still some people and community spaces where they feel they are not safe and welcome. Scholars have long raised this concern that although deinstitutionalization has moved people from institutions to mainstream communities, physical integration does not translate into social inclusion (Cummins and Lau 2003; Fichten et al. 2005; Ouellette-Kuntz et al. 2009).

While much of the interventions are centred on removing physical barriers and finding ways to support individuals to maximize their presence in communities, scholars argued that the public attitude towards people with intellectual disabilities and their willingness to get involved with this population is equally important to achieve meaningful social inclusion (Antonak and Livneh 1995; Burge et al. 2007; Ouellette-Kuntz et al. 2009).

Care workers reported instances where people were subtly being rude to their clients by staring at them or willfully ignoring them. Others were far more ill-mannered by asking a group of people with intellectual disabilities to leave the area. Aside from being a major barrier to successful inclusion, Cummins and Lau pointed out that being discriminated against and stigmatized also lower self-esteem and exacerbate feelings of isolation of people with intellectual disabilities (2003).

Interviewees shared how they act as a buffer between their clients and the public who are not very welcoming of this underserved population. In some instances, care workers try to explain to people they meet when they feel appropriate. But in certain cases where they feel that the other person is close-minded, they try to comfort their clients and make them understand that there is nothing wrong with them.

In a study conducted by Ouellette-Kuntza and colleagues on the public attitude towards people with intellectual disabilities in Ontario, Canada they used the concept of *social distance* (2009). This concept was originally used by Bogardus (1959) in America to assess the public's attitude towards immigrants from different countries and their willingness to get involved with this stigmatized population (Angermeyer and Matschinger 1997 as cited in Ouellette-Kuntza 2009). Social distance in this sense was defined as the "degree of sympathetic understanding between individuals or groups" (Bogardus 1959, 7). This concept was built on the premise that the physical proximity of two people does not reflect their closeness and connection to one another (Ouellette-Kuntza 2009).

While this concept has been later used to look at the public's perception of individuals with intellectual disabilities (Angermeyer et al. 2003, 2004; Corrigan et al. 2001; Gaebel et al. 2002; Lauber et al. 2004; Ouellette-Kuntza 2009; Stuart and Arboleda-Florez 2001; Van Dorn et al. 2005), I believe that this remains relevant to the issue of acceptance of immigrants in contemporary Canada.

Most of my interviewees reported experiences of discrimination and isolation due to limited social networks and opportunities to socialize. In the research conducted by Salami and colleagues, they found out that one of the barriers to community belonging of immigrants is the lack of ethnocultural diversity in community organizations that offer socialization opportunities and recreational activities. Additionally, the authors believed that the constant struggle to find and maintain employment narrows the opportunities for immigrants to nurture their social life (2019).

Care workers also reported that people thought lowly of their job and assumed they were simply bringing their clients to malls and recreational centres. This lack of appreciation contributes to the exclusion of immigrant care workers which support the previous findings of Salami and colleagues, "when immigrants find employment in precarious or low-paying jobs, there is a ripple negative effect on community belonging" (2019, 31). Additionally, this also creates challenges for future employment opportunities as some care workers expressed hesitation in including caregiver experience in their resumes for the fear of being seen as "only good enough to work as a nanny" (Tungohan et.al 2015, 98).

Disability support workers expressed how they are being constantly watched in the community as if people were waiting for opportunities to criticize them but never appreciate the actual work that they do. Immigrant women of color often experience "invisibility" and heightened visibility or "hypervisibility" in host countries. According to Ryland, hypervisibility is the "scrutiny based on perceived difference, which is usually interpreted as deviance" (2013, 2222). Considering that most care workers are migrants and women of color, there is a constant feeling of 'otherness' among them. Care workers always find themselves entangled with what was called the "matrix of oppression" (Wilkins-Yel et al. 2019) in which race, class, gender, status, and other socially constructed categories of difference put women of color at a great disadvantage (Dill and Zinn 1996). Ehrenriech and Hoschchild claimed that instead of being sisters and allies struggling to achieve common goals, migrant care workers find themselves in a disadvantaged position in relation to their class-privileged women employers (2005).

Scholars believed dominant groups are most likely to put minority populations under increased scrutiny, surveillance, and isolation due to their perceived difference and 'otherness' (Wilkins-Yel et al. 2019). These sentiments were constantly brought up by care workers who were always cautious with their every single move since they felt that even briefly checking their phone could be taken against them. Simpson and Lewis argued that heightened visibility and invisibility make working environments hostile for these minority populations (2005). One interviewee also shared how he was being shouted at when his client was limping slowly while crossing the street. Another support worker shared her struggle of dealing with her client who gets sexually aroused when he sees certain women in recreation centres. She shared how difficult and uncomfortable it was for her to deal with the situation, especially that people were holding her responsible for managing this behavior. Most care workers experience different challenges in their daily work due to the clients' behavior, employers' demands, and the public's attitude towards them and the people they support.

Previous research has shown that people neglect to appreciate the value of care work and that most tasks of care workers, especially bathing and toileting are considered 'dirty work' in the society (Casey 2011; Twigg 2000, 2004). This was demonstrated by the experience of one care worker where a random woman in the mall asked her how she was not grossed out by the client's constant drooling. The care worker felt extremely offended yet managed to keep calm and instead took pride that despite the excessive drooling, she managed to keep her client clean and healthy. This reaction supported several scholars' arguments that care workers have learned to look beyond the dirty aspects of their tasks and took pride in their work (Ashfort and Kreiner 1999; Stacey 2005).

Shaddock and associates have noted the prevalence of burnout among people in human services occupations (1998) such as disability support workers. As mentioned by the interviewees, their job did not only require physical labour but a huge amount of emotional labour as well which according to Brotheridge and Grandey tended to be very taxing (2002). Aside from the demand of physical and emotional labour, some care workers felt they were not supported by their employers. This lack of support together with the lack of appreciation from the community contribute to the emotional stress of care workers.

Care workers expressed the need to discuss how they feel towards their job among colleagues and supervisors. Most of them mentioned that all their meetings revolved around the individuals they are supporting and never about the care workers. They emphasized the need to have a supportive working environment for them to be able to support and provide the best quality of care to the clients. Similarly, Ford and Honnor (2000) noted in their study that the majority of workers were dismayed by the absence of follow-up to their concerns and felt as if they were not taken seriously by their agencies (see also Casey 2011).

Studies have shown that burnout can greatly affect the individual's efficiency at work when the person feels exhausted and lacks a sense of accomplishment (Fernet, Guay and Senécal 2004 as cited in Casey 2011). This problem should be addressed accordingly since research has shown that once the care worker experiences burnout, the level and quality of care provided to the client is affected as well (Maslach and Jackson 1981). It has been pointed out that burnout is one of main causes of high staff turnover in social services (Casey 2011). This creates a negative ripple effect, when the care workers leave, the clients are most likely to get disconnected from their previously established social network as well.

Aside from excessive workloads, increased risks, and ambiguity of their roles, Mitchell and Hastings noted that the lack of professional development opportunities and resources can also contribute to the care workers' burnout (2001). Most care workers are professional in their home countries and experience downward mobility as they assume lower-status jobs in the host countries (Zimmerman, Litt, and Bose 2006; Lan 2003; Parrenas 2000). While some care workers have found comfort in their new job, others still yearn to get a job that is in line with their previous profession.

Nonetheless, Gonzálex-Romé and colleagues proposed that burnout can be remedied when the employee feels enthusiasm towards the job, sees its value, and takes pride in it (2006). Similarly, Stacey believed that being rewarded and having autonomy, as well as the ability to develop one's skills are important for the employees (2005). However, all of these would not be possible unless employers actively engage and acknowledge their responsibility to help reduce the risks of burnout among care workers (Casey 2011).

Care workers shared that despite the challenges, establishing a positive relationship with their clients and employers (family) is one of the most rewarding parts of their job. Additionally, seeing their clients clean, healthy and happy gives them a great sense of fulfillment. They are also grateful for the community and the relationships they have forged with other clients and fellow disability support workers. Ford and Honnor pointed out that many care workers found moral and ethical support among colleagues who "provided a friendly, supportive outlet for job-related frustrations and the opportunity to share the workload in a social way" (2000, 352). This goes to show that despite the stigma towards their job, people who are in this field still find their work worthy and rewarding (Casey 2011).

Conclusion

In this research, I tried to seek a deeper understanding of the role of friendship in modern society and how this relationship develops for people with intellectual disabilities and migrant care workers alike. The caring attitude of care workers towards their clients later developed into friendships, which in turn create a positive experience for both parties. However, some participants were reticent to call it friendship considering their employer's emphasis on professional detachment and existing notions of people 'who can be friends' (Carrier 1999).

In her study on care as a social organization, Thelen reasoned that care practices should be taken as the starting point in understanding social relationships. She suggested to move past the public-private dichotomy and see care practices as elemental in constructing and dissolving social relationships (2015). While the debates on the public-private dichotomy on care provision maintained the division of intimate care provided in private households versus the impersonal, ‘cold’ institutional care (Thelen 2015; Hoschild 1995), I have argued in this thesis that paid carers were also capable of providing warm and affectionate care. By treating clients as their friends, support workers became more attentive to their needs and were able to understood their preferences better.

This thesis demonstrated that friendly relationships paved the way for healthier and more genuine interactions between people. Through friendship, care workers and care recipients developed interdependence with one another and this interdependence is crucial to their well-being and sense of belonging. For this reason, I would argue that we direct the same attention to friendship as we did on kinship, and understand its role in the integration of modern societies. Rather than being confined within the existing categories and definitions of *friends* and *friendships*, I propose that we acknowledge different ways of friendships (Desai and Killick 2010) and investigate these emerging relationships deeper.

In this thesis, I also aimed at exploring ways to create more opportunities for these underserved populations to develop friendships for themselves. I put emphasis on the need to encourage positive relationships between care workers and clients as well as with their agency/family employers. As I have pointed out, the interdependence between carers and clients, and employers will benefit everyone in the long run. Adequate support and positive relationships at work lessen the likelihood of burnout among care workers and improve employee retention.

While existing literature demonstrated that friendships help improve the quality of life of people with intellectual disabilities, I also emphasized the importance of looking after the well-being of care workers for them to be able to provide the best quality of care to their clients. Disability support workers need as much support as people with intellectual disabilities to fulfill their responsibilities in the community. Supporting the autonomy of people with intellectual disabilities is equally important as supporting the autonomy of care workers.

Migrant care workers form the backbone of the care economy and allow Canadians to perform their jobs by assuming their reproductive roles at home. If we want to ensure the sustainability of the care economy, we should provide care workers decent working conditions, fair wages, and access to basic rights and social protection. Care workers play an important role in facilitating the inclusion of people with intellectual disabilities, however, the high rates of staff turnover impede the continuity of these endeavours. Providing support and showing appreciation of the work that they do will go a long way in reducing the emotional strain of care workers. As well, exploring ways to help care workers socialize and find a sense of community belonging will help lessen feelings of isolation and loneliness. In turn, this will have positive effects in their ability to seek relevant activities and communities where people with intellectual and developmental disabilities can expand their social network. Interdependence which lies at the core of friendships in the context of care work is essential in fostering a sense of belonging and community-building, especially among people who have weak family ties.

While this thesis focused on the perspectives of care workers on friendships, I believe that examining this concept from the point of view of clients and employers would produce a more nuanced understanding of this type of friendship, the role of each party, and what function does it serve in specific contexts. As well, understanding the perspectives of care workers is crucial to provide them with the best support there is and to improve service delivery towards their clients. These findings can also be used in devising strategies to improve relations with clients and employers.

Recommendations

Based on the findings of my research, I suggest that service agencies explore ways to encourage friendly relations among care workers and clients without sacrificing professional boundaries. Perhaps, conducting participatory research or consultation with clients and care workers as to how to establish friendships while maintaining professionalism/ professional boundaries. Further research and strategies should be employed to facilitate friendship formation and create safe environments for people with intellectual and developmental disabilities.

We should strive harder to promote decent working conditions and supporting the autonomy of migrant care workers. Both sending and receiving countries should make policy changes to ensure that migrant care workers have access to basic rights and social protection in destination countries. Immigration policies should allow care workers to have permanent residency upon arrival to help lessen the emotional distress of care workers.

Contribution of this research

In addition to the existing literature on friendship, care work, and inclusion, this thesis contributes the following:

- Despite the stereotypes and homogenization of migrant care workers, this research shows that live-in caregivers have different experiences and work conditions with live-out care workers. In the same way that care workers who are permanent residents and Canadian citizens have different experiences with those who have precarious immigration status. A more detailed understanding of this difference is crucial in policy-making to ensure that these varying concerns are addressed accordingly.
- Friendship among care workers and clients does not impede the provision of high-quality care, rather, it provides opportunities for the care workers to deeply understand their clients. As well, friendship lessens the feeling of isolation and likelihood of burnout among care workers. Thus, friendship improves the quality of life of both caregivers and care recipients. I add the caveat, however, that closeness without respect can result in exploitation and negative relationships between both parties (Salami and Meherali 2018).

- Just like the people they support, migrant care workers also experience loneliness and exclusion. Thus, we should strive hard to find ways to promote their inclusion and citizenship.
- Care workers' perspectives and experiences in accompanying clients need to be taken into account when designing more inclusive policies and programs (e.g. social services, welfare payments, workplace regulation, and care/housing provision) for people with intellectual and developmental disabilities.
- While inclusion and friendship are something that cannot be legislated, raising awareness and promoting understanding of people with intellectual disabilities as well as the value of care work will help shape the public's perspective and attitude towards these minority populations.
- People with intellectual disabilities and migrant care workers are among the marginalized groups in society who happen to form a community of their own. This provided a sense of belonging for these populations who lack citizenship and a sense of community. Without the friendly aspect and affection put into this work, care workers will continue to provide impersonal care to their clients.

Overall, my thesis explored and presented the role of friendship in contemporary Canada. I believe this research made a distinct contribution to the analysis and understanding of modern societies and provided a new perspective on social organization brought about by the global division of labour.

Much of the literature in care work focused on intimate care which includes bathing, toileting, dressing, and feeding. In this thesis, I focused on the kind of care work and affective effort that foster friendships, which as I demonstrated earlier, tended to be taken in the periphery of anthropological studies.

For people with intellectual and developmental disabilities, especially those who live in group homes, family ties are rather weak or non-existent. Similarly, the majority of care workers are migrants who are separated from their families have a limited support system. In the absence of family and limited social connections, I claimed that these two disadvantaged groups find their way to create their own community and feel a sense of belonging.

In Thelen's proposition of care as a key element in social organization (2015), she quoted Firth's take on social organization in contrast to social structure: "working towards an order-though not necessarily the same order"(1955, 2). Following this discussion, I make a strong case that friendships will play an increasingly important role in helping modern societies cohere and improving people's quality of life.

Through ethnographic research, I was able to tease out the subtleties of friendship between care workers and clients which was difficult to obtain through surveys. Using this method, I was able to contextualize participants' perceptions of friendship and explore how and why these kinds of relationships emerge. This anthropological approach is essential in illuminating the complexities and specific characteristics of different types of relationships that keep societies together. Thus, I would suggest that we pay more attention on friendship in our anthropological inquiries just as how former anthropologists studied kinship in traditional societies.

Limitations

The results presented in this thesis should be considered in the light of some limitations. First, as mentioned in the Methodology section, I chose to interview disability support workers for theoretical and practical reasons. Most of the data in this thesis were directly provided by the care workers. For future research, it would be worthwhile to interview people with intellectual disabilities and employers to see whether they have similarities and differences in conceptualizing friendships. Although there are already some studies on people with intellectual disabilities' views on friendship, I suggest directing a focus on friendship's role in improving client-carer relationships and its importance in community building. Friendships between care workers and clients demand a more nuanced approach to understand better how both parties negotiate social positions and unequal power relations.

The second limitation of my research is the tendency for social desirability bias to emerge during the course of the interview. A lot of research participants are skeptical of my research when I first approached them fearing it might be reported to their employers or some government agencies. Social desirability bias refers to the mismatch between the participant's response to the researcher and the actual construction of the individual's reality (Bergen and Labonte 2019). This is a common challenge in qualitative research, especially on questions that are sensitive or controversial to the participant, thus resulting in responses that are deemed to be socially acceptable and desirable (Grimm 2010). This desirability bias was heightened by the absence of participant-observation, a widely employed data collection method in anthropology that enables the researcher to immerse in the day-to-day lives of research participants. While I have spent a considerable amount of time hanging out with disability support workers in recreation centres, I still feel it was not enough to triangulate their responses with actual observations.

Third, the diversity of the research participants presents a challenge to the current study, while care work is mostly occupied by women, there are also care workers from the LGBTQIA2S+ community. Their views on friendships also merit further research.

Fourth, the majority of the immigrant care workers came from Asia and Africa, perhaps, interviewing care workers from a different region in the future is important to show contrasts and similarities. Examining care work from a diverse perspective will give us a better understanding of the care economy. As well, the marital status of care workers was not clearly presented in this study although some participants mentioned juggling paid care work and reproductive roles at home. I believe that familial responsibilities will also have a significant impact on one's work and decision-making.

Finally, readers should also be aware that people with intellectual and developmental disabilities are not homogenous including their friendships and lived experiences. However, for confidentiality and ethical reasons, I was not able to discuss the unique characteristics of each individual as it was also outside of the scope of this study. Several researchers suggested that social experiences for individuals with intellectual disabilities vary across the lifespan.

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APPENDIX A: INTERVIEW QUESTIONS

Friendship and inclusion in Edmonton

Interview Questions:

1. Can you introduce yourself by stating your gender, approximate age, regional origin, and citizenship status?
2. How long have you done disability support work, either in general or with Skills Society?
3. How did you get into this line of work?
4. What does a typical work day look like for you?
5. Does your formal job description capture well what you actually do every day?
6. One aspect of disability support work is supporting social inclusion and facilitating friendship formation for adults with intellectual disabilities. Is this something that comes up in your work?
7. [If yes] Can you tell me a social inclusion "success story" from your work experience?
8. Can you give me an example of an experience that has been more challenging or has not worked out well?
9. Finally, would you be willing to tell me a story about what role friendship plays in your own life, outside of the work you do here?
10. Do you have any questions for me? Thank you very much for speaking with me today.

Prepared by:

Deanna Joyce Neri
Primary Investigator

Dr. Kathleen Lowrey
Research Supervisor

INTERVIEW QUESTIONS
(TAGALOG TRANSLATION)

Mga tanong:

1. Maari nyo po bang ipakilala ang sarili nyo sa pamamagitan ng pagbanggit ng inyong kasarian, tinatayang edad, kung saang rehiyon kayo galling, at kung ano ang citizenship status nyo ditto?
2. Gano na po kayo katagal nagta-trabaho bilang disability support worker, di lang po sa Skills kundi sa lahat lahat ng napagtrabahuan nyo po?
3. Pano po kayo napunta sa ganitong propesyon o trabaho?
4. Paano nyo po ba mailalarawan ang karaniwang araw sa trabaho nyo?
5. Ang lahat po ba ng ginagawa nyo ay tumutugpa sa kung ano ang nakasaad sa inyong job description?
6. Isa pong aspeto ng disability support work ay tulungan ang mga adults with intellectual disabilities magkaroon ng kaibigan at makibahagi sa komunidad, ito po ba ay parte ng inyong karaniwang trabaho o ginagawa sa araw araw?
7. [Kung oo], maaari po ba kayong magsalaysay ng kwento kung saan natulungan nyo silang magkaroon ng kaibigan o makibahagi sa komunidad?
8. May mga kwento din po ba kayo o mga halimbawang sitwasyon kung saan nahirapan kayo sa pagtugon nito?
9. May mga tanong po ba kayo para sa akin? Maraming salamat po sa panahon na inilaan nyo sakin ngayon.
10. Maaari din po ba kayong magsalaysay ng sarili nyong kwento tungkol sa pagkakaibigan o pagkakaroon ng kaibigan na labas po sa trabaho nyo?