

## Interdependence

# The Pathway to the Inclusion of People with Intellectual Disabilities and Immigrant Disability Support Workers

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Résumé de l'article

L'amitié et les liens sociaux améliorent généralement la qualité de vie et le bien-être. Cependant, des recherches montrent que les personnes présentant une déficience intellectuelle ont du mal à nouer des liens et à entretenir des amitiés. Les travailleurs de soutien aux personnes handicapées jouent un rôle indispensable et pourtant méconnu dans le développement des amitiés avec les personnes présentant une déficience intellectuelle. Étant donné que les travailleurs de soutien aux personnes handicapées sont en grande partie des femmes immigrées, ces personnes connaissent elles aussi l'isolement social alors qu'elles facilitent l'inclusion de leurs clients. Après avoir mené des entretiens approfondis avec des travailleurs de soutien aux personnes handicapées vivant à Edmonton, au Canada, pour mon projet de mémoire de maîtrise, je propose les observations suivantes. Premièrement, les employés et les clients sont mutuellement devenus amis, en raison, en partie de la faiblesse des liens familiaux et des réseaux sociaux limités. Deuxièmement, les relations authentiques ont aidé les employés à mieux comprendre leurs clients et leur ont donné un sens à la vie plus profond. Troisièmement, le contexte, l'environnement et la fréquence des rencontres sont essentiels au développement des amitiés. Quatrièmement, les amitiés entre personnes handicapées et non-handicapées sont essentielles au développement de la communauté. Dans l'ensemble, à partir de ces entretiens, je suggère que les amitiés authentiques entre les personnes présentant une déficience intellectuelle et les travailleurs sociaux peuvent contribuer à favoriser un sentiment d'appartenance communautaire et font partie intégrante du développement de la communauté. Ma recherche suggère également que la signification de l'amitié devrait être élargie au-delà des conceptions actuelles.

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# Interdependence

## The Pathway to the Inclusion of People with Intellectual Disabilities and Immigrant Disability Support Workers

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**Abstract:** Friendship and social connections generally improve quality of life and well-being. However, research shows that people with intellectual disabilities face challenges forming and maintaining friendships. Disability support workers play an indispensable yet under-recognized role in developing friendships with people with intellectual disabilities. Because disability support workers are disproportionately immigrant women, as they facilitate the inclusion of their clients, they too experience social isolation. After conducting in-depth interviews with disability support workers living in Edmonton, Canada, for my master's thesis project, I offer the following observations. First, staff and clients became friends with one another in part due to weak family ties and limited social networks. Second, relationships that felt genuine helped staff better understand their clients and gave the staff a deeper sense of purpose in life. Third, the context, environment, and frequency of meetings were essential for the development of friendships. Fourth, friendships among people both with and without disabilities were crucial for community development. Overall, based on these interviews I suggest that genuine friendships between people with intellectual disabilities and care workers can help foster a sense of belonging and are integral to community-building. My research also suggests that the meaning of friendship ought to be expanded beyond current understandings.

**Keywords:** Friendship; inclusion; people with intellectual disabilities; immigrant; care work

**Résumé :** L'amitié et les liens sociaux améliorent généralement la qualité de vie et le bien-être. Cependant, des recherches montrent que les personnes présentant une déficience intellectuelle ont du mal à nouer des liens et à entretenir des amitiés. Les travailleurs de soutien aux personnes handicapées jouent un rôle indispensable et pourtant méconnu dans le développement des amitiés avec les personnes présentant une déficience intellectuelle. Étant donné que les travailleurs de soutien aux personnes handicapées sont en grande partie des femmes immigrées, ces personnes connaissent elles aussi l'isolement social alors qu'elles facilitent l'inclusion de leurs clients. Après avoir mené des entretiens approfondis avec des travailleurs de soutien aux personnes handicapées vivant à Edmonton, au Canada, pour mon projet de mémoire de maîtrise, je propose les observations suivantes. Premièrement, les employés et les clients sont mutuellement devenus amis, en raison, en partie de la faiblesse des liens familiaux et des réseaux sociaux limités. Deuxièmement, les relations authentiques ont aidé les employés à mieux comprendre leurs clients et leur ont donné un sens à la vie plus profond. Troisièmement, le contexte, l'environnement et la fréquence des rencontres sont essentiels au développement des amitiés. Quatrièmement, les amitiés entre personnes handicapées et non-handicapées sont essentielles au développement de la communauté. Dans l'ensemble, à partir de ces entretiens, je suggère que les amitiés authentiques entre les personnes présentant une déficience intellectuelle et les travailleurs sociaux peuvent contribuer à favoriser un sentiment d'appartenance communautaire et font partie intégrante du développement de la communauté. Ma recherche suggère également que la signification de l'amitié devrait être élargie au-delà des conceptions actuelles.

**Mots-clés :** Amitié ; inclusion ; personnes ayant des déficiences intellectuelles ; immigrant ; travail de soins

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## Introduction

A part from families and romantic partners, social relationships like friendships can improve a person's emotional and mental well-being (Friedman and Rizzolo 2017). Friends can provide security and a sense of belonging. In times of trouble, people often seek refuge in, and comfort from, their friends. In times of triumph, people celebrate in the company of their friends. Previous research conducted across the United States and the United Kingdom between 2004 and 2016 shows that people with intellectual disabilities<sup>1</sup> face more challenges developing and maintaining friendships and are more prone to loneliness and social isolation than their non-disabled peers

(Friedman and Rizzolo 2017; Fulford and Cobigo 2018). People with intellectual disabilities rely heavily on care workers<sup>2</sup> for the development of friendships through supported community participation, community presence, and activities involving other people that open up possibilities for friendships to form and flourish (Van Asselt et al. 2015). Therefore, while the importance of friendship seems clear, what is less clear is what happens in Canada to people who have difficulties making and maintaining friends, in particular, people with intellectual disabilities and also those who are new to Canada?

This article begins with a brief overview of the anthropology of friendship. I then discuss the existing studies on the barriers to friendships of people with intellectual disabilities and immigrant care workers, and explain the anthropology of the good as the theoretical framework to understand the dynamics of the relationship between clients and care workers. The results and discussion sections that follow highlight: (1) the barriers and challenges to friendship and inclusion of both people with intellectual disabilities and immigrant care workers; (2) the factors that facilitate friendships and community-building; and, finally (3) the implications and importance of friendships in making modern societies cohere. Most broadly, this paper addresses the barriers and importance of friendships and why paying close attention to friendship in modern societies is important.

## **Methodology**

Between June and October 2019 in Edmonton, Canada, I carried out interviews for this study. I interviewed fourteen women care workers; eight of them were migrant<sup>3</sup> caregivers who came to Canada from Southeast Asia and Africa with a temporary visa; five were white Canadians, and one was Indigenous. I also interviewed six men; two were from Africa; one from an Indigenous community, one from Europe with Canadian citizenship; and two were white Canadian citizens. This study was conducted as part of my master's thesis. My supervisor had a prior connection to an Edmonton-based service organization offering residential services to people with developmental disabilities. I sent out emails and flyers to the organization and asked if they could forward them to their employees and post them on bulletin boards. We were also referred to five more organizations offering day programs, employment programs, and respite services for people with intellectual and developmental disabilities. Since most of the interviewees for this project were migrant women care

workers, the discussion centres around those eight migrant women's accounts because they were providing direct personal care for people with intellectual disabilities. The Canadian women and men participants were involved in the administrative tasks and planning of recreation activities for people with intellectual disabilities.

Five out of the eight migrant care workers arrived in Canada as live-in caregivers with temporary visas between 2006 and 2014. The other three arrived with Permanent Resident status with their families between 2010 and 2016. At the time of the interviews, the majority of them had children, were between their mid-forties and early fifties, and were from Asia and Africa. Two were in their mid-thirties from Asia and Africa, and one was pregnant. These migrant caregivers have tertiary education in their home countries and worked as teachers, engineers, social workers, and nurses. However, due to the non-recognition of foreign credentials and education, these women were not able to practice their profession in Canada. The majority of the interviewees worked for the same client. However, those who are permanent residents had more flexibility in switching employers and were able to work for one client and then another, depending on the demand. Interviewees who arrived in Canada as live-in caregivers had worked for a minimum of two years for each client. One of them worked for the same client for twelve years. The others switched employers and worked as community disability services practitioners in different service agencies.

For the methodology, I draw on Joel Robbins' (2013) "anthropology of the good", a framework in which anthropological studies represent suffering to build an empathetic connection to the readers in the hopes that it will be an impetus to social change. While stories of struggle are important in the aim of social justice, he is against flattening multi-faceted experiences as mere stories of suffering. Immigrant disability support workers and adults with intellectual disabilities are among the populations who belong to the "suffering slot" in anthropology (Robbins 2013). As I demonstrate, theirs are not "mere stories of struggle and suffering," but are also stories of success, joy, resilience, and resistance. Within this framework, instead of approaching disability as an attribute attached only to what Robbins (2013) wryly calls "suffering subjects", I 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.

Similarly, Thelen (2015) argues that care practices should be taken as the starting point in understanding social relationships. While debates on the public-private dichotomy on care provision set intimate care provided in private households against impersonal, “cold institutional care” (Hoschild 1995; Thelen 2015), I argue against this distinction and suggest instead that paid carers are capable of providing warm, affectionate care. Rather than staying within limiting and narrowly circumscribed categories and definitions of friends and friendships, I acknowledge different ways of friendships (Killick and Desai 2010) and closely investigate these emerging relationships.

### **On the Anthropology of Friendship**

Friendship plays a central role in many people’s lives across cultures (Beer and Gardner 2015). Yet until recently, anthropologists have paid little attention to friendship (Killick and Desai 2010; Pitt-Rivers [1983] 2016). Its relative lack of attention can be attributed 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 have made it difficult to study (Killick and Desai 2010).

To date, two significant debates around friendship appear in current literature. The first proposition as identified by Torresan (2011) conceptualizes friendship as a kind of relationship deeply embedded in western notions of individual autonomy. Friendship is a product of capitalist transformations in social and moral codes that separate individuals from society and into private or public spheres (Carrier 1999). Carrier (1999) argues that friendship is a voluntary relationship based on spontaneous, unconstrained sentiment between two autonomous individuals in a private domain. Furthermore, friendship can only develop between two social equals who can reciprocate without material interference (Carrier 1999; Winkler-Reid 2016).

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). 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). Carsten (2000) invites open and multiple definitions of friendship since “relationships of friendship do not necessarily map neatly on to local conceptions of kin and non-kin” (Killick and Desai 2010, 1). Thus, this view argues that any definition of friendship must allow for cross-cultural variations.

Following this latter more nuanced understanding, I situate friendships in a social and cultural context and acknowledge the conditions affecting the formation, maintenance, and disintegration of friendships (Adams and Allan 1998), which are embedded in a wider, complex network and interplay of relations (Policarpo 2015).

### **On Friendships of People with Intellectual Disabilities and Care Workers**

A study conducted across the United States shows that people with intellectual disabilities continue to be limited in friendships until recently (DaWalt et al. 2019). Due to this limited social network, most people with intellectual disabilities consider their paid staff to be their friends (Asselt-Goverts et al. 2015; Friedman and Rizzolo 2017). While friendships between staff and clients have considerable mutual benefits, some scholars argue that “paid relationships” cannot be considered as real friendships. This argument assumes that friendships can only ever be “private” arrangements and, thus, when money enters the picture the private arrangement turns into “business” (De Freitas-Cardoso 1987).

Similarly, research conducted in Canada shows that the majority of immigrants lack an established social network and often experience loneliness (Hanley, Larios and Koo 2017). This is not unique to Canada. The majority of immigrant women from African countries pointed out isolation and the absence of family members and social networks as some of the major challenges they encountered in migrating to western countries (Ogunsiji et al. 2011).

### **Autonomy and Interdependence**

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, scholars have contested western notions of independence and autonomy that emphasize the individual’s capacity for self-determination and self-government (Davy 2015). More specifically, an emphasis on personal autonomy has been criticized by feminist theorists for neglecting to consider that people, regardless of ability, are inherently social and relational (Davy 2015; Kittay 1999). 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; Silvers and Francis 2007).

Similarly, disability scholars challenge the western notion of autonomy for its cognitive bias that further marginalizes people with intellectual disabilities (Davy 2015). This myth of autonomy and independence has been largely contested by scholars, including Joan Tronto (2005, 130), who argues that “care is a fundamental aspect of human life”. No one is entirely independent. Everyone needs, receives, and provides different kinds of care in the different stages of their lives (England 2010); that is, people are interdependent.

Consequently, Davy (2015) suggests a reconfigured view of autonomy that recognizes every individual’s vulnerabilities, basic dependencies, and the need for ongoing support and care to be “autonomous” agents in society. 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 family members or paid carers, are highlighted as the people providing direct support and care to people with intellectual disabilities. This echoes Berube’s (2010) claim to recognize the role of guardians as people who are sometimes well-positioned to represent and speak for people with intellectual disabilities.

Disability support workers play an indispensable role in supporting the autonomy of people with intellectual disabilities in Canada. However, unfortunately, they too lack autonomy. The majority of immigrant care workers enter Canada through the Live-in Caregiver Program (LCP), which gives them temporary visas tied to a single employer and limits their access to social services and rights compared to citizens. Apart from the lack of citizenship, care workers also experience a lack of appreciation. Despite the significant skills, professionalism, and physical strength required, care work remains undervalued and gendered, seen as a less skillful “female job” that should be unpaid (Armstrong and Armstrong 2001). This lack of appreciation contributes to the exclusion of immigrant care workers who find that employment in precarious or low-paying jobs causes “a ripple negative effect on community belonging” (Salami et al 2019, 31).



## Results

### *1. Challenges in Friendship Formation and Inclusion*

#### *Social Exclusion Among People with Intellectual Disabilities*

I find that in 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 but this is their enjoyment. This is how they enjoy with friends and stuff like that.

~Archie<sup>4</sup>

Despite Canada's drive for multiculturalism and diversity, the question of inclusivity remains highly pertinent. Interviewees reported instances where people were subtly being rude to their clients by staring at them or willfully ignoring them. Other bystanders were far more explicit in their rudeness; they asked a group of people with intellectual disabilities to leave the park. Most of the interviewees expressed acting as a buffer between their clients and the public who were not very welcoming of this underserved population. In some instances, care workers tried to explain and educate people they met when they felt appropriate. But in certain cases where they felt that the other person was close-minded, they tried to comfort their clients and make sure they understood that there is nothing wrong with them.

#### *Limited Network of Care Workers*

It was only here [in Canada] that I realized how important it is to have friends, especially when you encounter family problems and you're a thousand miles away from them. You really need someone to listen to you but it's very hard to find friends here.

~Reese

It's not easy to be alone in a new country, you think about your family every time but you have to stay strong.

~Elliot

It's very difficult to find friends you can trust here. I just don't have the time to get to know them better. You won't know their intentions.

~Reggie

One interviewee expressed her view that forming friendships was difficult, even for non-disabled people like her. Given the nature of her job and responsibilities

at hand, socializing with other people was a luxury she could not afford. Other participants felt the same. The isolating nature of their job, extended hours at work to make ends meet, and familial responsibilities made it impossible for them to socialize and make new friends.

### *Friendships Between Paid Staff and Clients*

We are friends, we always hang out with each other and we understand each other. He was there in the lowest moments in my life. Even when I did not get a single response, I felt better having someone to talk to.

~Dallas

The limited social network and support systems of both people with intellectual disabilities and care workers paved the way for friendships to flourish between them, which serves to debunk the argument that friendships cannot exist within the paid support relationship. Genuine relationships with staff were important friendships for their clients, especially those with limited communication abilities. Paid staff became close peers to, and a constant source of emotional and social support for, non-verbal individuals. Interviewees said that most of their clients had limited communication abilities and expressed themselves non-verbally. Finding ways to effectively communicate took time; care workers needed to know the clients better to understand their likes and dislikes. Interviewees shared that hanging out with their clients frequently allowed them to understand their preferences and communication cues.

Care workers believed that without friendship and genuine affection, they would act with indifference towards their clients. They would not care very much about the clients' happiness so long as the care workers could successfully perform their daily tasks. Disability support workers believed that the best way to teach their clients how to make friends in the community was to model such interaction. Thus, some days, they acted and talked to their clients like friends.

## ***II. Building Connections and Genuine Relationships***

### *Mutual Support and Respect*

Yes, this is my bread and butter. But you know what made me stay in this job? The emotional support that this family has given me when I was struggling with my own family problems. They didn't treat me as a worker but as a family. They were there when I had no one else to turn to.

~Ollie

As much as interviewees tried hard to keep boundaries between work and personal life, there were times when their personal problems affected their mood at work. Although none of them lashed out at their clients during these trying times, they were aware that their mood significantly affected their clients. For care workers, their job does not only include physical labour but a great amount of emotional labour (Hochschild 1983) as well. However, as one interviewee shared, above, this vulnerable moment allowed her to form a bond with her client and the client's family.

From the very beginning, I already made an impression that we're partners. It's not like, "You're just a client and I'm the worker, therefore I should be followed." I don't like that. I always assure them that I'm not their enemy, I'm here to support them and we're in this together. When I first met them, they were exhibiting violent behaviours. I approached them and talked to them calmly and that's when we started to become buddies.

~Jamie

Another care worker said that establishing mutual respect from the very beginning resulted in a positive relationship with her client, whom she eventually considered her "best buddy." And while care workers are expected to provide daily care to their clients, interviewees also received emotional support from their clients. This reciprocity of emotional support contradicts the common misconception that clients are in a disadvantaged position as care recipients in comparison to their paid staff. Caring was a two-way street.

#### *Diverted Mothering*

I don't treat them as my client, I treat them as my own child. My employer saw that one time when she was supposed to get home late but she arrived earlier and saw me tucking them into bed like a child, you know? You would understand when you get a child of your own.

~Casey

Emotional attachment to clients was strongly discouraged by some employers, especially by service agencies; thus, care workers did a great amount of emotional labour to hide this affection towards clients and maintain professional boundaries. While most of the interviewees understood the need to detach themselves from their clients, others also felt that being affectionate towards their clients helped lessen their guilt and emotional stress for being away from their families. Most felt guilty about taking care of another family instead of their own, which is common among migrant workers, especially in domestic

service. Treating their client as their own child eased their homesickness and likelihood of burnout. Moreover, by developing this particular bond with clients they learned more about their needs, which allowed them to provide a higher quality of care. In the absence of family and close friends, care workers found comfort in the company of their clients.

### *Genuine Connections*

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 eight hours I need.

~Jamie

In contrast to previous research indicating the negative effect of friendships between staff and clients, the disability support workers in this study claimed that this affectionate relationship was the major reason why they did not want to leave their jobs easily. The genuine relationship within the paid support setting not only helped the client but also the care worker in a way that gave them a deeper sense of purpose and appreciation of their job. In some cases, the bond and friendship between care workers and clients improved staff retention.

### *Context, Frequency, and Environment*

Like Alex and Brie, they are our clients and we go to this Thursday activity together so we all become friends, the clients and care workers. My friends are their friends and vice versa. Tomorrow, we will have a new set of friends from a different program. As we attend more activities, we meet new people, and the more frequently we see each other, the more chances of friendships to develop.

~Elliot

Apart from the friends we meet through our regular activities, I also see to it that we establish a network outside of these programs. For example, today we are usually the last ones to get picked up by DATS so we try to make friends with other people too. Sometimes we join other groups for lunch here or make plans to go to Tony Roma's with other clients and caregivers.

~Archie

Considering the limited communication abilities of some people with intellectual disabilities, regular day programs and community activities were crucial in facilitating inclusion and friendship formation. Interviewees' clients were not always comfortable in new, unfamiliar settings. Going to the same program and seeing familiar faces helped them become more comfortable with other people. The frequency of meetings created opportunities for conversations and to find common interests among clients and staff. Another care worker met a lot of her friends through these community activities and day programs. Thus, she not only improved her client's social network but also her own.

### ***III. Community Building and Collective Responsibility***

#### *Advocating for Clients*

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.

~Ollie

Apart from the personal care and community support that disability support workers provided, they were also placed in advocacy roles. Despite the drive for inclusion in Canada, care workers noted there were still a lot of people who were unwelcoming and stigmatized people with intellectual disabilities. Most care workers became advocates and went beyond their staff responsibilities (that is, providing direct care and community support) to protect their clients. This alliance created opportunities for stronger relationships like friendships to develop.

#### *Rethinking Autonomy and Interdependence*

I support them to do their daily activities but they also help me relieve my stress. At times when I get too stressed out at work, especially dealing with other staff at the group home, I just talk to them. Even though they can't speak properly, I know they're listening and comforting me and that's more than enough for me.

~Dallas

When I was going through a very tough time with my family, I would just cry to them when I can't take it anymore. I don't want my children to see me crying. I guess that's how my relationship with them was strengthened.

~Casey

In contrast to the common assumption that people with intellectual disabilities are always dependent on the care workers, the interviewees' experiences showed that there was mutual support between them. On the one hand, care workers provided direct personal care to the clients. On the other hand, clients offered indirect emotional support to their carers. With the bond they developed with each other, migrant care workers felt less lonely and found comfort in the company of their clients. Care workers described their clients as friends with whom they shared their problems and who were present when they had no one else to turn to.

#### *Appreciating Care Work*

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 behaviours. We spend so much time trying to understand our individuals and making sure they are safe and happy.

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].

I think the other biggest thing too is that employers should take into consideration what the staff is feeling, right? Like checking on them, how things are going, having regular meetings maybe three or four times a year even. Coming in not for a meeting about the individual but coming in for a meeting about the staff and how we are being supported, finding out what else can we do that can change or help you guys to feel like this is a good environment for you.

~Jamie

Interviewees felt the public had little appreciation for their work and assumed they were simply bringing their clients to malls and recreation centres. Disability support workers felt they were constantly watched in the

community as if people were waiting for opportunities to criticize them while underappreciating their work. Many were cautious with every single move since they felt that even briefly checking their phone could be taken against them. Interviewees felt they were held responsible for their clients who sometimes acted out of the care worker's control.

Additionally, care workers felt the need to have a better relationship with their employers. They wanted regular check-ins with employers about how they were feeling towards their job and what support they needed to be able to provide the best quality of care.

### *Collective Responsibility*

So, I 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. I always take Elena with me even in the washroom and stuff. It's just difficult sometimes but you know you have support staff who will watch out for your other individuals.

~Reggie

Yeah, we're always in a group. Like everywhere we go, the clients themselves are friends that's how we also develop a friendship. So it becomes like a community of its own.

~Elliot

The frequency of meetings of clients and care workers in day programs and community activities paved the way for friendships to develop. These friendships then became small communities. Within these small groups, care workers felt they were understood and belonged. Interviewees found that being part of a community, where everyone felt safe and comfortable with each other, was helpful. Aside from sharing information on how to better take care of their clients, care workers also shared simple responsibilities when needed, such as having washroom breaks.

I think the challenge is to break down stereotypes 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 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.

~Reese

Other interviewees expressed the need to strengthen inclusion campaigns by fostering understanding and encouraging the active participation of the general public. Instead of treating them differently or tolerating their presence, care workers wished non-disabled people in the community would socialize with them and the clients. In this way, clients who may have had bad experiences in the past would slowly become more comfortable being in public. Care workers felt that the public has a limited understanding of people with disabilities, one that reproduces misconceptions that, in turn, create barriers to socialization.

## **Discussion**

In Thelen's (2015) proposition of care as a key element in social organization, she quoted Firth's (1955, 2) perspective on social organization in contrast to social structure: "working towards an order—though not necessarily the same order". Further, Thelen reasons that care practices should be taken as the starting point in understanding social relationships. She suggests moving past the public-private dichotomy to see care practices as elemental in constructing and dissolving social relationships (2015). While the debates on the public-private dichotomy on care provision maintain the division of intimate care provided in private households versus the impersonal, 'cold' institutional care (Hochschild 1995; Thelen 2015), I have argued in this paper that paid carers were also capable of providing warm and affectionate care. Friendships in a paid care setting helped the staff become more attentive to the needs of their clients and they were able to understand the clients' choices better. 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. Following this framework, I make a strong case that in modern societies like Canada where family ties are weakening, friendships will play an increasingly important role in social organization. In the succeeding paragraphs, I will elaborate on the formation of friendships and interdependence between people with intellectual disabilities and immigrant care workers.

People with intellectual disabilities who have limited verbal abilities relied on support workers to expand their networks and build community connections. For care workers to facilitate this connection, they first need to have a genuine, friendly relationship with them and understand their needs and preferences. This relationship took time to develop and the willingness



of both parties to get to know each other better. Some clients were outright uncomfortable with certain care workers. In the same way, there were also care workers who easily gave up when they did not get along with the client for the first few meetings and transferred to another client.

People with disabilities relied on their care workers for physical and social support, and care workers also depended on their clients for emotional support. Migrant care workers were separated from their family and friends; thus, in times of emotional distress, most of them turned to their clients to seek comfort. While they facilitated the inclusion of people with intellectual disabilities, they also struggled with social isolation. The undervalued importance of care work reflected the lower wages of disability support workers, which eventually led to working extended hours just to make ends meet. As a result, migrant care workers rarely got time to maintain a social life and expand their network. This lack of a social support system has been documented as greatly affecting immigrant women's well-being, in addition to contributing towards the struggle of securing jobs in gendered and racialized job markets (Okeke-Ihejirika, Salami, and Karimi 2016).

Inclusion does not simply mean presence in the community. As Stainton (2017) argues, lobbying, advocacies, and political action may result in the realization of formal citizenship, but inclusion is something that cannot be legislated. Care workers and the people they support needed a genuine social network to ensure they have access to opportunities to form friendships and participate in meaningful social activities. Reindeers (2002) believes that it is not only citizenship but also friendship that matters. For both people with intellectual disabilities and care workers, inclusion will remain elusive and problematic without supported social networks (Reindeers 2002) since "inclusion is something that must be felt rather than enforced" (Stainton 2017, 1).

The bond that staff developed with their clients later developed into friendships. These findings showed that the longer they stayed together, the better they understood each other. Some people with intellectual disabilities lived in a group home where they were visited by family members once in a while. Others lived with their families but often did not see their friends. Similarly, care workers, the majority of whom are migrants, were separated from their families and friends. When both the client and the care worker had weak family ties and support systems, they became closer to each other. Some would call their clients their family, others would refer to them as friends. Further

research with people with intellectual disabilities who can communicate verbally would be valuable, to see whether they consider paid staff as friends and how these relations develop.

This interdependent relationship debunked misconceptions that care work is a one-way street, where the care worker was the only one providing support to the client. Care was provided in both ways and support came in different forms: physical, social, mental, emotional, and financial. My research showed that different employers had different rules when it comes to establishing relationships with clients. Some service providers strictly prohibited friendly relations between staff and clients. Maintaining professional boundaries and emotional detachment were constantly emphasized due to high staff turnover that could put the client at a great disadvantage when the staff leaves. There were also service agencies that encouraged friendships between staff and clients, as they considered it vital to the realization of the latter's full citizenship. They did a careful screening of their staff to make sure they matched well with the client. For clients who can communicate verbally, they also partook in the selection process of the care workers they were paired with. In a similar study, data shows that direct employers (that is, family) like it when they see that the care worker is treating the client as their kin (Salami and Meherali 2018). Direct employers believe that the absence of emotional attachment from live-in caregivers reflects the lack of competence and dedication to one's work (Salami and Meherali 2018). As well, care workers whom I interviewed believed that friendships and affection were important components of their job. The absence of genuine affection towards clients often resulted in poor quality of care. Moreover, the friendship and bond between client and staff helped ease their loneliness and isolation. Some care workers expressed that being affectionate towards their clients helped lessen the guilt and emotional stress they felt for being away from their families. This inability to take care of one's own family due to physical distance has been termed by Parreñas (2000, 59) as *displaced mothering* or *displaced caretaking* seen as a "social consequence of the international division of reproductive labour". For this reason, care workers find themselves in a position of 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 has also been justified by several studies that show how migrant women are finding emotional rewards for pouring their love into another family (Parreñas 2000).

While it remains contentious whether friendships between staff and clients are beneficial or not, my research findings suggested that these friendships in the paid care setting have several benefits: they helped improve staff retention; lessened the chances of burnout among care workers; and, created a sense of belonging among care workers and people with intellectual disabilities. The positive relationship between staff and clients helped support both parties' autonomy and inclusion. In addition, this gave care workers a sense of fulfillment and appreciation of their work. Oftentimes, care workers felt that only their shortcomings were recognized in public but not the value of the work that they do. Seeing their clients happy and healthy gave them affirmation and motivation to continue providing the best quality of care.

Because of the stigma and discrimination by the general public in Canada against people with intellectual disabilities, care workers were often placed in roles of advocacy. Although not necessarily part of their job, many care workers defended their clients whenever they felt they were discriminated against by the general public. Most of the time, these alliances flourished into friendships such that even when they did not work for the client anymore, they still maintained contact and met each other once in a while.

Finally, in terms of facilitating inclusion, care workers emphasized the need to break down stereotypes and appealed for the community to genuinely accept their clients. One of the main challenges experienced by care workers was finding a safe and welcoming space for their clients. Care workers believed that everyone should do their part in fostering a sense of belonging for marginalized populations.

## **Conclusion**

This paper provided insights into the barriers and facilitators of friendships among a small group of people with intellectual disabilities and immigrant care workers in the city of Edmonton, Canada. The lack of an established support system paved the way for friendships that later turned into flourishing community ties. Additionally, the weak ties within the families of both the clients and the care workers appeared to have contributed to a special bond and genuine connection that formed between them. Further, this study contributed to the limited friendship studies and to new understandings of the role of friendships in contemporary everyday life. In contrast to the assumption that friendships within the paid care setting cannot be genuine, I argued that the friendly aspect and affection put into this work were integral, as care

workers would otherwise continue to provide impersonal care to their clients. Friendship among care workers and clients did not impede the provision of high-quality care; rather, it provided opportunities for the care workers to deeply understand their clients. As well, friendships lessened the feeling of isolation and improved staff retention.

Other insights also emerged from my research. For example, I learned how the personal challenges of immigrant care workers while they are supporting the inclusion of people with intellectual disabilities often go unnoticed. Using the anthropology of the good framework, I theorize that despite challenges, these two disadvantaged groups developed interdependence and found ways to create their community and sense of belonging. I suggest that *care* is the foundation of friendships between clients and staff, which is crucial in fostering a sense of belonging as the social organization of contemporary societies transform. I contend that while inclusion and friendship are something that cannot be legislated, raising awareness and promoting understanding of people with intellectual disabilities will help to break down inclusion barriers. As well, recognizing the value of care work will help reshape the public's perspective and attitude towards underserved groups such as those with intellectual disabilities.

Finally, service agencies can learn from this research to recognize the importance of genuine relationships in the paid care setting and to better communicate and support care workers to ensure a higher quality of care. Overall, this paper offers a tangible set of practices to better support care workers and people with intellectual disabilities. Because friendship played a key role in sustaining paid care, my research suggests that anthropologists might want to better understand friendships and its role in the current transformations underway in Canadian society and beyond.

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## Notes

- 1 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 [a] disability" than "disabled person." 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.
- 2 I use the term care work and support work interchangeably to refer to both direct and indirect care provided to people with intellectual disabilities. Some interviewees identify themselves as disability support workers who accompany clients in day programs and community activities, others also provide direct care such as feeding, bathing, dressing, changing diapers etcetera, while also providing community support.
- 3 I used the terms immigrant and migrant interchangeably since some of my interviewees started with the Live-in Caregiver Program (LCP). Most of them are already immigrants but the experiences shared during the interviews go back to when they were still temporary workers. Thus, I use migrants and immigrants interchangeably to describe care workers who move from their country of origin for employment.
- 4 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.

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