Examining Policy Objectives and Implementation in the Home Care Program in Winnipeg, Manitoba: An Autoethnographic Account from a Home Support Worker.

By

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Abstract

The purpose of this study is to examine the home care program in Winnipeg, Manitoba, the methods employed by agencies in the implementation of the policy, and its impact on beneficiaries of the program. The mandate of the home care program is twofold: 1) to provide services to persons assessed as having inadequate informal resources to return home from hospital or to remain in the community, and 2) to assess and place individuals in long-term care facilities if and when home care services cannot maintain them safely and/or economically at home and to provide them with home care services until they are placed (Roos et al., 2001).

Home care can mean different things to different people. Home care is a general term used to reflect a wide range of social, medical, and non-medical support services that are conducted for purposes of enabling compromised individuals to live safely and independently in their communities (Auditor General of Manitoba, 2015).

I choose this topic because, having worked for more than four years as a home support worker with multiple agencies in Winnipeg, my goal in this project is to connect my experience and give an accurate and interesting account of the Home Care Policy and how it is implemented on the ground. I focus on the practices, procedures, and methods employed by the various home care agencies in Winnipeg in implementing the policy (the home care). I also examine other home care modules and point out some practices and procedures elsewhere that can be incorporated into the home care program in Manitoba to make it even better. As a support worker, I look at provisions in the policy that are properly followed and those that are not and how this impacts the beneficiaries of the program.

By using an autoethnographic approach and reflecting on my own experience and observations, this study provides first-hand information on the home care culture in Manitoba, its impact on the beneficiaries of the program, and suggestions of possible ways of improving upon the program.

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Dedication

I would like to dedicate this project to my mother Madam Felicia Oti. Despite not having any formal education, she did everything humanly possible to ensure that I went to school and I am so glad I have been able to make her proud. Without her persistence and unflinching financial and emotional support, I would not have made it this far. A special mention goes to my Aunty Madam Janet Afram who has also supported me in various ways throughout my education from high school to my Master's degree. They are my heroes.

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Chapter 1: Introduction

1.1: Connecting me to disability and support work

This chapter looks at my personal experience with disabled people from my country (Ghana) both as a young boy growing up and later, as a teacher in a high school. It includes my family's history with disability.

It also deals with my relationship with a student with an impairment in elementary and junior high school and my experience with disabled students as a teacher at a high school in Ghana for almost seven years. It explains how these experiences informed my decision to study for a degree in Disability Studies and how I took a job as a home support worker upon my arrival in Canada.

1.1.2: My family history with disability

My maternal grandmother and my uncle had a stroke one year apart while I was in high school. I was seriously affected by this turn of events as my mother who was financially responsible for my education had to quit her job to take care of my grandmother. They battled with the condition for over five years before their demise.

A few years after, my oldest brother and his wife had a baby girl who developed a disability at age three. The financial difficulties I endured at high school were nothing compared to the stigmatization, name-calling, and gossip directed at my family. I had friends who used to come to my house to call me to either go and fetch water or go to school together. Suddenly, it all stopped when the information started spreading at my school. A couple of friends deserted me too. A few loyal friends I had would come and tell me about hearing gossip about the situation in my family.

We lived in a small village where rumors spread very fast. My family was and still is considered rich because two of my aunties had traveled abroad and my three uncles were doing well in their fields of endeavor. There is a perception that anyone who travels abroad becomes rich overnight and so to have two people from the same family meant that we were very rich.

The word in town was that my grandmother had gone to see a spiritualist asking for riches and the price she had to pay was for herself and other members of her family to be struck by illness. Others said a member of the family may have committed an atrocity. As a result, it was assumed we were experiencing the consequences. Some friends approached me and asked me to look for a powerful ‘man of God’ to pray for me and my family because in their view the illness was going to be passed on from one generation to another unless the covenant with the gods was broken. Other friends kept their distance and did not want to be associated with me when this news began to spread.

I come from a part of the world where most physical and mental disabilities are blamed on supernatural causes. Impairments are viewed as punishment for wrongdoing either by the individual himself or his/her ancestors. As a result, all sorts of rumors began to surface about the possible cause of the illnesses that befell the members of my family. One certain thing was that no one believed the illnesses resulted from natural causes.

Therefore, most disabled people and their families do not receive the love and support they require in their various communities across the country. Some people try to distance themselves from persons with impairments. For instance, in the Akan ethnic groups specifically, the Asante tribe to which I belong, before a marriage can take place, both families traditionally conduct a background check and top on the list of things they look for is whether or not there are people with disabilities either physical or mental in either family. Baryeh (2015) writing about the Asante concept of marriage and its implications for Christian marriage today states that

> once they are certain, they approach the woman’s people and ask for her hand in marriage. The woman’s family invariably asks for some time to consider the matter. Both families

> make sure enough investigation is done. This is to satisfy them that there is nothing to prevent the union from taking place. They find out whether there are any hereditary diseases in the family, whether there is a record of criminal activity in the family, and whether the family is of good moral standing. (p. 33)

The fear is that some of their offspring may have similar impairments or traits should the marriage take place. Marriage arrangements no matter how advanced may be called off for this one reason. This shows the level to which people detest persons with disabilities. It is little wonder that disabled people are not allowed to take up leadership positions such as kingship or queenship even if they are the right candidates for the position.

1.1.3: Relating to a friend with a disability at elementary and junior high school

Because of this negative attitude toward persons with disabilities in my community and country as a whole, most disabled people are locked in their houses and rarely go out. The few that muster the courage to venture out navigate a lot of social and physical environmental barriers that are extremely unfriendly to disabled people.

One such person was my best friend and schoolmate (Paul) in elementary school and junior high school. He was paralyzed from his waist down. He was one of the few fortunate people to own crutches. Others with similar conditions had to crawl on the bare floor or stay at home to avoid the hassle unless they needed to go out. Having crutches did not make life less difficult for Paul. Since elementary school, he had to climb stairs and perform activities daily that were extremely difficult for someone using crutches. That was how I became friends with him. He almost always needed some form of help to navigate the school environment which was created without considering disabled people.

Elevators and escalators are not readily available in my country. It is only in the larger cities where a few such facilities have them. So, in almost every classroom in our school, from kindergarten to junior high school, one had to climb a minimum of three stairs to get into a classroom. This was demanding for Paul, but the only alternative was to stay home as every school in the city had a similar structure.

From our classrooms to the food vendors was about three minutes' walk, but for Paul, it took longer. During coffee breaks, he could not walk to the canteen, buy food, eat and return to class within fifteen minutes. And yet he was not exempted from punishment anytime he came back late from break. Most of the time he had to stay in class and I went to get food for both of us.

During vacations, we had to carry out tables and chairs home from school because most of the doors and windows were broken and there was no security to ensure that items were not stolen. Paul could simply not do this, so anytime school reopened, I had to assist him in carrying his table and chair to and from school.

We were also punished for coming to school late with no exceptions. Paul's reason was always the same, 'I cannot walk fast like the other students.' It was entirely up to the teacher to decide whether or not to punish him. Some were sympathetic to his situation others were not.

My friendship with Paul helped me to better understand disability and do away with the negative perceptions my people held about persons with disabilities. Paul was a regular guy trying to live his life just like any other person. There was nothing strange about him, he just could not walk. What drew me closer to him was that Paul knew no bounds; despite the difficulty the unfriendly environment posed, he persevered and today he is a professional teacher in Ghana.

1.1.4: Relating to students with impairments as a teacher

Because of my relationship with Paul and my family history regarding disability, when I became a professional teacher in October 2010, I took a special interest in students with disabilities in my school. I understood that with proper guidance and support disabled students could achieve their educational goals just like Paul. I was also fully aware that both the social and physical setting made it extremely difficult for these students to pursue their education. So, I tried, in my small way to keep encouraging and supporting these students not to give up on their aspirations.

When the time came for me to further my education, I did not doubt that I wanted to study something related to disability to be better equipped to support persons with disabilities.

In the high school where I taught, no provisions were made to assist disabled persons by the school's management or the government. Yet, I can remember at least ten students who had physical impairments during my time as a teacher. Not only were these students not supported, but they were also held to the same standards as their non-disabled colleagues. For example, those who were in boarding school were expected to wake up early morning every day, complete whatever chores they had and get to class at a specified time. At mealtime, all students were expected to use a fork and knife for most of their meals and were expected to finish their meals within a set time to return to class. The same standards are applied to examination.

For non-disabled students these may have been easy routines, but that was not the case for those students with impairments. I recall one of my students who had a mild form of cerebral palsy telling me how hard it was for him to use a fork and knife during dining. I had to talk with the teacher responsible for the dining hall to grant him an exemption to use a spoon. That made life a bit easier for him. He also told me his handwriting is really terrible and sometimes unreadable when he tried to write quickly. So, as brilliant as he was, he performed poorly on class tests and examinations that were time controlled. He needed more time to prepare for class and other activities in school and he often got into trouble for either leaving the residence late or arriving late to events.

The other students with impairments also had difficulties. At the time I was just a classroom teacher and not a member of the school's management team. There was very little I could do to support them. It was only in my subject area that I could for instance give a take-home assignment instead of a class test or allow for enough time to finish their test if it had to be taken in class. I also had a few friends among my colleague teachers, so I tried to intervene on their behalf anytime they needed my help.

I was not a better person than the other teachers in the school, but from my experience, when people have had no encounters with people with disabilities, their attitude toward them is sometimes different, especially in an environment where impairment is thought of as a punishment for wrongdoing. But for me, I had a friend in elementary school and family members who had impairments, so I understood how much help and accommodations some of them needed in a school environment that was so unfriendly to people with disabilities. I also understood how it felt to be stigmatized so I always tried to reach out to these students to make them feel they were not alone.

In the end, I felt I was not doing enough for these students. I was a mere classroom teacher; I could not even influence the school's management decisions not to mention that of the community regarding disability. That was when I began nursing the idea that if I wanted to do more for people with disabilities, I needed to learn more about disability so that my views on the topic would carry some weight and hopefully positively impact the lives of people living with disabilities in my country. That is what motivated me to apply for a Master's program in Disability Studies at the University of Manitoba.

1.1.5: How I became I home support worker

Home support work is something that is not popular in my country if it exists at all. Care for the sick, disabled and the aged is entirely the responsibility of the family. So, coming to Canada, the idea was not to work as a home support worker, but I was certain I was willing to support persons with disabilities during and after my studies in any capacity I can. Luckily, I had friends who were already in Disability Studies and told me home support work is perfectly in line with my area of study. Some were even home support workers themselves, so they led me to their agencies to submit my resume after we had an extensive conversation about what support work entails.

I also made several applications online as I needed a job urgently to be able to support myself financially. There were a few agencies who wanted applicants with some form of experience and holding at least a class five driver's license which I did not have at the time. But several others had no such requirements.

Barely a week after submitting my applications, I started receiving phone calls from the agencies to schedule an interview for the job. I was happy but very nervous as I did not know what to expect from these interviews. There were both written and verbal interviews depending on the agency. Some of the interviews seemed to me like they were looking for someone who had experience on the job even though the advertisement said there was no experience needed. Some for example gave a scenario and asked me how I would intervene in the situation.

After a couple of interviews, I was hired. I quickly booked an appointment for my first aid and CPR training. I was told during my job offer that this was a requirement. I also had a criminal record check as well as adult and child abuse checks. It took two to three weeks to receive the results from the various checks. However, once I produced the results from the checks, I was ready for orientation.

At the orientation, I and other new hires were told about the agency's policies and how they wanted services delivered. After that, we were required to sign all the necessary employee documentation. There was just one day of orientation after which we were told we could receive a call anytime to be scheduled for the field training.

The agency did not have a regular group of people that they provided care for. They only provided support staff for other agencies when they were requested. I was hired as casual staff as there were no guaranteed shifts. We were all expected to have at least two training shifts after which we could be scheduled to work alone. Just two days after the orientation I attended my first training shift and the second one followed the day after.

I was scheduled to be trained by two regular staff and I was supposed to watch them provide care and ask them anything that I did not understand about the care delivery process. I was also expected to take part in the delivery of care to familiarize myself with the process. Each shift was eight hours long, so I had a total of sixteen hours of in-house training in two different homes.

All my training shifts were in the morning (7:00 am – 3:00 pm) so, in both homes, the people receiving care were still sleeping when I arrived. On my first shift, I was told to spend some time reading their respective care plans to have a fair idea of the support each person at the home requires and what is expected of staff. I spent close to an hour reading as there were three individuals receiving care at that home. It was hard to remember everything I read as each care plan was five to six pages long. I had also not met these individuals in person so I did not know which care plan belonged to whom.

On my second training shift, I requested to be introduced to the individuals before I read their care plan. That way it was easier to know who I was reading about. I was taken around by the team lead and introduced to them in their respective rooms as they were all still in bed after which I read their care plans. I was also given a tour of the home to know where to find food, cleaning supplies, washer, etc.

During both training sessions, things were quite straightforward. Both homes seemed to have established morning and afternoon routines. In the morning, staff assist the care recipients to brush their teeth, taking a shower and wearing new, clothes having breakfast, and taking their medication. I was told this was the morning routine and it usually starts around 7 am and ends around 10 am.

Lunch is made and served around noon and medications are administered if any. Snacks may be served a bit later and that concludes the afternoon routine. I was told that is how care was delivered daily unless there is an appointment or scheduled outing in which case things are done a bit differently.

After my training, I was told I could pick a shift in any home as the services delivered are similar with very little variation. I was also told that I will be working with a regular staff most of the time so they can guide me if it happens to be my first time in that particular home.

In the delivery of home care services, some homes are known as difficult homes, and it is usually difficult to get staff to work in such homes. They are often homes with aggressive residents who have a record of both physical and verbal abuse. There are other group homes with four to five care recipients all needing help with feeding, bathing, and using the bathroom. Most of these duties are for health care aides who are duly trained and compensated for those services. But some agencies leave this responsibility to home support workers who are neither trained nor adequately paid to carry on those responsibilities. So, the staff tries to avoid working in these ‘difficult homes’ so that they are not overworking and getting underpaid.

New casual recruits are usually trained in these homes so that they can be called upon anytime there is a shortage of staff as is the case most of the time in these homes. Most support workers are immigrants from various parts of the world, so when we meet at work, we have detailed conversations as there is a lot of downtime in the delivery of home care services such as when the people we provide care for are napping, watching television, or just relaxing in their rooms.

During these conversations, we ask the senior staff about their experiences working in the other homes to have a fair idea of what to expect in a particular home before choosing to work there. It is fair to point out that some of the information given by some staff regarding the individuals in the various homes during my training was entirely inaccurate. I found out a lot more myself started working and got to know the people I was supporting better.

I started working full-time as a home support worker in April 2017 and I have not looked back since. It is not all rosy, there have been ups and downs just like in any other job. It is hard to describe what a typical day at work looked like when I started working because it varied greatly from one home to another depending on the agency in charge of the home I worked. I moved around a lot and worked morning, evening, and overnight shifts. Each shift comes with a different set of responsibilities.

There were, however, certain constants in each shift regardless of the agency I was working for or the time of the shift. For example, something that is done in almost every home I worked is cooking breakfast, lunch, or dinner depending on the shift. Some homes even had a weekly meal plan specifying what meal staff should prepare every day of the week. There are few occasions when food is either ordered or the staff go out with the individuals in the home for a meal.

Overnight staff is responsible for keeping the home tidy. They do most of the cleaning, mopping, dusting, and laundry. And at the end of each shift, a log is written on each participant's activities at the home from the beginning to the end of the shift.

Aside from these duties that are always carried out by almost every staff regardless of the agency, there are other services, programs, and activities that are particular to certain agencies or some homes within the agency. They include day programs, therapy sections, family visits respite services, and other such services.

I was trained in entirely adult-male homes for my two training shifts. After my training, however, I worked in homes of all genders and age groups. I found it very interesting that after my training I was told I could work in any other home because every home I worked in had a unique set of people requiring different support.

As it is in life, there have been both good and bad times. I have been attacked both verbally and physically in the course of my work including a few instances when the police had to be involved. For example, during one of my shifts, one of the individuals receiving the care was upset because his planned outing was canceled at the last minute. He began to damage some property in the home and all attempts to calm him down were to no avail. I had to call the police to come and deal with the situation. Even though I had nothing to do with the cancellation of the event, I became his enemy somehow because I had the unpleasant duty of calling the police on him.

I also recall the first time working alone in a home I had not been trained in. The person I was supporting requested that I fry him potatoes. He was so angry when the food was served because he wanted them cut into squares. Unfortunately, it was my first-time cooking potatoes so, I had very little knowledge as to the shape and size to cut them before frying. He ended up eating the food but had a few unfriendly words to say to me.

In his defense, most of the things he said seemed to be directed towards the agency responsible for his care and not me as an individual. I did not think that was the first time a staff messed up his meal or did something he was not pleased with. So, he commented, ‘They keep bringing me people who cannot even support themselves to support me.’ This statement seemed to me to be born out of years of frustration with staff and services that did not meet his needs and expectations.

Before I was scheduled to work at this home, I was informed by my agency that the individual I would be supporting had anger issues so I should not take anything he said to heart. Because of this label, some staff avoided working in this home. Today when I reflect on the incident, I conclude that what I experienced was an individual who was frustrated by sub-standard services that has been offered to him over the years and not ‘a person with anger issues’ as he had been labeled by the agency and the staff who worked at the home. I say this because after working with him for a while and getting to know how he wanted things done, he never had any issues with me and apologized for the incident that occurred during our first meeting.

What I have come to realize is that most of the individuals I support are frustrated by the system that seeks to assist them. For some agencies, all they want is to get staff at their various homes. The training of the staff, their commitment to the job, and the quality of service they deliver are all secondary. I recall some of the job interviews I had, and it seemed to me that all that some of these agencies were looking for was someone who had a class five license and the right documentation to work in Canada.

Some people may have great experience working with persons with disability and yet because they do not own a vehicle or possess a license, they are refused employment. Others who may not have the right attitude or any experience at all working with persons with disabilities may be given the job. Unfortunately, it is those receiving care who are disadvantaged by these decisions and indecision.

Some agencies rely on the vehicles of their staff to transport the people in care homes to and from appointments and other outings. They pay the staff mileage, which is very little compared to purchasing, licensing, and maintaining a van for the home or using a taxi. Initially, my thinking was that these agencies preferred people with their own means of transportation and holding valid licenses so that they can operate the agency’s vehicles and be called upon anytime their services were needed. But that does not seem to be the case. So, notwithstanding the experience or qualifications of an applicant, he/she may be refused employment if they do not own a vehicle the agency can rely on.

Home care policy leaves a lot of the decision-making to the regional health authorities. They are responsible for the assessment of eligibility to the program, care planning, and coordination of services among other things. The expectation is that they would involve the people needing care every step of the way, which they do to a large extent. However, almost all the decisions made are based on the professional assessment of the individual's needs and their expert opinion on what services are available and required to keep the individual safely at home.

There is the option of self/family managed care where funds are given to an individual or their family manager to privately recruit, hire, schedule, and manage staff to deliver home care services. But this is also based on an assessment by a case coordinator. The complexity of calculating employment deductions and ensuring workers' compensation coverage makes most families and individuals shy away from this option and instead rely on services provided by the regional health authorities and the agencies working under them to deliver home care services.

The cuts in healthcare funding coupled with the profit motives of some home care agencies sometimes lead to the delivery of sub-standard services. The expectations of most recipients of home care services are not met, and as someone directly responsible for their care (direct support worker), they see me as part of the problem.

I am a representative of the agency responsible for their care and responsible for implementing rules and regulations of the agency, some of which they were not enthused about. I recall an elderly man who hated attending the day program and yet according to his case coordinator it was good for his mental health and so he had to attend every weekday. I had a responsibility to get him ready to be picked up every morning around 9 am and I could tell he hated me for that.

I am often in the direct line of fire whenever the people I provide care for feel like venting their frustrations. Sometimes I understand that because they feel like we are with them 24 hours a day and so we understand their frustrations and yet we do nothing about it. Even though I do not make any of the major decisions regarding their care, I am the person they see every day and I have a part to play in their care. This means I am not exempt from blame for their problems just like any other person responsible for their care.

There are times that I become emotionally attached to the people I support due to my own family's history with disability. Both my maternal grandmother and my uncle died of a stroke after they battled with illness for over seven years. My mother was primarily responsible for taking care of my grandmother so my siblings and I gave her a helping hand whenever we could.

Caring for disabled people is much more challenging when there are limited resources to deliver care. In our case, we lived in a house with no toilet facilities. The entire village had just two public toilets, one for males and the other for females. There was no wheelchair to move my grandmother around, and even if there was there is no way she could have used the public toilet because of how it was built. For the first three years of her stroke, she had to use a chamber pot anytime she had to use the bathroom.

There are no such challenges here in Winnipeg, at least not in the homes I worked in as a support worker. But it still hurts to see the people I provide care for go through pain and discomfort almost on a daily basis. Sometimes it is so heartbreaking and emotionally draining and I dare say it is probably the most difficult part of the job I do as a support worker.

I recall in one of the homes where I used to work, I had such a wonderful relationship with the person I was providing care for only to go there one day and see bruises all over his body. He had episodes where he banged his head against the wall or generally did things to hurt himself. When I asked him what happened he told me he could not help it. It feels like he is possessed when he is experiencing these episodes and has no control of his actions until it is over.

Staff is supposed to restrain him in such moments to prevent him from harming himself but sometimes he either overpowers them or causes some damage before he is restrained. After these episodes, it takes weeks for him to heal only for it to reoccur again and again.

I am his support worker and sometimes I wish there was something I could do to prevent those episodes from recurring, but unfortunately there is not much anyone can do in that regard except hope to intervene promptly to prevent him from causing harm to himself during these episodes.

But all in all, I can say that the positives far outweigh the negatives. Several people show genuine appreciation for the service we offer either to themselves or their families. There are families who either visit or call to check on their family members in care homes and they always express their appreciation for the services we offer their loved ones. Some even go a step further to send in gifts on occasions like Christmas and Thanksgiving as an expression of their gratitude.

That aside, the thumbs up we get from those who cannot talk and the ‘thank you’ from those who can on a daily basis is further indication of appreciation for the services we deliver. We get paid, but it is heartwarming to be appreciated. For me, it is a testament that we are doing something and meeting the needs of the people we provide care for.

But one thing I have realized is that home support workers perhaps need more training than is currently offered. Most support workers are immigrants from countries where these services do not exist. Personally, aside from my family experience, I had no prior experience working with persons with disabilities, as was the case with several support workers. Even for those with some experience, it is not in a formal setting as is the case here in Canada.

It becomes difficult to maintain professional composure in a home environment where there are no supervisors most of the time. Not everyone has the discipline to go about their duties diligently when they are not supervised. That aside, there is downtime when the people receiving care are either watching television, napping or just relaxing in their rooms. Sometimes one can even forget that he/she is at work. It takes better training, professionalism, and self-discipline to be able to work efficiently with limited supervision.

Some of the individuals in care also have very complex and unique conditions. There are those with tubes fitted to the stomach who are fed and given medication through the tube. A small mistake will see everything they have taken in through the tube come back out. Others have catheters inserted for fluid removal and oxygen to aid their breathing. All this equipment requires some level of expertise to operate. A little mistake can have serious consequences for the individual concerned. The current training regime does not seem to prepare support workers well enough for these challenges.

Initially, when I started working as a home support worker, I was full of praise for the authorities and whoever helped to put such a system in place to support persons with disabilities. The reason was simple: no such system exists in my country. So, families either have to find a private individual to provide care for a disabled member of their family or a relative may have to sacrifice their job to provide care for the disabled member of the family. Those who are not fortunate to have caring family members are basically on their own. They end up begging on the streets and living on the benevolence of others.

But people with similar conditions here in Canada have access to home care services that shelter them, put food on the table, provide healthcare services, and in some cases 24 hour staffing. I could only wish that these services were available in my country, hence my admiration when I first learned about the program.

This seeming bias would have had a significant effect on this study if it had been conducted during my early days of employment as a home support worker. I had very little knowledge about service delivery and how the program was structured. I did not also know that the beneficiaries of the program had several grievances regarding service delivery and other conditions of service. I thought of it as a perfect program put in place to meet the needs of people with disabilities and in my opinion, the program was delivering on its mandate.

Compared to Ghana, where I come from, this was novel and so I could not help but admire the system. I said to myself a couple of times that my mom would not have left her job to take care of my grandmother if we had a home care service in Ghana as is the case here in Canada. I was not too concerned about whether the program was delivering on its mandate or not. I was impressed with the concept and idea of having a program in place to take care of the disabled people in society.

But months into my employment I heard several complaints from both staff and the individuals receiving care about various shortfalls in the delivery of home care services. The complaints of staff were mainly about limited full-time employment opportunities, poor wages and salaries, and generally poor conditions of service. Some had been on the job for years and had not seen any incremental rise in salary.

On the side of the care recipients, they had issues with staffing, their care plans, and the quality of services delivered. Aside from staff shortages, many agencies rely on a casual pool of staff which makes it difficult for the people receiving care to build any rapport with the staff. Their care plans are also not updated regularly to meet their changing needs. When they get the opportunity to review them, their views are often overridden by the expert views of medical professionals. They also had complaints about the timeliness and quality of services delivered under the home care program.

As a student in Disability Studies and given my interest in disability-related issues because of my family history, I was always interested in knowing more about the home care program and the possible cause of the various grievances from both staff and the recipients of home care services. So, I continued to ask questions whenever the opportunity arose to have a better appreciation of the issues confronting the home care program. After all, I was employed in the same field and so sooner or later those issues were going to affect me one way or the other.

One thing I wanted to understand was the cause of the grievances by both staff and the beneficiaries of the program. Was it the policy that was framed in a way that did not meet the needs of the beneficiaries or could it be the poor implementation of a perfectly crafted policy?

At the time I had very little knowledge of the home care policy in Manitoba and how it was implemented on the ground, so I did not have the slightest idea where the problem could be coming from. In my mind, I knew it could either be a result of a poor policy framework, poor implementation, or both. I was curious to know more so I searched further.

When I started reading the document that serves as a guide to the delivery of home care services in Manitoba, I began to realize that there were some aspects of the program that are not properly implemented on the ground. Care plans were not reviewed regularly to align with the current needs of the people in group homes as required by the policy. There is also a deficit in staff training and assigning the right staff based on the assessed needs of the people receiving care. Service delivery was not uniform across different agencies which also suggested to me that some of them were not delivering services according to the policy.

I also realized there are certain aspects of the policy itself that needs tweaking to enable the program to better serve the needs of its beneficiaries. I noticed there were a lot of grey areas in the policy which allowed regional health authorities and home care agencies to use their discretion.

The eligibility assessment, care planning, and staffing are all entrusted to the regional health authorities who engage home care agencies to carry out some of these responsibilities on their behalf and with their supervision. However, as mentioned earlier, the profit motives of some agencies impact the quality of services they deliver.

The idea is not to necessarily apportion blame, but to examine the home care policy and point out what I have observed and experienced as a field worker implementing the program on the ground.

Chapter 2: Statement of Topic

This chapter examines the purpose of the study, the main research question and sub-questions, and the importance of the study.

2.1: Statement of purpose

An examination of the home care program in Winnipeg, Manitoba and the methods employed by agencies in the implementation of the policy.

2.2: Research question

- How is the Manitoba home care program experienced on the ground and how does it impact the lives of the beneficiaries of the program?

2.2.1: Sub questions

- What are the connections and intersections with Manitoba home care policy?
- How does the home care culture in Winnipeg impact training, service delivery, and policy implementation?

2.3: Importance of the study

“Public policy” refers to a strategic action led by a public authority to limit or increase the presence of certain phenomena within the population (National Collaborating Centre for Healthy Public Policy [NCCHPP], 2012). The study, therefore, examines how the implementation of the home care policy is impacting the lives of people with disabilities on the ground.

The Manitoba home care program (the Program) provides healthcare, personal care, and household services to people living at home and needing support but not necessarily the level of care provided in a hospital or a personal care home. The Department of Health, Healthy Living, and Seniors (the Department) funds and oversees the program. Manitoba’s five regional health authorities (RHAs) manage and deliver program services (Auditor General of Manitoba, 2015).

Available data and research indicate that there will be a surge in the proportion of the population that will require home care services in Manitoba in the next 15 to 30 years (Auditor General of Manitoba, 2015). A closer look at the policy and how it is implemented is important to address any possible lapses to ensure the sustenance of the program and delivery of quality and timely services and to make provisions and accommodations for the projected increase in the number of recipients of home care services in Manitoba in the coming years.

An audit by the Auditor General of Manitoba in 2015 found that

> also, of concern is that departmental oversight of the program was very limited. While the Department has developed home care standards to be followed by all regional health authorities, it does not ensure the authorities are complying with standards and does little to ensure desired service quality and client outcomes are set and achieved. (p. 1)

In the same report, he goes on to say,

> We found several opportunities to improve service quality, particularly with respect to the timely preparation and completeness of need assessments and care plans and regarding the timeliness and reliability of direct services. Left unaddressed, these and other issues discussed in the report may jeopardize the care and welfare of home care clients. (p. 1)

This audit was conducted a little over five years ago so is important to inquire whether service quality has improved and the level of compliance to set standards by the various regional health authorities.

The study forms a basis for further studies into other aspects of home care in Winnipeg, Manitoba such as staffing, incentives for home support workers, and supervision among others all of which would help make the program better.

The study is unique with primary first-hand information concerning the home care policy and how it is implemented on the ground. I rely on my experiences and observations. I feel confident relying on Carolyn Ellis' words that meaning is more significant than facts. Ellis (1999). A lot may have been said and written about the home care program in Manitoba but it is important to realize who is doing the writing and with what lens they are looking at the program. Ellis (1999) recommends telling "a story that readers could enter and feel a part of it" and prefers concentrating "on the meanings rather than facts" (as cited in Thurova, 2009, p. 674). When a lie is repeated several times, it begins to sound like the truth. That is why I am relying on my own experiences and observations and not on what has previously been said or written about the home care program. This way, I bring my perspective regarding the implementation of the home care program in a way that readers especially those involved in the program can relate to.

Chapter 3: Review of Relevant Literature

This chapter reviews relevant literature relating to staffing and care planning in the delivery of home care services in Winnipeg. Home care policies and their implementation across other countries and provinces are also looked at to see what changes can be made and what can be learned from them to improve upon the home care program in Manitoba.

3.1: Staffing (Recruitment, training, retention, and quality of direct support workers)

Home care services were established in 1974. Its primary purpose was to allow people to remain at home for as long as possible. In 1997, the newly established Regional Health Authorities (RHA) took over responsibility for the operation of home care services. For the past number of years, home care has annually served approximately 39,000 clients with approximately 15,000 admissions and 15,000 discharges annually (Toews, 2016).

This emphasizes the importance of the home care program as an essential part of the delivery of healthcare services in Manitoba and as such, the need to address any pertinent issues confronting the industry. Based on the figures above, it is fair to speculate that majority of Manitobans have received, are receiving, or will receive some form of home care services at some point in their lives.

Staffing has been a long-standing concern in the delivery of home care services. Research by The Government of Manitoba Minister of Health, Seniors and Active Living (2016) states that "Recruitment and retention of home care personnel is a constant challenge at any one time there is a vacancy rate of 8-10%" (p. 3). The Auditor General of Manitoba (2015) also acknowledges this problem of staffing in his report when he states,

> the delivery and scheduling of home care services is a logistically complex undertaking. Within any one regional health authority, many services are required by many clients

> throughout the day and every day. And many clients prefer to be assisted by the same home care workers, day in and day out. (p. 1)

The shortage of home support workers has worsened over the past year or two with the onset of the COVID-19 pandemic. From my observation, the majority of home support workers are migrants. Closure of borders and travel restrictions imposed to help curb the spread of the virus also hurt staffing in the delivery of home care services. It is no secret that the majority of home support workers in Manitoba and perhaps across the country are immigrants.

So, the closure of the borders except for essential travel was bound to lead to staff shortage which as noted above has been the case even before the closure of borders. This affected various sectors of the economy in terms of labor supply, but the home care program is probably one of the hardest hit as the majority of its employees are drawn from the immigrant population. Even in agencies that had no staffing issues, the requirement that staff stays home for 14 days if they have any symptoms or are known to have been close to an infected person made it difficult to fill shifts with several workers having to quarantine.

Sethi (2020) explain that personal support workers and other healthcare workers have been on the front lines of the COVID-19 pandemic, working selflessly to care for the ill and vulnerable. They experience anxiety, stress, occupational burnout, fatigue, guilt, and fear. A few even died. I recall working alone in houses where two staff were required to be on shift and sometimes had to stay several more hours because no staff could be found to take over from me.

But even more worrying is research by The Government of Manitoba Minister of Health, Seniors and Active Living (2016) which reveals that all the regions in Manitoba are projected to experience an increase in home care admissions over the next 20 years until 2037. Based on a year-over-year percentage change calculation, this increase would be between 2%-3% per year, or a yearly increase equivalent to 3.5%.

This clearly shows that significant numbers of the population are going to require home care or other support services in the coming years. This is because the Auditor General of Manitoba (2015) in his report on the home care program states,

> most of the Program's clients are seniors. As Manitoba's senior population is expected to grow rapidly between 2021 and 2036, a corresponding growth in the demand for home care services is likely. This likely increase in demand, in combination with increasingly complex care needs and financial pressures on the entire health care system, presents a significant risk to the future delivery of home care services. (p. 1)

This suggests that not only do authorities need to put measures in place to accommodate these numbers, but there is also the need to take home support workers through rigorous training to be able to properly care for residents with complex care needs. Wadehra (2021) believes that as Canada's population ages, caregivers will become more essential than ever. Valuing care work and care workers as a critical part of our economy is crucial for post-pandemic economic recovery and gender equality.

Home care services are going to be highly sought-after post-pandemic, even more than what was originally projected. This is because at the time of these projections (2016), no one envisaged there would be a global pandemic of this magnitude. Many may have died during this pandemic but several others have also developed new medical conditions or have had their existing impairments worsened by the pandemic. The numerous job losses and several months of lockdowns affected the mental health of many. A study conducted by the Centre for Addictions and Mental Health (CAMH) published by the Mental Health Commission of Canada reports that youth are experiencing mental health challenges during the pandemic, including depression and anxiety. For those with existing mental health conditions, rates were even higher (Mental Health Commission of Canada, 2022, p. 3).

As a result, some may have developed medical conditions that they are going to live with for the rest of their lives. So, several people may require home care and other support services as a direct consequence of the COVID-19 pandemic. According to Statistics Canada, youth are at higher risk of experiencing poor mental health (compared to other age groups) during the pandemic (Mental Health Commission of Canada, 2022). The youth are naturally outgoing so their inability to go out and socialize for a prolonged period was bound to have a toll on their mental health leading to some requiring support services.

These numbers, in addition to the projections made by both the Auditor General of Manitoba (2015) and The Government of Manitoba Minister of Health, Seniors and Active Living (2016) regarding the number of people who may need home care services from 2021 to 2036 due to old age, suggest that there will be a lot of pressure on the home care program in the future. Aside from financial and logistical considerations, staffing is another important area that ought to be looked at in any plan to care for the increasing number of people who may require home care services in Manitoba in the coming years

The study by The Government of Manitoba Minister of Health, Seniors and Active Living (2016) further reveals that the prevalence of cognitive impairment will increase as will Activities of Daily Living (ADL) impairment where hands-on assistance is required. The proportion of home care residents with complex care needs is estimated to increase at the same rate as the increase in the number of residents. If projections hold, home care services in Manitoba will essentially have to double their efforts within 20 years to provide the required service needs of residents.

This further raises staffing concerns and the need for rigorous training. The current training offered to home support workers does not prepare them well enough for people with complex care needs. In their study, Ohta et al. (2020) make it clear that home care workers may be able to identify the early stages of acute diseases in their patients. The improvement of their detection skills may contribute to better health care for home care patients.

People in care homes indeed go for routine medical checks. Home support workers can easily detect mood changes, changes in intake of food, and even change in frequency of the use of the bathroom among the people they support. With a little more training I am sure I and the other support workers can be of more assistance to these individuals, especially those who cannot communicate the distress they may be experiencing.

As it is now, home support work is an entry-level job requiring no prior experience or rigorous training. A first-aid certificate, background checks, and usually a day or two orientation program are all that is needed. All other experience is acquired on the job. It is therefore not surprising that there are reported burn-out and stress among caregivers. With such limited training, the staff is overwhelmed by the demands of the job. Murphy et al. (2007) observe that many caregivers occasionally experience burn-out, which has been described as overwhelming feelings of despair with no end in sight. For most support workers, it may be their first time working with people with impairments, so without the necessary coaching, the task becomes extremely hard, especially at the early stages of their employment. Imagine being asked to work with someone who is deaf and yet you have not trained in sign language or any other way of communicating with the person.

In general, caregivers indicate high levels of stress: “There is also evidence to show that most caregivers are ill-prepared for their role and provide care with little or no support, which could also lead to burn-out” (Aloraibi et al., 2011, p. 115). Supporting people with impairments is very demanding. Every day comes with different challenges some of which are difficult to handle if you do not have proper logistics and training. The benefits of caregiver training are enormous for both parties (caregivers and care receivers).

Caregiver training according to Peeters et al. (2010) might have advantages of reducing health care costs, improving the patients' quality of life, reducing the caregiver's anxiety and stress, and helping to create better social relations with the care receiver. Also, caregiving can make people confident about their own abilities (Peeters et al., 2010). Qualifications and more importantly training of home support workers need serious re-examination.

People have absolute confidence in doctors and other professional health care providers because they know these people have been properly trained to perform surgeries and other complex medical procedures. People in care homes do not have such confidence in their staff and rightfully so because they are often not adequately trained for their role.

I have friends who have been on the job for over 12 years as home support workers and yet all they have to show in the form of training are first aid certificates and non-violent crisis intervention (NVCI) certificates. Acquiring both certificates takes just 16 hours. Most agencies in Manitoba require their staff to repeat the first aid training every two to three years. Those who have been on the job for many years have taken this training several times.

If some additional clinical skills were taught every two to three years instead of repeating the same training over and over, some of these individuals would have been very skilled by now and could provide many other services to people with complex care needs at the comfort of their homes.

If this is properly considered and implemented, a lot of hospital beds will be freed and wait times at hospitals reduced, achieving one of the aims for which home care services were established in the first place. As it is now, people in care homes are transported to and from hospitals for simple things such as taking blood and urine samples, temperature, and blood pressure checks among others. If properly trained and equipped, home support workers can play the role of quasi-nurses, and these simple procedures and even more can easily be done at home with the samples either picked up or sent to the appropriate quarters for further examination.

It should be known that "the complexity and acuity of client needs are continuing to increase. Nurses are delegating more tasks to Home Care Attendants (HCAs). The lack of continuity in the assignment of Health Care Aids and insufficient time allocated to complete the assigned task remains an issue". (The Government of Manitoba Minister of Health, Seniors and Active Living, 2016, p.3).

Health care aids working under Winnipeg Regional Health Authority (WRHA), for instance, are often scheduled to visit at least four homes in their eight hour shifts to perform personal care and hands-on duties like bathing, shaving, and bed transfers among others. It is too much work for the time allocated and how much they are paid because they must move from one home to another sometimes in very unfavorable weather conditions. It is no surprise to me that there is a lack of continuity in the assigning of health care aids because as soon as they find a job that is less demanding and offers better salaries they move on.

The point about scheduling challenges is further emphasized by the Auditor General of Manitoba (2015) in his 2015 audit report on the Manitoba home care program when he asserts,

> scheduling challenges made it difficult for both Regional Health Authorities (RHAs) to provide a consistent set of workers for each client. This can be problematic because it can take time for each new worker to become familiar with a client's home, medical condition, and care needs. (p. 5)

This is true because a care home may have up to five people and sometimes even more. It is not easy to even remember their names, not to mention their medical conditions and their care needs. Sadly, when staff are becoming familiar with the people they work with, they move on due to poor working conditions.

Home care services are an integral part of health care delivery in Manitoba. From the discussion above, the services of home support workers would be invaluable in the coming years. I believe it is prudent to build their capacity to improve upon the services they currently deliver and to empower them to take on additional responsibilities to ease the pressure on the mainstream healthcare providers. This will come with some additional costs to the program, but I am positive that the long-term benefits would be enormous.

According to Sethi (2020), The Employment Outlook (2019-2021) notes that along with those who leave school, a significant number of new immigrants belong to the personal support work occupational grouping. Considering that many of those workers will inhabit Black, Brown, immigrant, and/or refugee bodies, one of them will be taking care of each of us or our family members at some time in our life (Sethi, 2020). It is therefore in everyone’s interest that the home care program is properly streamlined with properly trained and motivated support workers so that individuals and families would be assured of quality home care services should they require them at any point in their lives.

Perhaps the issue of staff training and motivation is not important because earlier, most workers are immigrants from countries labeled as less developed, so they are content with whatever they are offered by their employers. The meager salaries they are offered are big money when converted to their home currencies. However, with time, reality catches up with them. Bills begin to pile up and they either have to look for a second job or sometimes quit the care job when they find another job that pays better.

Wadehra (2021) indicates that migrant care workers provide care for children, seniors, and people with disabilities from a position of precarity, despite the fact that care work is a permanent and crucial part of the economy. With group homes and personal care homes being hardest hit by the COVID-19 pandemic nationwide, getting people to work in such spaces has become harder than before. It is therefore important to motivate those who are already on the job to keep them and to attract others to solve the problem of staff shortages.

As I alluded to earlier, one thing that is at the heart of the delivery of quality health care services worldwide is funding. Funds are needed to put up infrastructure, provide logistics, hire, train and retain staff. To cope with the ever-increasing demand for home care services, injection of funds in the area of staff training and motivation will make perfect sense. I could not agree more with The Government of Manitoba Minister of Health, Seniors and Active Living (2016) which states that "as the needs of clients increase ensure training and education opportunities are available to the caregiver with funding attached to allow for implementation" (p. 3).

Six years later, I do not think this recommendation has been followed. To the best of my knowledge, no new training regimes have been introduced in the delivery of home care services aside from the mandatory first aid and CPR training and Nonviolent Crisis Intervention Training (NVCI) for staff working with people who have a history of violent behavior.

In another study, Ohta et al. (2020) state that home care involves various medical care professionals. Among these, the home care workers may be one of the most frequent visitors. Therefore, home care workers may be highly likely to detect acute conditions in home care patients. If they can identify the subtle changes in the home care patients that lead to acute care conditions, medical staff such as doctors and nurses may be able to intervene with these patients quickly (Ohta et al., 2020).

Home care workers identifying changes in the people we support is very easy due to the rigorous documentation of literally every aspect of their life. Excessive documentation seems to be part of the home care culture here in Winnipeg. There are houses where we are required to document anytime a resident uses the bathroom, what they eat, their activities for the day, and the time they go to bed among other things. With such documentation, it is easy to tell when there is a change in the pattern. But my point is, home support workers can do far better than following residents to the bathroom to check whether their stool is loose or solid and performing just basic housekeeping chores.

Several support workers are pursuing various levels of studies in universities in Canada, myself included. My wife who is also a support worker is a trained nurse with three years of working experience in Ghana. There are many others with such qualifications working as support workers because they do not have the certifications to practice their respective professions in Canada. Unless home care agencies are benefitting from keeping their workers less trained so they can continue to pay them less and maximize profit, I do not see why these workers should not be taken through in-service training and refresher courses to be better equipped to take on more responsibilities at care homes. They could also perhaps be called upon to support the hospitals and clinics when there is a shortage of nurses such as the one experienced in several provinces when the on-going COVID-19 pandemic was at its peak.

Building the capacity of home support workers in Manitoba is important because there seems to be a plan already in place where after hospitalization people are made to receive home care services as part of their recuperation. A study by Roos et al. (2001) points out that “Winnipeg also appeared to have more targeted use of home care: there were somewhat more new admissions to home care following a hospitalization episode, and these clients received services over a shorter period than was true in other regions” (p.7). I believe doctors would be willing to discharge patients to continue their treatment in the comfort of their homes if they knew that home support workers had enough training to carry out some clinical duties.

Though the Government of Manitoba through the regional health authorities runs home care services, a greater part of it is contracted out to third-party providers. “‘We are initially going to go out to a third-party provider to provide the enhanced home care service for us,’ Lori Lamont, the WRHA's vice president of inter-professional practice, told the Winnipeg Sun. 'We're going to contract that out'" (Brodbeck, 2017). The WRHA says it will evaluate the new program over the next three years to see whether it should continue to be contracted out or whether it should be done in-house. Either way, Lamont says it will become a permanent part of the WRHA's home care service (Brodbeck, 2017).

Perhaps the unwillingness to build the capacity of home support workers stems from the profit motives of most third-party providers of home care services here in Manitoba. Rendering these services on behalf of the various regional health authorities, the primary motive of most of these agencies is to maximize profit. A well-trained and skilled workforce would most definitely demand better wages and conditions of service, something most of these agencies are not willing to offer as it may affect their profit margins.

That aside, the quality of services provided by a third-party provider may not be the same as a state-run institution. It is no surprise that from the onset the Winnipeg Sun reported that the Manitoba Government and General Employees Union, which represents government home care workers, will not like the plan. They have already complained about the contracting out initiative last month when they got wind of it from WRHA brass (Brodbeck, 2017).

Further to the subject of contracting out home care services to third-party providers, Howes (2015) asserts that virtually all the growth in the Long-Term Services and Supports industry is in home and community-based services that are increasingly being dominated by the fast-growing for-profit home care agency industry where franchises are making substantial inroads. It is fair to examine if the desire to maximize profit by these home care agencies in any experience compromises the quality of home care services delivered in Manitoba.

Whereas some agencies may have a genuine desire to support patients in care homes, others may be in the business for the wrong reasons. More Manitobans died of COVID-19 in for-profit personal care homes at a rate higher than in those run by the province or not-for-profit organizations, a CBC News (2021) analysis reveals. The report further stated that, while for-profit care homes have only one-quarter of the nursing home beds in the province, they account for 44 percent of care home deaths (CBC News, 2021).

The question of taking the "profit" out of long-term care has come to the forefront since the pandemic as several studies and media reports have shown similar results when it comes to outcomes in long-term care. In Ontario, a CBC News Marketplace analysis found several Ontario for-profit homes had death rates higher than the non-profit and publicly run nursing homes. CBC News (2021). It is also worth relating from the Canadian Centre for Policy Alternatives (CCPA) (2020) that underfunding by governments, even in not-for-profit homes, has the same effect with not-for-profit care managers feeling the pressure to cut costs too.

My opinion may not be conclusive, but as someone who has worked for both for-profit and non-profit home care agencies, I can say that it is not a mere coincidence that death rates are higher in for-profit care homes across different provinces. Though they both operate in the same provinces under the same rules and provide similar services, the culture and methods of the for-profit and non-profit home care agencies are quite different.

Generally, the non-profit agencies tend to hire more regular (full-time) staff, they are mostly unionized, their houses are regularly supervised and inspected, and the residents receive comparatively good quality services. The hiring of regular staff for instance limits disruptions in scheduling and helps residents to build rapport with their staff. The unions help to address workers' grievances and ensure better working conditions. This helps to keep them motivated and willing to stay on the job longer. The regular supervision and inspection also help to keep staff on their toes knowing that a supervisor can walk in anytime unannounced.

The same cannot be said for for-profit home care agencies. They rely heavily on casual staff to avoid paying benefits such as health and dental coverage. Most if not all of them are not unionized so workers have no one backing or assisting them when they have grievances. They also assign home support workers responsibilities of health care aids without the corresponding pay. If there are activities and outings for residents, they are often poorly planned. Because of the aforementioned culture of for-profit home care agencies, most of their employees are often aggrieved, affecting the quality of service they deliver.

The ultimate losers are the residents in such homes who often find themselves at the receiving end of the anger and frustration of aggrieved staff and an inept agency, a toxic combination that affects their quality of life. As part of their culture, the pre-occupation of the for-profit home care agencies is to satisfy licensing requirements to keep them in business. This is usually an inspection of the building, bathrooms, and medication storage among others. The actual well-being of residents and staff does not seem to be the priority from what I have observed and from conversations I have had with other colleagues who have been on the job longer than me.

The COVID-19 pandemic has exposed several home care agencies and I agree with those calling for a re-examination of the profit motives of home care agencies. I believe that going forward, a thorough background check should be done to determine the motive behind setting up a home care agency before licenses are issued. Existing agencies should be keenly monitored to ensure that they are delivering the services for which they were issued their licenses and not merely making money at the expense of the individuals they are supposed to support.

According to Roos et al. (2001), home care is a core program of Manitoba health: all regional health authorities (RHAs) are required to provide home care services to persons who meet the criteria of the program’s mandate (Roos et al., 2001). In their bid to keep these agencies in check to ensure the delivery of quality services to home care residents, occasional visits are made by officials from the Regional Health Authority. These visits are to ensure that standards are being adhered to by the various agencies delivering home care services.

The Auditor General of Manitoba (2015) discovered that "The Department set standards for RHAs to follow in delivering home care services, but it did not monitor RHA compliance with its standards or make the standards publicly available" (p. 4). Similar standards are expected of group homes and home care agencies across the province with little variations. But from my observation, it seems there is too much concentration on physical infrastructure by the supervisory bodies than the quality of service delivered by agencies running home care services. Hardly do they engage either the staff or residents on their visits to ascertain what transpires on the ground.

In 1996, the Government of Canada identified disability issues as a top priority with the aim of greater inclusion for all people with a disability (Prince, 2006). I believe that if this is to be achieved, several alterations ought to be made to ensure that home care services meet the needs of people with disabilities. The ability to hire, train and retain highly motivated and dedicated home support workers is a step towards ensuring the delivery of quality home care services. Staff are the liaison between authorities and residents and the ones who implement the home care policy on the ground. Hiring, rigorously training them, and keeping them motivated on the job gives the program a better chance of success.

3.2: Care planning and general decision-making in care homes

Care planning according to Burt et al. (2013) is the process by which health care professionals and patients discuss, agree on, and review an action plan to achieve the goals or behavior change of most relevance and concern to the patient, and a 'care plan' is a written document recording the outcome of a care planning process.

Looking at the definition of care planning, three keywords stand out: discuss, agree and review. The question that arises is whether these processes are followed through in developing care plans for people in care homes in Manitoba. The document guiding the delivery of home care services states,

> If eligible, you, your family/representative, and your case coordinator will decide on your care plan. Your care plan will take into consideration how your existing or potential supports can provide assistance and identify community resources available to you. You will receive a copy of your care plan, which will be signed by you and your case coordinator. This ensures mutual understanding of the services you will receive. (Government of Manitoba, n.d. p .2)

This would suggest that the outcome of a care planning process would almost always be satisfactory to the resident as it is supposed to be a collaborative process that involves either themselves or their representative every step of the way. However, it is common to hear from residents a phrase like ‘I am only allowed’ as opposed to ‘I have decided or agreed to.’ One question that begs an answer is, if these individuals discuss, agree on, and review their care plan with health care professionals before a final draft is made and signatures appended, why then will they be dissatisfied with portions of the plan? I have not been privileged to witness a care planning process, but if the feedback and actions of the residents I work with is representative, then I can say in most cases it looks like they want the opposite of what is written in their care plan.

Perhaps as Hamraie (2017) puts it, the answer can be found in the expression that this human landscape has been built around the idea of the “normate template” or “normate human” which, based on statistics is the white, non-disabled, young, masculine, and European male. This may explain why people with disabilities in care homes often have such little input in their care planning and other activities of daily living.

Hargreaves (2000) also asserts that people with disabilities “are looked upon, identified, judged and represented primarily through their bodies, which are perceived in popular consciousness to be imperfect, incomplete, and inadequate" (p. 185). With this mindset, it is understandable why their inputs and concerns regarding their care plan are often ignored and their life is controlled and managed based on the expert views and opinions of medical professionals.

Kristiansen et al. (2009), writing about how perceptions about disability erode the autonomy of people with disabilities, state,

> One unfortunate outcome of mechanical applications of either one of these individualistic approaches to disability has been paternalism: making decisions on behalf of others for their own good even if contrary to their own wishes. Part of paternalism is a kind of expert system where the authorities of relevant knowledge and craft determine how the phenomenon in question should be understood and dealt with. In the religious framework, it is the clergy who are in possession of the truth; in the medical discourse, it is the doctors. In either case, the autonomy of people with impairments has too often been trampled upon and they become merely passive recipients of the benevolent assistance provided by professionals and other believers of the dominant disability discourse. (p. 3)

This seems to be an apt description of what transpires during care planning and would explain why most recipients of home care services are dissatisfied with their care plan and the services they receive. Everything from their diagnosis to drug prescriptions, what they can and cannot do is all based on what doctors and other medical professionals think is best for their survival.

It is, however, heartwarming to know that over the past 20 years, writing by persons with disabilities has transformed understanding of the real nature of impairments and disabilities. According to the Oliver (1998), they move beyond the personal limitations that impaired individuals may face to social restrictions imposed by an unthinking society. Disability is understood as a social and political issue rather than a medical one, and this leads to critical questioning of medical interventions, attempts to cure impairments or to restore "normal" bodily functioning. Instead, social and political solutions are sought to challenge disabling discrimination (Oliver, 1998, p.317). This approach is gradually empowering people with disabilities to break free of the dominance of their lives by the medical profession.

According to the document that guides the provision of home care services in Manitoba, the case coordinator, in collaboration with the resident/caregiver(s) and other health care partners, is responsible for: identifying goals and objectives for care; identifying appropriate resources/options to meet identified needs; assisting resident/caregivers to access community resources, and other programs and services; and coordinating services provided by the home care program (Landers et al., 2013). The document places the resident at the center of decision making and all other supporting staff are to merely assist them to gain access to the resources available to them in the community.

Non-disabled people sometimes require the assistance of others to access certain resources in the community. The problem is that when it comes to persons with disabilities, they have to surrender their autonomy and sometimes privacy to be able to enjoy certain services and resources in the community that they are entitled to. Brisenden (1986) notes that “the problem comes when they determine not only the form of treatment (if treatment is appropriate) but also the form of life for the person who happens to be disabled” (p. 174).

Barnes (1999) asserts that consequently, disability theorists and the Independent Living Movement are currently attempting to challenge the myth that anyone is actually ‘independent’ when independence is defined in terms of complete self-reliance and propose. Instead, we are all dependent on one another and a variety of existing structures for access to resources and meaningful lives (Corbett, 1997; Davis, 1998; Barnes, 1999; Wendell, 1996). Several studies have investigated the abilities of practitioners to foster patient autonomy or self-management, although not particularly in home care. (Jacobs, 2019, p. 1640-1).

According to the University of St. Augustine for Health Sciences, the purpose of a nursing care plan is to document the patient’s needs and wants, as well as the nursing interventions (or implementations) planned to meet these needs (USAHS Blog, 2021). Care plans are structured as a five-step framework: assessment, diagnosis, outcomes and planning, implementation, and evaluation. (USAHS Blog, 2021). It is interesting to note that out of this five-step structure, the only level where the patient has any say is during the assessment.

The assessment depends on their ability to explain what they are experiencing both physically and medically. For patients who cannot assess their medical condition, the entire care planning process is done without their input unless they have a family member representative. In her executive summary on health care consent, commissioned by the Law Commission of Ontario, Judith Wahl et al. (2016) asserts that, across health settings, policies, practices, and associated forms have been developed to encourage or require patients (or their SDM(s)) to articulate their preferences for future health care. This push for pre-planning has extended across the many settings where health services are provided. Unfortunately, it is clear that not all elements of this pre-planning comply with applicable health legislation, nor reflect the limits prescribed by law (Wahl et al., 2016, p.ii).

It gets more interesting when a patient’s assessment of his condition is contrary to the views held by the medical professionals. Usually, it comes down to the support services and resources available and what the medical professionals think is best to achieve the set goals.

The structure of the care plan as noted above is perfectly in line with the basic steps of the scientific method which are identifying a problem, creating a hypothesis, testing the hypothesis, drawing conclusions, and refining the hypothesis. So, people with disabilities or impairments in care homes are identified as the problem, and measures such as medical procedures and services are put in place to resolve the perceived problem. But from my experience and interaction with the people I support, most of them seem to have come to terms with their situation and all they need is an environment and support services that would enable them to live their lives like anyone else.

Most people in care homes have already undergone several uncomfortable medical treatments and yet their medical conditions are not better than before. For those in the medical profession, accepting that certain conditions cannot be cured and that some people are okay and willing to live with their disability does not seem to be an option. Unfortunately, some persons with disabilities cannot even argue for themselves. Even for those who can, their views are often overridden by ‘expert medical opinion.’ Until residents or their representatives have a greater say in the care planning process, agitations and complaints will continue to be rife in the delivery of home care services.

According to the Government of Manitoba (n.d.), after a resident is assessed and deemed eligible, a care plan is drawn and signed by both the resident and the case coordinator, ensuring mutual understanding of the services the resident will receive. Usually when an individual signs a document it suggests that he/she is satisfied with the content of the document.

I remember having a conversation with a resident who had several issues with his care plan and asking him why he signed on to a document he does not agree with. His response was simple, “At the time, the alternative to signing that document was to live on the street as I had nowhere or no one to go to.” So just as some people are refusing to get vaccinated against the COVID-19 virus, I am certain that many residents in care homes would refuse the numerous doses of medicine and other uncomfortable medical procedures if they had the finances and ability to organize their care.

I recall a resident venting his frustration over his inability to invite his girlfriend for a sleepover because his care plan and rules of the house do not allow it. In his words “this is supposed to be my house and yet I need permission from people who do not live here on what I can and cannot do here."

As a home support worker and a student of Disability Studies, most of the time I share their sentiments. I think it is unfair to make such rigid rules for adults living in places they call their home. We all make decisions and choices in our daily lives. As and when we deem it necessary, we change these decisions to suit our current circumstances. People in care homes are denied this opportunity and until their care plans are reviewed, they are stuck with choices which could have been made years ago under entirely different circumstances.

Pelletier (2016) mentions that across Canada there are several examples in which different levels of government have attempted to protect the rights and interests of people with mental and physical disabilities. Two examples are Canada's Charter of Rights and Freedoms (Charter) and Manitoba's Human Rights Code (Code) (Pelletier, 2016).

Manitoba's Human Rights Code clearly states that "implicit in the above principle is the right of all individuals to be treated in all matters solely on the basis of their personal merits and to be accorded equality of opportunity with all other individuals" (Manitoba Human Rights Code, 1987, p.1). To protect this right, the code further states that it is necessary to restrict unreasonable discrimination against individuals, including discrimination based on stereotypes or generalizations about groups with whom they are or are thought to be associated, and to ensure that reasonable accommodation is made for those with special needs (Manitoba Human Rights Code, 1987).

This is a clear demonstration of some efforts made to ensure that people with disabilities and other minority groups are not discriminated against based on their identity. The inability to satisfactorily do so may be attributed to several factors. For persons with disabilities, it is often due to the ableist physical and social environment, lack of inclusive educational and work environments, and the limited decision-making power afforded people with disability in issues relating to their health and well-being. Until these challenges are addressed, people with disabilities would continue to be marginalized despite the efforts to ensure equality.

I believe care plans and their implementation in care homes in a way restricts care receivers as to what they can and cannot do. I have seen people not given food in their own homes because they are not supposed to eat after a certain time and others denied their smoking because they can only smoke a certain number of times in a day. These restrictions are often in the guise of trying to assist the individual to either lose or gain weight or stay healthy. These may seem minor, but it erodes the independence and autonomy of these individuals. I think a little flexibility in the implementation of these plans would do a lot of good to people in care homes.

Prince (2006) argues that policies more than just convey particular models of people and communities; they also communicate certain values and cast specific roles. So, policymakers should ensure care plans meet the needs of the people they are meant for and that the various roles assigned to people under the policy are performed accordingly to ensure better service delivery in a way that does not undermine the independence and dignity of care receivers under the home care program.

The International Council of Nurses (ICN) (2012) instructs that the observance of dignity should not be limited by the individual’s age, color, creed, culture, gender, sex, nationality, race, social status, or health status. Kennedy (2016) however believes that, while dignity is accepted as a universal need that is fundamental to the well-being of every individual in all societies, the actual “practical” meaning of dignity remains complex and unclear because it is a multidimensional concept (p. 45). For people in care homes, this could mean having control over decisions regarding their care and not being treated like kids because of their impairment.

3.3: Home care as practiced in other jurisdictions

Home support involves help with daily activities (e.g., getting up and around, getting dressed, using the bathroom, preparing meals, and taking medications) as well as basic health care tasks, social support, and relational care. Home support workers provide these services in residents' homes in order to enable them to "live independently for as long as safely possible" (BC Ombudsperson, 2012, p. 10). These services are an extension or a branch of healthcare delivery in many countries and in fact, in most countries and provinces they are run either by the national or regional health authorities.

> The past forty years have seen a spectacular transformation in the Long-Term Services and Supports industry that cares for elderly persons and persons with disabilities. Before the mid-1970s, most people who needed significant levels of support were housed in nursing homes, mental hospitals, and state institutions for persons with developmental and intellectual disabilities. (Howes, 2015, p. 100)

According to the same writer,

> Since that time, changes in federal Medicaid policies, driven by fiscal pressures as the proportion of the population needing care grows, have combined with cultural and legal shifts to favor deinstitutionalization and aging in place. (Howes, 2015, p. 100)

This has however come with its challenges. People receiving home care services have several complaints akin to those expressed by their colleagues in institutions. It ranges from the inability to make their own decisions, staff shortage, and poor service delivery among others. It is worth celebrating the de-institutionalization process but is not enough to merely get people out of institutions. People in care homes ought to be able to make their own choices and receive good quality services that meet their needs.

The popularity of home care services in Europe and America is understandable as it comes with numerous benefits. Notable among these benefits are freeing up space (beds) in hospitals and clinics and affording patients the opportunity of receiving care in the comfort of their homes instead of spending days or even months in medical institutions. It also employs hundreds if not thousands of people as managers, clinical case workers, coordinators, health care aides, and home support workers among others. This reduces the unemployment rate in many countries and serves as a source of livelihood for many.

Van Eenoo et al. (2018) mention that because of the enormous benefits of home support, several models have been developed all over the world to ensure the delivery of efficient and satisfactory home care services that meet both the collective and individual needs of persons in care. Queensland Health (2000) as cited in Van Eenoo et al. (2018, p. 40) defines a care model as a multifaceted concept which broadly describes the way health services are delivered. Due to the complex nature of mobilizing funds, and human and material resources in the delivery of home care services, countries across the globe are continuously searching for the best possible framework to ensure the delivery of both effective and cost-efficient home care services.

The World Health Organization’s Chronic Care Framework illustrates that new care models have to include both organizational-level and policy-level building blocks. (World Health Organization, 2004). Though they all seek to serve the same or similar purpose, the delivery of home care services varies from province to province and from one country to another. Ultimately, the aim is to ensure that persons in care can stay home independently as long as possible while receiving essential support with activities of daily living.

Like any other sector of the economy, finance is an important consideration in the delivery of home care services. As noted by several sources, both in Europe and the United States, decision-makers are searching for models to redesign home care and organize healthcare in a more sustainable way. (Kringos et al., 2015; Landers et al., 2016, as cited in Van Eenoo et al., 2018, p. 40). The number of infections and deaths recorded in care homes across North America and Europe on the onset of COVID-19 has compounded the problem of delivery of home care services. It has exposed the inadequacies in the delivery of home care services such that the authorities concerned can no longer hide from it. I am without a doubt that when things normalize, the entire home care program would be given another look by authorities concerned. Hopefully, various governments would inject more funds and pay better attention to staff recruitment and training, the housing of people in group homes, and the general delivery of home care services across provinces.

Donabedian's (1997) framework for assessing the quality of care suggests that structural characteristics, care processes, and outcomes are related to one another (Donabedian, 1997, as cited in Van Eenoo et al., 2018). According to the same source, structural characteristics are defined as the physical and organizational characteristics of the settings in which care occurs. This includes aspects of material resources (such as facilities, equipment, and money), human resources (such as the number and qualification of staff), and organizational structures (such as involvement of medical staff, methods of quality monitoring, and system of reimbursement). The care processes denote what is actually done while giving and receiving care (Donabedian, 1997, as cited in Van Eenoo et al., 2018).

To ensure the delivery of quality home care services, all these factors ought to be in place and properly coordinated. It appears to me that more attention is given to the structural characteristics and not the care processes. It is hard to monitor what transpires in every care home, but occasional visits and interaction with the people receiving care can give authorities a fair idea of what steps to take to improve upon the delivery of home care services.

American and European literature indicate that the home health care of the future needs to be more patient- and person-centered; more integrated and coordinated across settings, services, and care professionals; provide high-quality care for example by offering specialized care; and technology-supported (Bienkowska-Gibbs et al., 2015; Kringos et al., 2015; Landers et al., 2016 as cited in Van Eenoo et al., 2018). Though not perfect, the coordination of home care services among various professionals is something that is already in place among most agencies in Winnipeg, Manitoba. The various health professionals liaise in the delivery of services.

The WRHA's website lists intake, assessment, care planning, service coordination, and delivery as key activities of the home care program. What seems to be lacking is the need to make home care services more patient-centered. As it is now, the services are too generalized, especially when two or more patients are housed in the same building. People of different ages, nationalities, and cultures are sometimes housed together and provided the same services even though they have different preferences for food, entertainment, and clothing among others.

A study conducted by the World Health Organization in 2014 reveals that,

> The world is facing a situation without precedent: We soon will have more older people than children and as both the proportion of older people and the length of life increase throughout the world, key questions arise. Will population aging be accompanied by a longer period of good health, a sustained sense of well-being, and extended periods of social engagement and productivity, or will it be associated with more illness, disability, and dependency? How will aging affect health care and social costs? Are these futures inevitable, or can we act to establish a physical and social infrastructure that might foster better health and wellbeing in older age? (WHO, 2014, p.1)

These findings by the WHO validate studies conducted in Manitoba regarding expected demographic trends in the coming years (2021 to 2038). It is prudent therefore that these questions occupy the minds of policymakers going forward to be able to put the right legislation and resources – both human and infrastructural – in place to be able to deal with the challenges these changes in demographics may pose. There is no doubt that people in the latter parts of their lives would love to stay at their homes with their loved ones and receive the necessary support services and not spend their last days in an institution.

According to Landers et al. (2016), a 2010 AARP (formerly the American Association of Retired Persons) survey found that nearly three-quarters of a survey population of those age 45+ strongly agreed with the statement, “What I’d really like to do is stay in my current residence for as long as possible” (p. 1). This is echoed in the last stages of life, where the Dartmouth Atlas researchers found that more than 80% of patients say that they “wish to avoid hospitalization and intensive care during the terminal phase of life” (Landers et al., 2016, p. 264).

I could not agree more with these findings as a home support worker.

It further emphasizes the need to expand and improve home care services as most people prefer these services over hospitalization and institutionalization.

It is at this crucial stage where home care services need massive improvements and investment, but some states and governments are instead reducing expenditure on health care delivery. “There is a sense of urgency since growing numbers of care-dependent older persons with chronic conditions are served in the community, along with a shortage in the primary care workforce, and reductions or changes in public health care expenditures”. (Van Eenoo et al., 2018, p. 40). This is supported by other authors like (Bienkowska-Gibbs et al., 2015; Kringos et al., 2015; Rodrigues et al., 2012; Landers et al., 2016).

I agree with a study conducted in the United States which states that meeting this challenge will require envisioning the potential value of home-based health care, creating a pathway for home-based care to maximize its potential, and integrating it fully into the United States health care system. (Van Eenoo et al., 2018, p. 40). Here in Manitoba, home care services are run by the various Regional Health Authorities and home care is one of the thirteen services the authority is required to deliver. So, integration may not seem to be the problem. It is however noticeable that the home care program does not receive the same attention as mainstream healthcare delivery (hospitals and clinics). For example, while there are highly trained doctors and nurses at the hospitals and clinics, most home support workers can only boast of first aid and CPR training even after years of employment.

If properly resourced with equipment and well-trained staff, the home care program can take a lot of pressure off the mainstream healthcare facilities as many more services could be delivered in the comfort of the homes of the beneficiaries of the program. I believe this potential ought to be exploited especially with all projections pointing to a possible surge in the number of people who may require home care services in the coming years.

The same study that recommends enhancing the potential of home care services, however, is quick to recognize that there is no "one size fits all" model (Bienkowska-Gibbs et al., 2015; Kringos et al., 2015; Landers et al., 2016 as cited in Van Eenoo et al., 2018). According to Kringos et al. (2015), the economic situation, the national political landscape, the structure of the health care system, and prevailing attitudes and beliefs among the populations force each country to put a different focus while improving health and home care in their country. This accounts for difference in the delivery of home care services across different countries.

A similar stance is taken in an article published in the International Journal of Nursing Studies; "in order to improve the efficiency of health and home care, policymakers need information on which type of home care delivery or which home care model provides the best outcomes in their country" (Van Eenoo et al., 2018, p. 40).

A model that may work perfectly in one country or province may not work in another. It is always important to consider the prevailing circumstances before adopting a particular model. In some instances, a combination of models (mix and match) may be the way to go especially in countries with mixed nationalities.

The need to re-examine and in some cases change models to meet the changing needs and demands of home care services is not peculiar to countries in North America. Jacobs (2019) mentions,

> home care in the Netherlands is currently subject to dramatic changes. Over the last decade, healthcare is shifting from an illness-based model to a health-focused preventive model. New health and social care policies are forcing chronic and complex healthcare needs from secondary to primary care and from medical disciplines towards nursing and other paramedical professions. (p. 1639)

Perhaps going forward more attention and resources should be channeled towards these preventive models.

It seems obvious that across many countries, the idea is to keep older people out of institutions.

> The core strategy of these new policies is aging-in-place: by organizing health and social care in the community, thereby enabling older people and people with a chronic disease or disability to live independently in their own home environment. This new policy is influenced by a view of positive health, defined as ‘the ability to adapt and self-manage in the face of social, physical, and emotional challenges.’ (Jacobs, 2019, p. 1639)

Writing about the specific case of the Netherlands, Jacobs (2019) notes,

> Self-management is regarded as crucial for experiencing health and has become a key concept in the programs of large umbrella organizations in the Netherlands for long-term care and social care and patient advocate organizations. It is closely linked to similar

> concepts such as self-reliance and autonomy, which all refer to a capacity to care for or organize care for oneself in accordance with their own needs and values. (p. 1639)

This is even more important in a multicultural environment like Canada. In my experience as a home support worker, I have encountered both staff and residents from all over the world. One obvious thing is that, based on their origin and upbringing, these individuals have different tastes and choices and an appreciation of this is very important when providing care for these individuals.

It is widely acknowledged, though, that full autonomy is impossible; as Jacobs (2019) explains, social relationships play an important role in this capacity. With the support of friends, neighbors, family members, and volunteers, it should be possible to live independently even in old age or with a chronic disease or disability. This is captured by the term 'joint-reliance' or 'joint-sufficiency' (Jacobs, 2019, p.1639). In society, we rely on one another and the same is true with people in care homes and their care providers.

Nobody is fully autonomous, but the concern is that when it comes to major decisions that affect a person's health and life in general, they should have the final say in the line of action to be pursued. This is what seems to be lacking when it comes to people in care homes. Usually in an institution, people do not have much of a say. There are usually rules made by the caregivers regarding medication, meals, and general activities, and everyone in the facility is expected to abide by these rules. The home environment is supposed to empower the care receiver to make his own choices while receiving support services.

One of the main reasons why several disability rights groups advocated for de-institutionalization was to empower people to take control of their care and support services and not to be told what to eat, when to sleep and what activities to engage in like kids in institutions. Jacobs (2019) believes that on one hand, in-home care persons can remain relatively free of institutional constraints. "This they called 'emboldened autonomy': 'the home setting can mute care-giver authority and encourage patient autonomy". (Jacobs, 2019, p. 1639). "However, personal relationships and lifestyles at home do not match well with the requirements and procedures of care, which may result in eroded autonomy. (Jacobs, 2019, p. 1640). Patients then become increasingly objects of care: passive, not identifying with their actions, and without a voice in the construction of their daily lives and care". (Jacobs, 2019).

This is prevalent in care homes in Winnipeg, especially among patients diagnosed with intellectual disorders. They may not be able to understand complex scenarios, but there are simple things that they can clearly express either their approval or disapproval with and yet they do not get the opportunity to make these choices. I recall a 60-year-old man in one of the homes I worked in who resented the day program which was part of his care plan. Despite making his feelings being clear to the authorities, he was still made to attend the program because according to his case manager it was good for his recovery process. This is just one of many instances I have witnessed where patient autonomy is eroded.

If people in care homes cannot make their own choices and decisions even regarding non-clinical matters, then the purpose of deinstitutionalization seems to have been defeated. There seems to be an unending battle regarding what patients want and what medical officials believe is best for them to stay healthy. Despite the best efforts of both human rights and disability rights advocates, medical professionals still seem to have a great deal of control over the lives of people in care homes.

But not all studies support policies that promote autonomy for patients and people in care homes. Jacobs (2019) explains,

> most studies are critical of current healthcare practices and policies that promote patient autonomy, for two reasons. First of all, a qualitative study indicated that people with a chronic disease associate self-management with having to make important decisions by

> themselves in a state of physical and psychological vulnerability. They prefer a care worker to be a buddy to share responsibility with, instead of taking full responsibility themselves. Second, these studies critique the one-dimensional view of autonomy and control in healthcare. Patients' need for autonomy and their understandings of these concepts show a lot of individual variation. A qualitative study with frail older adults found that perceived control in healthcare depends on multiple internal and external factors, such as self-confidence in organizing care, perceived support from the social network, and the availability and adequacy of healthcare services. (p. 1640)

There are certain instances where the opinion of an expert is required, but there are several basic things that I believe people in care homes should be allowed to decide for themselves and have the flexibility to change their decisions from time to time if they so desire. For example, there should be flexibility in basic things like what to eat and when to eat, when to sleep and wake up, and planning of their outings and other daily activities. This would ensure some autonomy while still following medical procedures and advice.

Different countries realize that people with disabilities have been marginalized and discriminated against over the years. Eisenmenger (2019) defines ableism as the discrimination of and social prejudice against people with disabilities based on the belief that typical abilities are superior. For this reason, most countries are finding ways to build an inclusive society where everyone can fully participate regardless of their impairment.

According to Racine et al. (2018), in Sweden, the main disability policy is titled “Dignity and democracy in Sweden” written in 2012 with the aim of offering equal opportunities to disabled members of Swedish society including a state-owned service and goods provider (Samhall founded in 1980) that specifically hire people with functional impairment. Many countries have not gone this extra mile. They count on employers not to refuse people jobs based on their disability. But the reality is that many employers refuse to offer positions to people with disabilities because they are unwilling to make the necessary adjustments to accommodate them.

Racine et al. (2018) discusses the specific case of Sweden where the local governments are the principal agents responsible for the welfare of persons with disabilities. Parallel to this, the Swedish Agency for Disability Policy Coordination (Handisam) is tasked at a higher level of promoting a society in which everyone can participate on equal terms regardless of functional capacity while each of the government bodies are also responsible for issues touching on disabilities within their areas of activity (Racine et al., 2018). This seems to me like a more holistic approach targeted at eliminating discrimination against persons with disabilities at all levels in Swedish society, a good example worthy of emulation. Eliminating discrimination against people with disabilities should be tackled at all levels of government (national, regional, and local) if any success is to be achieved.

Manitoba is known for its pioneering role in disability rights activism, but it is still not out of place to zoom in on how other countries around the world model the delivery of home care services and address disability-related issues as a whole. Some valuable lessons can be learned from their models to improve upon the delivery of similar services in Manitoba and Canada as a whole. Studies in other advanced countries confirm that “due to the complex and ever-changing nature of home care services coupled with limited resources both in Europe and the U.S., decision-makers are searching for models to redesign home care and to organize health care in a more sustainable way”. (Van Eenoo et al., 2018, p.40). several other studies support this point of view including (Kringos et al., 2015; Landers et al., 2016). I believe a similar thing can be done here in Manitoba to make home care services better, efficient, sustainable, and more importantly able to meet the needs of people receiving various home care services.

Chapter 4: Methodology

This chapter looks at the method use in this study. I use autoethnography to write about the homecare policy. The study is based on my observations and experiences as a home support worker working for four different agencies over four years in Winnipeg, Manitoba. It looks at what the home care policy says about staffing and care planning and juxtaposes that with what I have observed to be the established home care practice here in Winnipeg to see if the policy is being implemented on the ground as planned or otherwise and its impact on the beneficiaries of the program.

It interrogates some of the challenges facing the delivery of home care services and establishes whether these challenges are because of improper implementation of the program on the ground or defects with the policy itself. It further looks at other models and practices in the delivery of home care services in Europe and other parts of the world to see if any lessons can be drawn from their models to improve upon the delivery of home care services in Manitoba.

Though there are several studies on the home care program in Manitoba, none that I have seen is conducted by someone who works in the field (direct support worker). So, I believe my study is unique in that regard with primary, undiluted information on how the home care policy is implemented on the ground.

The study is an autoethnography based on the researcher's experiences. Autoethnographers describe their own lives in a certain group or community and that is what I did in this study by writing about my experiences as a support worker within the Manitoba home care program.

I have worked in individual homes, group homes, and personal care homes over the past four years as a home support worker, but I intend to concentrate more on my experiences in group homes as this is where I have worked the most and had the most of my memorable experiences. According to the Oxford English Dictionary (n.d.), "a group home is a home where a small number of unrelated people in need of care, support, or supervision can live together, such as those who are elderly or mentally ill".

4.1: Legislation governing home care in Manitoba

No provincial legislation specifically governs the Manitoba home care program. It was established through a provincial order in council in 1974. Regional Health Authorities deliver home care services under the authority of The Regional Health Authorities Act. This Act lists home care services as one of the 13 health services Manitoba Regional Health Authorities must deliver and administer (Auditor General of Manitoba, 2015, p. 7). The Canada Health Act specifies the conditions and criteria the provincial and territorial governments must meet to receive federal funding for health care.

Under this Act, home care is an "extended health service" not an "insured service." This means that home care services are not guaranteed under this Act, unlike hospital services. The Health Services Insurance Act establishes the Manitoba Health Appeal Board. The Manitoba Health Appeal Board Regulation under this Act specifies the right for a person dissatisfied with a Regional Health Authority decision related to the Program to appeal to the Board (Auditor General of Manitoba, 2015).

4.2: Autoethnography

Autoethnography is an approach to research and writing that seeks to describe and systematically analyze personal experience in order to understand cultural experience (Ellis et al., 2010). Autoethnography is a qualitative research method that utilizes data about self and its context to gain an understanding of the connectivity between self and others within the same context (Ngunjiri et al., 2010).

According to Ngunjiri et al. (2010), this research method is distinctive from others in three ways: it is qualitative, self-focused, and context conscious.

As a qualitative research method, autoethnography takes a systematic approach to data collection, analysis, and interpretation of self and social phenomena involving self. This systematic and intentional approach to the socio-cultural understanding of self sets autoethnography apart from other self-narrative writings such as memoirs and autobiographies (Ngunjiri et al., 2010).

Second, autoethnography is self-focused. The researcher is at the center of the investigation as a “subject” (the researcher who performs the investigation) and an “object” (a/the participant who is investigated) (Ngunjiri et al., 2010). Access to sensitive issues and innermost thoughts makes this research method a powerful and unique tool for individual and social understanding (Ellis, 2009).

Third, autoethnography is context conscious. Rooted in ethnography (the study of culture), autoethnography intends to connect self with others, self with the social, and self with the context (Reed-Danahay, 1997; Wolcott, 2004). A variety of others--“others of similarity” (those with similar values and experiences to self), “others of difference” (those with different values and experiences from self), and “others of opposition” (those with values and experiences seemingly irreconcilable to self) are often present in stories about self (Chang, 2008, p.52).

This multiplicity of others, according to Ngunjiri et al. (2010), exists in the context where a self-inhabits. Therefore, collecting data about the self ultimately converges with the exploration of how the context surrounding self has influenced and shaped the make-up of self and how the self has responded to, reacted to, or resisted forces innate to the context (Ngunjiri et al., 2010). Ethnographic attention to the socio-cultural context is the foundation of this research method (Ngunjiri et al., 2010).

Consequently, autoethnography is one of the approaches that acknowledges and accommodates subjectivity, emotionality, and the researcher’s influence on research, rather than hiding from these matters or assuming they do not exist (Ellis et al., 2010).

Furthermore, Ellis et al. (2010) believe scholars began recognizing that different kinds of people possess different assumptions about the world, a multitude of ways of speaking, writing, valuing, and believing, and that conventional ways of doing and thinking about research were narrow, limiting, and parochial.

The forms of autoethnography differ in how much emphasis is placed on the study of others, the researcher’s self and interaction with others, traditional analysis, the interview context, and power relationships (Ellis et al., 2011).

Indigenous ethnographers, for instance, work to construct their own personal and cultural stories and seek to disrupt power in research where particularly privileged outside researchers (white, Christian, masculine, able-bodied) attempt to tell the stories of one’s subjugated and colonized groups (Gatta et al., 2019). They bring their own perspectives to the story’s ones told by the subjugator and give the world a different angle on these stories (Gatta et al., 2019).

Narrative ethnographers on the other hand refer to writings presented in story form that incorporates the researcher’s experiences into the ethnographic descriptions and analysis of others. Here the emphasis is on the ethnographic study of others, which is accomplished partly by attending to encounters between the narrator and members of the groups being studied (Tedlock, 1991).

Reflexive, dyadic interviews focus on the interactively produced meanings and emotional dynamics of the interview itself. Though the focus is on the participant and her or his story, the words, thoughts, and feelings of the researcher also are considered.

Reflexive ethnographies document ways a researcher changes as a result of doing fieldwork. Reflexive/narrative ethnographies exist on a continuum ranging from starting research from the ethnographer’s biography to the ethnographer studying her or his life alongside cultural members’ lives to ethnographic memoirs (Ellis, 2004).

Layered accounts, interactive interviews, community ethnographies, co-constructed narratives, and personal narratives are all forms of autoethnography and, as mentioned earlier, it all depends on the emphasis the researcher places on themselves, others, interaction with others, power relations, traditional analysis and interview contexts.

A researcher uses tenets of autobiography and ethnography to do and write autoethnography (Ellis et al., 2010). An autobiography is simply an account of a person's life written by themselves.

When researchers use ethnography, they study a culture's relational practices, common values, beliefs, and shared experiences for the purpose of helping insiders (cultural members) and outsiders (cultural strangers) better understand the culture (Maso, 2001). Ethnographers do this by becoming participant observers in the culture, taking field notes of cultural happenings as well as their and others' engagement with these happenings (Geertz, 1973; Goodall, 2001). I use these two methods (autobiography and ethnography) to write a community autoethnography examining the policy objectives of the home care program in Manitoba, how it is implemented on the ground, and the impact on the beneficiaries of the program.

Similar to interactive interviews, community autoethnographies use the personal experience of researchers-in-collaboration to illustrate how a community manifests particular social/cultural issue (e.g. whiteness) (Toyosaki et al., 2009). Community autoethnographies thus not only facilitate "community-building" research practices but also make opportunities for "cultural and social intervention" possible (Kardorff & Schonberger, 2010, p. 59).

Research is an extension of researchers' lives. Although most social scientists have been trained to guard against subjectivity (self-driven perspectives) and to separate self from research activities, it is an impossible task. Scholarship is inextricably connected to self-personal interest, experience, and familiarity (Ngunjiri et al., 2010).

4.2.1: Why I used auto ethnography

I used this method for my study because firstly, most often reports and incidents regarding happenings in the delivery of home care services are written and sent to people in higher authority by supervisors. These supervisors do not work in the field and so may not have first-hand information or may not fully appreciate what happens on the ground. Even if they do, owners of agencies would like their establishment to look good in the eyes of provincial and federal governments to keep them in business, so they may choose and pick which information to make public. I have no such commitment. So, telling my story and sharing my experience in the field I believe would provide a better insight into the home care program as these stories constitute primary undiluted information about the realities in the delivery of home care services and the home care culture in Winnipeg, Manitoba.

Autoethnography introduces stories of a person or a group of people of different cultures, languages, or beliefs. In general, autoethnography can be viewed as observing different people's lives while engaging oneself in the process (Thurova, 2009). That is exactly what my study is about, writing about my experiences and observations working with different agencies and people (both staff and residents) as a home support worker. I chose to be a home support worker due to my desire to help the vulnerable people in society which dates back to my days at an elementary school in Ghana where my best friend was a wheelchair user.

Despite the numerous social and environmental challenges my friend encountered, he persevered and today he is a professional teacher and is living his life to the fullest. This convinced me that with the necessary support systems in place, persons with impairments can live fulfilled lives and contribute positively to society. Using autoethnography permits me to tell my story in the context of the home care program in Manitoba.

Though some writers discredit autoethnography as lacking an academic, theoretical, and methodological base and being individualistic, others like Etherington (2004) believe that people writing about themselves is “a healing endeavor that strengthens our connections with our body, mind, and spirit through sharing our experiences and newly discovered self-knowledge” (p. 34). He further states, “In telling our stories we are also re-affirming and re-educating ourselves, our experiences and our lives and creating new stories” (p. 35).

For the most part, those who advocate and insist on canonical forms of doing and writing research are advocating a White, masculine, heterosexual, middle/upper classed, Christian, able-bodied perspective. Following these conventions, a researcher not only disregards other ways of knowing, but also implies that other ways are necessarily unsatisfactory and invalid. Autoethnography, on the other hand, expands and opens a wider lens on the world, eschewing rigid definitions of what constitutes meaningful and useful research (Ellis et al., 2011).

Also, (Ellis, 1999 cited in Thurova, 2009, p.9) argues that the field “gazes inward for a story of self, but ultimately interprets culture” On the issue of validity, reliability, and generalizability, Ellis opines, “validity means that our work seeks verisimilitude; it evoked in readers a feeling that the experience described is lifelike, believable, and possible” p.674. She further states that “there’s no such thing as orthodox reliability in autoethnographic research. However, we can do reliability checks”. P. 674. She goes further to say that “A story’s generalizability is constantly being tested by readers as they ask if it speaks to them about their experience or about the lives of others they know”. P.674. So, despite the criticism of autoethnography as a research method, there remain a good number of scholars who hold divergent views and continue to use the method to good effect.

In my case, I chose autoethnography because it is the method that allows me to tell my story as a home support worker detailing my joy, frustrations, and general observations of the home care program, how it is implemented on the ground, and the impact on beneficiaries, especially persons with disabilities in group homes in Winnipeg, Manitoba.

4.2.2: Organizing my autoethnography

Methods of data collection that are common within autoethnography include observation, reflective writing, and the gathering of documents and artifacts (Duncan, 2004). In my case, I have been taking notes of memorable occurrences at work, both positive and negative, and meaningful interactions with co-workers and residents. This forms a very important source of information for this study. Names of residents, co-workers, and agencies are not mentioned in the study to ensure confidentiality. In some instances, I use a 'she' when I am talking about a 'he' or completely make no mention of the sex to further protect the identity of the individuals I refer to.

My objective is to be able to tell my story as detailed as possible without giving out people's identity.

Part of my story will be a recollection of events and occurrences in the course of my work. Some of these events may have taken place several years ago, but as Ellis (2004) puts it, "it's amazing the details you can recall, and for how long, if the event was emotionally evocative" (p. 117).

Winnipeg may be a big city, but depending on which field you belong to, you keep meeting the same people in a different setting in your line of duty. For example, there are people who over the years have moved from being personal support workers to clinical case workers, home coordinators, day program coordinators, et cetera. So, my biggest worry was how to tell my story without giving clues as to which individual, agency, or event I refer to.

Some people confided in me and had honest conversations with me (both staff and residents) and I did not want them to notice the positions they took were not disability-friendly or did not conform to best practices. But eventually, I had to put out the information knowing that most writers of autoethnography face a similar dilemma in putting out their work. Besides, ethical rules were abided by to ensure that no harm comes to individuals and agencies that were involved in the study.

In the end, these stories may help reform individuals, institutions, and public policies. There are several ways of organizing autoethnography. In my case, I write my story with personal commentary, analysis, and discussion throughout the study. The idea is to give proper context to each story so that readers can get a better comprehension of the story.

According to Finlay (1998), reflexivity is about acknowledging your role in the research, including prior experiences, beliefs, assumptions, and how they influence the research process. It requires openness and acceptance that the researcher is part of the research. I have lived over three decades of my life in a country where there are no home care services. The responsibility of caring for the disabled, aged, and people with mental illness lies entirely with their family and benevolent support from friends and other well-wishers. For instance, when my grandmother suffered a stroke while I was in high school, my mother who was a trader and financially responsible for the education of myself and my other siblings had to quit her job to take care of my grandmother for seven years until her passing. I am certain my mother and her other five siblings could have paid for home care services for my grandmother if there were any available. Instead, she had to quit her job which made life at high school all through to university very difficult for me financially.

It is also common to see people with mental illness walking the streets either naked or half-naked and feeding on whatever they lay their hands on. Most of them are homeless and live on the streets often until their demise. Living in such an environment where government responsibility towards the citizenry is minimal molds you in a way that you are wowed when you see other governments put in place initiatives to take care of their own. It also makes you overly appreciative of any little government support because something is often better than nothing.

So, coming from this background and with this mindset, upon arrival in Canada and noticing a program designed to take care of people with disabilities, my first impression was that this is perfect, and I was full of praise for the program.

If this study was conducted at the early stages of my course, it would probably have been only praise-singing and not a single criticism because of the non-existent state-organized support services for people with disabilities in my home country. But my assumptions and ideas began to evolve as I got to understand that things work quite differently here in Canada than what I was used to. I recall one of my lecturers (Dr. Diane Driedger) explaining in class that the thinking here is that there is no guarantee that your children or family will take care of you in time of need no matter how you invest in them, but with government, they can be held accountable if they renege on their promise.

My initial assumption was that receiving home care services was a big privilege and that no one had a course to complain about. But based on conversations I had both in school and at work and documents I read about the program, I began to see things differently. I came to understand that it is more or less a social contract, and the government has a responsibility to fulfill its part of the bargain. So, months into my research, I no longer saw people complaining about home care services as being petty or unappreciative, but as people fighting for good quality services that they rightfully deserve.

But even after coming to understand things in the Canadian context, I still think the home care program is a brilliant idea that needs to be maintained and sustained as part of the healthcare delivery system. So, I sought to understand the possible cause of grievances among both residents and staff about the program could be. Luckily for me, I was hired by an agency that provided support staff for other agencies when they are short-staffed. So, I got the opportunity to work in several homes with different residents and staff under different agencies. Knowing what my research topic is, I had conversations everywhere I worked trying to understand how things are done in terms of company policy and service delivery among others. Over the four years, I can recount over fifty stories from residents, staff, and others performing administrative functions under the home care program.

Though all the stories and experiences are related to the home care program in Manitoba, not all of them are relevant to my topic. I had to sieve through them, put them into themes and select the ones that are in line with my study. There were several interesting stories and experiences that I wanted to talk about, but in the end I had to omit them to tell a coherent and interesting story relevant to my topic.

My biggest anxiety was how to organize my study in a way that will make interesting reading to my audience while touching on the home care program and the methods employed by various agencies to implement the program. I am no expert in autoethnographic writing. I have written stories and articles before, but this is my first ever autoethnographic research. Looking at the expertise of the likes of Carolyn Ellis, I was wondering if I could come close to putting out such a document. My objective was to "…tell a story that readers could enter and feel a part of. You'd write in a way to evoke readers to feel and think about your life and their lives in relation to yours" (Ellis, 2004, p. 116). I was wondering how I was going to achieve this as a novice writer. I had to read widely for weeks to have a better understanding of how to conduct autoethnographic research.

The actual study took a little over five months, but the information gathering spans well over three years. There are days that I wrote several pages and other days I struggle to complete a single paragraph. Reliving these moments triggers emotions, the good, the bad, and the ugly. It helped me to reassess myself as a support worker and given the opportunity there are several things that I will do differently.

Chapter 5: Theoretical Approach

This chapter discusses the three models of disability that influence disability policies and programs across several Western cultures and advocates the use of the social model to best meet the needs of people with disabilities.

The three theoretical approaches I discuss in this study are the moral model, medical model, and social model of disability. Each model perceives disability differently and thus proposes different ways and methods of dealing with and relating to people with disabilities. Several writers have written in support and against these models based on their understanding of the causes, effects, and ways to either cure or live with a disability.

Oliver (2013) asserts that many academic papers and some books have been published whose main concern has been to attack, reform, or revise the social model, and reputations and careers have been built on the back of these attacks. The battle of ideas is understandable because these points of view regarding disability have a great effect on the way people with impairments are perceived and treated in society.

Devlieger (2005) however believes,

> in real life, and in particular in the context of a globalized society, this juxtaposition does not reflect evolutionary stages. Nor does this juxtaposition of models reflect the existence of these models in different places or times. Rather, in globalized contexts, one should consider the existence of modes of thought as sometimes juxtaposed, but more often intertwined. (p. 6)

He further asserts that while one model may be dominant in one context, snippets of our modes of thought intervene. For example, in a hospital, disabled people, their family members, and professionals may be overwhelmed by the contours of the medical model of disability yet be equally confronted and engage with parts of other models (Devlieger, 2005).

Indeed, several hospitals have a section for spiritual healing. Patients admitted at these hospitals undergo medical treatment alongside prayers and other forms of spiritual healing. In the same hospitals, certain accommodations are made to ensure that people with mobility issues can either use wheelchairs, escalators, or elevators. This addresses the issue of physical barriers posed by the environment even though most hospitals in general are tilted towards the medical model.

It should be understood that these models are intertwined in several communities at different times. Some communities may be more tilted towards a certain model of disability, but it does not necessarily mean they use that model exclusively in matters relating to persons with disabilities or that a snippet of the other models cannot be seen at play in these communities.

5.1: Moral Model of Disability

The first is the moral model of disability familiar from the Bible and generally, the prevalent view is antiquity. According to this view, disability is a sign of the moral flaws of an individual or his or her progenitors. For example, according to Garland-Thomson (1995), an infant’s impairment is the result of one’s parent’s moral failures. According to this position, disability is a disadvantageous state, usually a visible impairment visited upon individuals (and their families) as retribution (Garland-Thomson, 1995; Silvers et al., 1998; Stiker, 1997/1999).

It is based on the never-ending competition between good and evil and locates unfortunate events as the working of evil (in people, witches, or the emanation of evil, the Devil) (Devlieger, 2005). Under this model, all impairments are viewed as punishment for a wrongdoing. Those born with impairments are believed to be paying for the wrongdoings of their forefathers and those who become disabled in the course of their lives are presumed to be paying for the sins they may have committed in the past.

While one would think that the moral model would point to a definition of disability as a punishment, this is not always the case. In some instances, disability as a problem is positively defined as a gift, a challenge given to special people (Landsman, 1999; Ingstad, 1997). Some persons with a disability give up on life and blame their failures on their impairment. Others manage to overcome both the physiological and environmental challenges and live successful lives.

This ideology may not inform the thinking of many at the policy level as most advanced countries like Canada rely on scientific studies and research in arriving at policy decisions rather than religious and superstitious beliefs. It is however worth pointing out that based on my observation, most of the home support workers in Winnipeg are immigrants from countries where such religious and superstitious beliefs are rife and so it will not be surprising if some of them believe in such an ideology. Personally, there was a time that I always attended shifts as a support worker on Sunday right after church. I was not alone; I know of several religious leaders and members of various religious groups who work here in Winnipeg as home support workers.

I have observed that in many care homes, staff have their own set of cutlery, plates, cups, and bowls that the residents are not allowed to use. This could be because of the ableist thinking that people with disabilities are somehow inferior to non-disabled people and do not deserve to share the same materials with them. Others may think that some of the people in care homes have impairments because of their wrongdoing and so may have no empathy whatsoever towards them. It is therefore worth interrogating how this religious view of disability influences the way members of these religious groups view, perceive, and relate to people with disabilities in care homes.

5.2: Medical Model of Disability

It is without a doubt that most of the individuals and agencies operating home care services in Manitoba and elsewhere believe in the medical model of disability. Trained in the medical field where this is the predominant idea, it is to be expected that they will lean towards this way of thinking. The way a phenomenon is viewed and understood informs the measures employed to remedy the situation.

The medical model Devlieger (2005) believes owes its dominance to its technical superiority and its insistence on asking questions that point to understanding the mechanics of the phenomenon of disability and its continuous feeding of the illusion that a medical solution can be found. Because of the numerous pieces of literature backing their claims regarding the causes and possible cure for impairments, many in the field of academia tend to lean towards this point of view regarding disability. According to Devlieger (2005),

> The medical model of disability is the result of a long history in which a human-centered cosmology replaced one that placed God at the center. It benefited from increased rationality and the development of modern societies. This view of the world has spread to all parts of the world. And while it was successful in diminishing the power of the so-called religious or moral model of disability, the latter survived and took on new dimensions. (p. 7)

The new generation believes in things that can be proven scientifically. The moral model seems to be rooted in spirituality and religious beliefs that are hard to prove scientifically or make any logical meaning out of. But the medical model is backed by data carefully presented to illustrate the possible causes and treatment and outcomes for different kinds of impairments.

In the words of Devlieger (2005), the cultural coherency of the medical model is derived from its placing the source of disability in the natural world, localizing disability in the individual, pointing to human experts as being in control, and operationalization as a measurable defect as perhaps its most distinctive characteristic. It is therefore not surprising that despite the efforts of disability rights movements and proponents of the social model of disability, the medical model continues to dominate in the formulation and implementation of policies regarding impairments and disability.

Kristiansen et al. (2009) assert that the medical model of disability has become the common view that attributes the cause of the individual's deficit either to bad luck (accidents), inadequate health practices (smoking, bad diet), or genes. This position views disability as the inevitable product of the individual's biological defects, illnesses, or characteristics (Kristiansen et al., 2009). Disability becomes a personal tragedy that results from the individual's pathological condition (Barnes et al., 1999; Oliver, 1990; Oliver, 1996; Priestley, 2003; Silvers et al., 1998).

Areheart (2008) explains that, under the medical model, people with disabilities are often characterized as having individual attributes of incapacity and dependence. Accordingly, given the view of disability as an individual problem, appropriate assistance is understood either as rehabilitation efforts to enable the individual to overcome the effects of the disability, or medical efforts to find a cure for the individual. Either way, the focus is on the individual and how she can overcome her condition (Areheart, 2008).

Even those with disabilities have sometimes adopted this view. As Areheart (2008) puts it, understood simply as a biological trait, disability leaves the individual in need of physiological assistance to remediate the effects of the disability. Medication, hospitalization, and in some cases, institutionalization is seen as the way to remedy the situation and restore normalcy.

Devlieger (2005) however explains that, throughout its existence, the medical model has never proven to "resolve" disability, its solutions remaining partial, feeding into the real but sometimes also illusory promise of enhancing the quality of life (p. 7). Good quality of life is subjective. To those in the medical field, this probably means a life without illness and providing a cure for the impaired members of the population. To persons with disabilities, however, good quality of life could mean providing enabling environments and the necessary support services such that despite their impairments they can go about their duties and live their lives like any other member of society.

The medical model seems to shape most healthcare policies and their implementation. This model dictates that every individual who does not meet their criteria of what they presume to be ‘normal’ has to be fixed or cured one way or the other. It views persons with disabilities as the problem that needs fixing and not the environment. This often leads to the prescription of medications and other medical procedures to which the person needing care may object.

Areheart believes that “the medical model relies on normative categories of “disabled” and “non-disabled” and presumes that a person’s disability is a personal, medical problem, requiring but an individualized medical solution; that people who have disabilities face no 'group' problem caused by society or that social policy should be used to ameliorate., The medical model views the physiological condition itself as the problem. In other words, the individual is the locus of disability”. (Areheart, 2008, p. 186).

Despite the general trend toward social constructionist accounts of identity, and in particular the shift to a social model of disability among activists and academics, society seems to have retained a medical paradigm for understanding disability (Areheart, 2008). No one is focusing on the environment that makes it almost impossible for people with disabilities to access public spaces and to live their lives just like everyone else.

Perhaps this is because disability and its theoretical underpinnings have not received the same degree of scrutiny as other aspects of identity such as race or gender (Areheart, 2008). Disability issues are not topical. They do not get the same coverage on radio and television stations regularly as other marginalized groups do. (Media smarts, 2016) published a report by the Canadian Association of Broadcasters which found an overall lack of coverage of disability issues by television news outlets. The few times matters related to disability are discussed, it is usually the voices of medical professionals, most of whom do not have any form of disability that are heard on the topic and not the people with disabilities themselves. That is why Brisenden (1986) espouses that "*our* experiences must be expressed in *our* words and integrated into the consciousness of mainstream society, and this goes against the accumulated sediment of a social world that is steeped in the medical model of disability" (p. 174, author's emphasis).

Brisenden (1986) further opines that if society was organized on a more equitable basis, many of the problems associated with not being physically 'perfect' (as if such a concept had any logical basis) would physically disappear. If public buildings and the businesses conducted in them are designed to accommodate people of different heights, shapes, and sizes, many people who have been labeled as disabled can go about their businesses without needing the assistance they currently require.

There is a constant search for cures and ways to make people with disabilities look and feel better according to the definition of what looks and feels better by people in the medical profession. In this quest, the opinions and feelings of the people whose health is the subject matter (persons with disabilities) are relegated to the background.

Most research into illness, impairments, and cures is conducted by medical professionals who are deeply rooted in the medical model. Most of what the public know about disability comes from medical professionals and not the people with disabilities themselves. When persons with disabilities are involved in this scientific research regarding a certain medical condition, their views or participation are merely used to authenticate the findings of medical researchers.

McKeever & Miller (2004) and McLaughlin (2005) assert that the role of 'patients'' own narratives has often tended to be reduced to a process of eliciting information regarding specific symptoms of disease or of abnormality. They have no control over decisions regarding which remedy best works for them and how their medical condition is described by the medical profession.

Persons with disabilities have over the years been labeled as ‘morons’ and ‘idiots’ such that their views on their medical conditions and their experiences with disability are discredited. It is medical professionals who define and explain the medical conditions of persons with disabilities and prescribe possible remedies. Their views are widely accepted by the public because their assertions are often backed by scientific evidence.

Brisenden, a writer who has an impairment, mentions that the opinions of disabled people on the subject of disability are not generally rewarded with the same validity as the opinions of ‘experts,’ particularly medical experts (Brisenden, 1986). Medical researchers are indeed able to back up their claims about disability and illness with evidence, but they lack the lived experiences of persons with disability. It is one thing knowing about an illness, but it is an entirely different experience living with it. That is the part of the story that is usually lost in the disability discourse, the experiences, feelings, and opinions of persons living with disabilities.

I agree with Brisenden (1986) when he says that the medical model of disability is one rooted in an undue emphasis on clinical diagnosis, the very nature of which is destined to lead to a partial and inhibiting view of the disabled individual. According to him, in order to understand disability as an experience, as a lived thing, we need much more than the medical ‘facts,’ however necessary these are in determining medication (Brisenden, 1986). The problem comes when they determine not only the form of treatment (if treatment is appropriate), but also the form of life for the person who happens to be disabled (Brisenden, 1986).

The packaging and delivery of home care services in Manitoba seem to be along the lines of the medical model. Persons with disabilities in various care homes are seen and treated as having physical, medical, and social problems that need to be fixed before they can fit well into society.

What they can and cannot do is written down in a single document called a care plan. Though they live in places that are supposed to be their homes, they barely make any decisions regarding their health and lives in general because, in the wisdom of medical professionals, it is by following their care plan that they can have a good quality of life.

5.3: Social Model of Disability

I rely on the social model to debunk the notion of disability espoused by the moral and medical models and to advocate for a disability-friendly environment where persons with disabilities can thrive despite their impairments. The medical model looks at a person's impairment first and focuses on the impairment as the cause of disabled people's inability to access goods and services or to participate fully in society. The moral model on the other hand blames a person's impairment on the moral flaws of the person themselves or their ancestors. These standpoints are sharply contrasted with the social model.

The social model identifies systematic barriers, derogatory attitudes, and social exclusion as the factors which make it difficult or impossible for individuals with impairments to function fully in society. I wish to elaborate on the need to make accommodations for persons with disabilities and individuals in care homes to thrive in the environment instead of trying to 'fix' them.

According to Devlieger, in the same way as the medical model defined itself in contradiction to the moral model, so did the social model in contradiction to the medical model. Perhaps the strength of the social model was and is in its possibility of reconceptualizing disability as the result of social relations and between people and their material conditions and environments Devlieger (2005).

Oliver believes models are ways of translating ideas into practice and the idea underpinning the individual model was that of personal tragedy, while the idea underpinning the social model was that of externally imposed restriction (Oliver, 2004).

Samaha (2007) states that although once obscure, the social model is now standard learning in Disability Studies. Its causation story has been a message of the disability rights movement since the 1970s, and in 1990 the model was successfully launched in Western academia by Michael Oliver's *The Politics of Disablement: A Sociological Approach*.

The idea behind the social model of disability stemmed from the Fundamental Principles of Disability document first published in the mid-1970s (UPIAS, 1976) which argues that disabled people are not disabled by our impairments but by the disabling barriers we faced in society.

They further argued that, in our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society (UPIAS, 1975).

Disabled people find themselves isolated and excluded by things such as flights of steps, inadequate public and personal transport, unsuitable housing, rigid work routines in factories and offices, and lack of up-to-date aids and equipment (UPIAS Aims paragraph 1). This point of view provides an alternative to the thinking that disability is a curse for wrongdoing or that it is people's impairments that prevent them from participating in society.

> This radically different view is called the social model of disability, or social oppression theory. While respecting the value of scientifically based medical research, this approach calls for more research-based on social theories of disability if research is to improve the quality of disabled people's lives. (Oliver, 1998, p. 317)

Samaha (2007) explains that for many advocates and academics, a social model of disability is foundational. It defines their field of study and it counsels everyone to see “disability” as a disadvantage caused by the confluence of two factors: (1) a person’s physical or mental traits plus (2) the surrounding environment, which is at least partly constructed by others. Both factors might be necessary before disadvantage takes hold (Samaha, 2007).

Working with persons with disabilities, I fully understand how medical professionals sometimes determine what people in care homes can and cannot do. It ranges from the food they can and cannot eat, activities that are safe for them to participate in and those that are not, and whether they get to stay in a group home, personal care home, or under intensive care at the hospital. All these decisions are made based on the facts of their diagnosis and what they believe is the best way to keep these individuals safe. In making all these determinations, the views and concerns of the individuals in question are often not considered.

The reality of the matter according to Brisenden (1986) is that under the guise of objective scientific inquiry, a particular image of disabled people is being fostered in the minds of the audience, and it is an image full of negative implications which are in themselves disabling. The cure sometimes turns out to be more deadly than the disease itself. Descriptions and medical terminologies that are given to persons with disabilities make them look scary, unhealthy, and useless. Terms like ‘mentally retarded,’ ‘deaf and dumb,’ and ‘spastic’ are still used in the medical field in referring to persons with disabilities. This does not only paint a negative image of persons with disabilities, but it also tends to describe a whole person or a group of people by his or her impairment.

But as Brisenden (1986) puts it, as well as the ‘facts,’ therefore, we need to build up a picture of what it is like to be a disabled person in a world run by non-disabled people. This involves treating the experiences and opinions of people with disabilities as valid and important.

More than this, they must be nurtured and given an overriding significance in order that they begin to outweigh the detached observations of the medical ‘experts,’ which have invested in them the power of history (Brisenden, 1986).

As a person with a disability and speaking for others with a similar condition, Brisenden further states that their experiences must be expressed in their words and integrated into the consciousness of mainstream society, and this he believes goes against the accumulated sediment of a social world that is steeped in the medical model of disability (Brisenden, 1986).

Too often the stories of marginalized groups are told by privileged people who themselves have not experienced any form of marginalization. Most proponents of the medical model are scholars and medical experts who themselves may not have experienced any form of disability. They thus say and do things that do not represent the feelings and desires of persons with disabilities.

The only way to change this narrative is for people with disabilities to tell their own stories and share their experiences. Brisenden (1986) believes that,

> It is vital that we insist on the right to describe our lives, our disabilities, and that we appropriate the space and proper occasions to do so. After all, the way something is presented will condition to a great extent the way it is received, as any newspaper or television editor will tell you. If the experience of disability is always presented in the context of the medical implications it is supposed to have, it will always be seen as largely a matter of a particular set of physical or intellectual dysfunctions and little else. In this way, the myth is perpetuated that disabled people require medical supervision as a permanent factor in their lives. As in society generally, the language used and the situation in which it is expressed will determine the message that goes out to those listening. (p. 174)

People with disabilities must control what goes into the public domain regarding disability and the accommodations that ought to be made to meet their needs. Wrongful descriptions and terminologies have disabling effects on people with disabilities.

Brisenden (1986) believes there are plenty of colloquialisms that indicate the damage that can be done through inappropriate terminology. Disabled people are seen as weak, pathetic, and in need of sympathy when they are referred to as ‘cripples.’ A person with cerebral palsy, when referred to as a ‘spastic,’ has to suffer the indignity of being equated with a raving, dribbling, ‘idiot’ – these are the facts beyond the medical ‘facts.’

What we have to get to, instead of this, is the real person inside the image of disability (Brisenden, 1986). Indeed, some of the people deemed normal by the medical profession may have several deficiencies and yet they are not referred to or identified by their deficiencies so why is it different when it comes to persons with disabilities.

To quote Brisenden (1986),

> to begin with, we are not “the disabled.” We are disabled people or even people with disabilities. It is important that we do not allow ourselves to be dismissed as if we all come under this one great metaphysical category “the disabled.” (p. 175).

To those not knowledgeable about disability-related issues, it will seem to them that all people who are blind for instance have the same needs and require the same level of assistance in their daily lives. But that is far from the truth. Two people can be diagnosed with the same impairment and yet their abilities and inabilities are sometimes worlds apart. I have witnessed this several times in my line of duty as a support worker, and yet a picture is painted in the minds of people as though all persons with disabilities have the same needs and require the same medication and services to get better.

According to Brisenden (1986), the effect of this is a depersonalization, a sweeping dismissal of disabled people's individuality, and a denial of their right to be seen as people with their own uniqueness, rather than as the anonymous constituents of a category or group. These words that lump us all together 'the disabled,' 'spina Bifida,' 'tetraplegic,' 'muscular dystrophy,' are nothing more than terminological rubbish bins into which all the important things about us as people get thrown away (Brisenden, 1986).

It is little wonder that disability benefits and other social support services including home care services are delivered as though all persons in care homes require the same services. It is only by getting closer to them that you recognize how wrong these assumptions are and how diverse the needs of these individuals are even though they are all grouped under the big umbrella of disabled people. Their individuality and personal preferences are so glaring for anyone paying attention to notice.

Brisenden (1989), commenting on the categorization of people as normal and abnormal, further asserts that people with disabilities are seen as 'abnormal' because they are different; they are problem people, lacking the equipment for social integration. But the truth is, like everybody else, they have a range of things they can and cannot do, a range of abilities both mental and physical that are unique to them as individuals. The only difference between them and other people according to him is that they are viewed through spectacles that only focus on their inabilities and a sort of medicalized social reflex regarding our abilities. (Brisenden, 1986). picture is painted as though those deemed normal are impeccable and have no flaws or deficiencies. But that is not the case. As humans, we all have our strengths and weaknesses. Terms like gifted, talented, and inventive are used to describe people who have unique abilities to make or create things. Yet when others due to their uniqueness and the barriers created by the environment are unable to perform certain tasks, they are described with words like ‘retarded,’ ‘dumb,’ ‘cripple,’ ‘idiot,’ and others. Perhaps this is the perfect excuse to exclude these individuals from certain social spaces in society.

Brisenden (1986) believes that this labeling process results in people with disabilities being excluded from all spheres of social life and allows people to treat them either as ‘morons’ or as creatures from another planet. Yet it is in fact the posture of society at large that constitutes the most disabling part of being disabled, not the physical effects of whatever condition one happens to have unless it leaves the individual utterly bed-ridden or completely fatigued (Brisenden, 1986).

It is undeniable that the effects of certain conditions can affect the functioning of an individual. Either by birth, through accidents, or aging, people develop conditions that make it difficult for them to perform certain tasks. But there are several other instances where on top of their disability, the environment further disables people with impairments.

In the view of Brisenden (1986), overall, it is the organization of society, its material construction, and the attitudes of individuals within it that result in certain people being disabled. We are only people with different abilities and requirements, yet we are disabled by a society that is geared to the needs of those who can walk, have perfect sight and hearing, can speak distinctly, and are intellectually dextrous (Brisenden, 1986).

Disability has been part of humankind for generations and yet our communities continue to be built and organized as though we are unaware of people who cannot see, walk or talk. Everyone, especially those in positions of power, seems to ignore the existence of persons with disabilities in our communities, hence their difficulties and challenges are compounded with the invention of new technology and facilities as their abilities and inabilities are often not taken into consideration.

Brisenden (1986) refers to the problem of access to buildings and facilities in the community and to the callous disregard with which the needs of persons with disabilities are ignored despite the efforts of sundry committees, working parties, and other bodies on their behalf. It is either that these bodies are not doing enough, or their proposals and opinions are just being ignored. Either way, much ought to be done to rid society of the medical view of disability that focuses on an individual's impairment and not the disabling environment.

Brisenden (1986) is of the view that people with impairments are disabled by buildings that are not designed to admit them, and this, in turn, leads to a whole range of further disablements regarding their education, chances of gaining employment, their social lives, and so on. The disablement lies in the construction of society, not in the physical condition of the individual (Brisenden, 1986).

This argument is usually rejected, precisely because to accept it involves recognizing the extent to which people with disabilities are not merely unfortunate but are directly oppressed by a hostile social environment (Brisenden, 1986). This is a difficult admission for politicians, charity organizations, and civil society to make. So, they continue to view disability as an individual problem and not a problem born out of society's inability to meet the needs of people with impairments. With limited support services in place, people with disabilities go through a lot of difficulties to achieve success in society.

Those people with disabilities who have achieved success in our society today usually have done so through a process of struggle that continues day in and day out. Yet the benefits according to Brisenden (1986) far outweigh the disadvantages of the struggle. It is difficult to compete in an environment where all the odds are against you. Yet some persons with disabilities have chalked significant successes in different fields of endeavor through hard work and perseverance.

This is proof that given the right environment and the necessary supports in place, persons with disabilities can function effectively in society and will not have to depend on charity and the benevolence of groups and agencies, some of whom have their own agenda other than helping people with disabilities. This is not to say people with disabilities do not require any form of assistance, but that their independence and dignity should not be sacrificed while offering them support.

As Brisenden (1986) explains, it is important to note the sense in which we use the term ‘independence,’ because it is crucial to everything we are saying. We do not use the term ‘independent’ to mean someone who can do everything for themselves, but to indicate someone who has taken control of their life and is choosing how that life is led (Brisenden, 1986). People with disabilities can be supported and yet maintain their independence and choose the services they want to be delivered and how they want them delivered.

When independence is restored to people with disabilities and the necessary accommodations are made for them, they can live to fulfill their potential despite their impairments. What is needed is a recognition by various players in society (architects, educational institutions, employers, et cetera) that not everyone can operate at the same pace and be flexible in their demands.

As noted by Driedger (2003) in her research about the personal experiences of women with chronic illness in the workplace, most of the women could have benefited from flexible work time. Some women have responsibilities as wives, mothers, and full-time workers. All three responsibilities are very demanding and so little accommodations such as being able to perform some of their work duties in the comfort of their homes and flexibility at work to attend to other family duties would be of great benefit to them.

The study further suggests that to include people with chronic illness in the workforce, society must re-examine its paradigm for life and work balance (Driedger, 2003). The COVID-19 pandemic has indeed taught us that several jobs that one’s required workers to be physically present at work can be carried out effectively by employees at the comfort of their homes.

Perhaps this is a perfect opportunity for most employers to reexamine their recruitment processes and the demands they make of their employees. Several people, myself included, have been refused employment because they do not possess a driver’s license and a reliable vehicle. Not everyone can drive or own a vehicle and yet this becomes a restriction preventing people from gaining employment. This and many others are the restrictions society places on people with disabilities and yet they blame their impairment as the reason for their inability to fully part take in society.

According to Charlton (1998), there are several barriers in society that restrict people with impairments physically, economically, and socially. It is the removal of these restrictions that would enable persons with disabilities to function effectively in society despite their disability. The social model is attempting to challenge the current paradigm framing disability as something that is normal and not to be considered inferior (Charlton, 1998).

Certain illnesses are indeed curable when detected early and the right medication is administered. But several other impairments are simply not curable, or their cure has not been found yet. People are born with impairments, others get into accidents that cause impairments, and some are unable to perform tasks that they could previously perform as they age. All these are normal, natural events and occurrences that can happen to anybody. Yet society continues to have a negative posture towards persons with disabilities.

Kristiansen et al. (2009) explain that since the 1960s, the medical understanding of disability has been fiercely criticized by writers and advocates of the social model. It has been argued that medicine portrays disability in a biased manner that leads to practices and social arrangements that oppress people with impairments (Kristiansen et al., 2009). Interventions are aimed solely at the ‘abnormal’ individual while the surrounding environment is left intact (Kristiansen et al., 2009). Resources are not directed at changing the environment but rather on ways to ‘improve’ or ‘repair’ the impaired individual. Kristiansen et al. (2009) believe this leads to a social and moral marginalization of disabled people, preventing their full participation in society. This phenomenon is rife under the home care program where people with disabilities under the program are made to undergo procedures and treatments aimed at curing them.

Disability is a social justice issue that should be dealt with through social interventions, not an individual problem that is to be dealt with through medical interventions (Kristiansen et al., 2009). Sociological viewpoints combined with a strong political commitment to the self-empowerment of people with impairments have become the ontological and epistemological foundation for disability studies (Linton, 1998; Oliver, 1996; Priestley, 2003).

Indeed, the way a phenomenon such as disability is understood and explained constitutes the basis for practical interventions geared at removing the possible hardships associated with disability (Kristiansen et al., 2009). A certain view and understanding of disability inevitably direct our responses and actions (Kristiansen et al., 2009). In other words, if the cause of impairment and disablement is seen to be spiritual, it is only natural to address the issue with spiritual maneuvers such as exorcism and faith-healing. If disability is understood in terms of medical knowledge and is confused with impairment, then it is only reasonable to concentrate on improving a person’s ability with medical interventions (Kristiansen et al., 2009).

I wish to emphasize the social model as a way of perceiving disability in this study to add my voice to the call to first, engage people with disabilities in matters and policies that affect them and elucidate their views on what would make life better and easier for them rather than resulting to medical solutions which at times only compounds their problems. Secondly, I wish to advocate that the physical environment should be made inclusive and devoid of barriers that make it practically impossible for persons with disabilities to function effectively.

Finkelstein (2001) asserts that it is society that disables us, and disabled people are an oppressed social group. The central issue in our campaigns for a better life therefore ought to be concerned with issues around *emancipation* and this requires struggles for social change rather than concentrating on individual experiences, ‘rehabilitation,’ et cetera (Finkelstein, 2001, p. 2).

5.3.1: Dichotomy in social model thinking

Despite the criticisms of the social model of disability, it lays bare certain facts which serve as a foundation for disability rights movements to argue about the disabling environment and wrongful terminologies used to refer to persons with disabilities.

For instance, Shakespeare (2010) notes that impairment is distinguished from disability. The former is individual and private, the latter is structural and public. While doctors and professionals allied to medicine seek to remedy impairment, the real priority is to accept impairment and remove disability (Shakespeare, 2010). This distinction is important because impairment is often equated to inability. Indeed, there are several people with impairments who are business owners, lawyers, lecturers, et cetera. On the other hand, there are other impaired people who could not realize their dreams due to societal and environmental challenges. The social model makes it clear that instead of focusing efforts on curing people with impairments, the environment should rather be enabling and inclusive such that their impairments do not disable them from participating in society.

The social model is also distinguished from the medical or individual model. “Whereas the former defines disability as a social creation a relationship between people with impairment and a disabling society, the latter defines disability in terms of individual deficit” (Shakespeare, 2010, p. 216). Individuals may have their impairments, but these are made visible and disabling when the environment presents obstacles that make it impossible for people with impairments to safely navigate. So, the social model recognizes impairments but blames the posture and physical build of society as the cause of disability.

Disabled people are distinguished from non-disabled people. According to Shakespeare (2010), disabled people are an oppressed group, and often non-disabled people and organizations such as professionals and charities are the causes or contributors to that oppression. Civil rights, rather than charity or pity, are the way to solve the disability problem. Organizations and services controlled and run by disabled people provide the most appropriate solutions. Research accountable to, and preferably done by, disabled people offer the best insights (Shakespeare, 2010).

5.3.2: Strengths of the social model

The social model has been effective politically in building the social movement of disabled people (Shakespeare, 2010). Disability rights movements ride on the back of the social model to demand inclusion and access to public spaces. The model serves as a framework, something various disability groups have regularly pointed to in arguing that with the right mechanisms in place, people with disabilities can fully participate in society despite their impairments and that it is the society that needs fixing and not their impairment.

By identifying social barriers which should be removed, the social model has been effective instrumentally in the liberation of disabled people. Oliver (2004) argues that the social model is a “practical tool, not a theory, an idea or a concept” (p. 30). Shakespeare (2010) also explains that the social model demonstrates that the problems disabled people face are the result of social oppression and exclusion, not their individual deficits. This places the moral responsibility on society to remove the burdens which have been imposed and to enable disabled people to participate (Shakespeare, 2010). Terms like ‘useless eaters’ have been used to refer to people with disabilities in the past. This way of thinking is changing thanks to the new ideas espoused by the social model.

The social model has been effective psychologically in improving the self-esteem of disabled people and building a positive sense of collective identity. According to Shakespeare, in traditional accounts of disability, people with impairments feel that they are at fault. Language such as ‘invalid’ reinforces a sense of personal deficit and failure. The focus is on the individual and her limitations of body and brain (Shakespeare, 2010). Shakespeare (2010) believes that a lack of self-esteem and self-confidence is a major obstacle to disabled people participating in society. The social model has the power to change the perception of disabled people. The problem of disability is relocated from the individual to the barriers and attitudes which disable her. It is not the disabled person who is to blame, but society. She does not have to change, society does. Rather than feeling self-pity, she can feel anger and pride (Shakespeare, 2010).

5.3.3: Weakness of the social model

Scholars have debated the social model’s force, but its limitations are more severe than have been recognized (Samaha, 2007). Many writers have pointed out the shortfalls of the social model. Oliver (2013) states that almost from the beginning, critics of the social model began to emerge. Initially, these came from the major disability charities and many professional organizations who felt that their dominance of our lives was under threat (Oliver, 2013). Years later, some disabled people and academics involved in the newly emerging disability studies also began to question the value and relevance of the social model (Oliver, 2013). Many academic papers and books have been published whose concern has been to question, reform, or revise the social model. Reputations and careers have been built on the back of these attacks according to Oliver (2013). Some of these criticisms of the social model are discussed below.

First, the model neglects impairment as an important aspect of many disabled people's lives. "As individuals, most of us simply cannot pretend with any conviction that our impairments are irrelevant because they influence every aspect of our lives" (Crow, 1992, p. 7). On the same subject, Williams (1999) also states that "endorsement of disability solely as social oppression is really only an option, and an erroneous one at that, for those spared the ravages of chronic illness" (p. 812). Some people experience chronic pain and other impairments which leave them bedridden. For these individuals, no matter how enabling the environment may be, they may not be able to for instance attend school, work certain jobs or even work at all. These situations do exist and so we cannot pretend that once the environment is conducive everyone can fully participate irrespective of their impairment as the social model wants us to believe.

Another criticism of the social model is the crude distinction between impairment (medical) and disability (social). According to Shakespeare (2010), in practice, it is the interaction of individual bodies and social environments which produces disability. For example, steps only become an obstacle if someone has a mobility impairment (Shakespeare, 2010). Our abilities and inabilities become visible based on our interaction with the environment. So, to paint a picture as though it is only the environment that disables people with impairments is misleading.

The concept of the barrier-free utopia is another thing the social model is criticized for. In the words of Bury (1997),

> It is difficult to imagine any modern industrial society (however organized) in which, for example, a severe loss of mobility or dexterity, or sensory impairments, would not be 'disabling' in the sense of restricting activity to some degree. The reduction of barriers to participation does not amount to abolishing disability as a whole. (p. 137)

It is hard to imagine what a perfect environment where everyone can fully participate despite their impairment would look like. No matter how hard a society may try, certain groups of people will be excluded from certain jobs or activities due to their impairment.

Oliver (2013) again believes that the social model has barely made a dent in the employment system because although it has identified many of the disabling barriers in the international labor market and with the behavior of employers, the solutions offered have usually been based on an individual model of disability. People with impairments across the globe require different accommodations at the workplace to be able to fit into the job market. There is no 'one size fits all' approach to solving the employment or unemployment problem facing people with disabilities. So, the solutions preferred by the social model may not be applicable in certain situations and circumstances.

Some of the criticisms of the social model are valid. In defense of the model, however, it is just a model that is supposed to serve as a guide and be built upon to better the lives of people with disabilities. It does not in any way claim that it has all the solutions to the problems facing people with disabilities. It merely serves as a framework upon which various disability rights movements can and have relied upon to assert their rights and demand an inclusive environment.

Oliver (2013), who is widely regarded as the protagonist of this model in response to some of these criticisms, says,

> my own response to these attacks has always been fairly relaxed because I have never seen the social model as anything more than a tool to improve people's lives and I have been happy to agree that it does not do many of the things its opponents criticize it for not doing. (p. 1025)

Even theories are sometimes disputed and revised when further studies bring out new findings that were previously unknown. The social model is no exception. It may not reflect all the problems facing people with disabilities and I doubt there is any single document that does, but it is still a very effective tool for confronting various forms of discrimination and exclusion against people with disabilities across the globe.

Oliver (2013) broadly puts the criticisms of the social model into two main groups. He states,

> It is not my intention to reprise these criticisms here but basically, they can be divided into two main areas of concern. The first of these suggests that there is no place for impairment within the social model of disability. The second alleges that the social model fails to take account of difference and presents disabled people as one unitary group, whereas in reality our race, gender, sexuality, and age mean that our needs and lives are much more complex than that. (p. 1025)

Oliver (2013) further explains that overall, these critics have argued that the social model is only a limited and partial explanation for what is happening to disabled people in the modern world. In recent years it has sometimes seemed as if these criticisms have received more prominence than the social model itself (Oliver, 2013).

The criticisms directed at the social model for not recognizing impairments are not entirely accurate. The model only explains how some people with impairments could have fully participated in society if the right environment was created. Samaha (2007) explains that key to the social model is a distinction between personal impairments and disability. According to Samaha (2007), akin to the sex/gender distinction of the 1970s, the social model indicates that at least some impairments disadvantage only because of their interaction with a social setting. Thus, the model defines ‘disability’ as a disadvantage caused by the confluence of (1) personal impairment and (2) a social setting comprising architecture, economics, politics, culture, social norms, aesthetic values, and assumptions about ability (Samaha, 2007). It is therefore an unfair criticism of the model when writers say it does not recognize impairment as a cause of disability and solely blames society.

On the issue of the social model failing to recognize differences between people with impairments, Oliver (2013) asserts,

> I and others have often pointed out that focusing on impairment and difference will only de-politicize the social model and will not lead to the development of any approaches or alternative models that are likely to be useful in developing campaigns to improve or defend the lifestyles of disabled people. (p. 1025–1026)

Today the social model is criticized as not being all-encompassing and representative enough of the needs of people with impairments, and yet no one can point to an alternative or a better model that best meets the needs of people with disabilities. These criticisms have caused divisions among the resolute and united front of disability rights movements that previously converged around the idea of the social model.

These divisions and criticisms only play into the hands of politicians and other charitable organizations who may not necessarily have the interest of persons with disabilities at heart. It gives them ground to cut benefits and reallocate resources meant for people with disabilities with the excuse of meeting the needs of the most vulnerable in society.

In the words of Oliver (2013), cuts in our benefits are being justified on the grounds that the intention is to give more to those who are severely impaired (deserving) and not to those who are not (undeserving). Disabled people’s differences are being used to slash their services as their needs are now being assessed as being moderate, substantial, or critical, and many local authorities are now only providing services to those whose needs are critical (Oliver, 2013).

Oliver (2013) further asserts that the disabled peoples’ movement that was once united around the barriers disabled people had in common now faces deep divisions and has all but disappeared, leaving disabled people at the mercy of an ideologically driven government with no one to defend them except the big charities who are driven by self-interest.

This is the sad reality people with disability are living with today. Years after the social model, one will have expected the circumstances of people with disability to be far better than it was 30 to 40 years ago, but that does not seem to be the case. If the analogy of Oliver (2013) is anything to go by, people with disabilities are worse off than they were 30 years ago.

So, Oliver (2013) believes those who have talked down the social model while failing to replace it with something more meaningful or useful must bear a heavy burden of responsibility for this situation. Remarkably they have been rather silent in speaking out or building alternative models to address what is happening to disabled people now. Surely it is time to either re-invigorate the social model or replace it with something else (Oliver, 2013). After over thirty years of criticism and yet failing to replace the social model, I doubt if there is a better model to replace it.

But all hope is not lost; it seems some efforts are already underway to reinvigorate the social model. According to Finkelstein (2003), in February 2000, Greater London Action on Disability (GLAD) held the conference ‘Reclaiming the Social Model of Disability.’ Amongst the key points from the conference, we are told,

> We need to produce an updated social model of disability that; includes a positive statement about us; recognizes our diversity and difference; recognizes institutionalized discrimination; talks about choice; recognizes that not all the things that exclude us are about society’s barriers and talks about barriers (attitudes and access). (C, 2003, p. 3)

“‘We need to consult widely on this new definition’” (Cited in Finkelstein, 2003, p.3).

This probably should have been done long ago instead of the energies expended in running down the model. It is still better late than never. The problems facing people with disabilities are still enormous and if a solution is to be found, the social model either in its current form or remodeled has a great role to play as a guiding document.

Chapter 6: My Experiences as a Support Worker

This chapter takes account of my experiences as a home support worker. It looks at how I got hired as a support worker, the training I received, and various encounters at the workplace both with colleague workers and the people I provide care for. It also looks at the patterns in the delivery of care and how most agencies organize the care delivery process and the care homes.

6.1: My journey as a home support worker

6.1.1 How I became a support worker

Home support work seems to be the go-to job for most immigrants upon arrival in Canada. This is probably because, unlike other jobs, the only certificate required is a First Aid and CPR certificate which can be obtained within eight hours. I recall being nervous when I was going to take the exam for my first-aid certificate. My landlady at the time who was a home support worker herself walked to me and said, “Relax, no one has ever failed that test.” That, I believe, sums up how easy it is to get started as a home support worker.

Some agencies even pay for their recruits to have the training for free and also pay for their existing staff when they have to renew their certificates. So, when I arrived in Winnipeg in February 2017, my friend who was a student of disability studies recommended that I apply for a job as a home support worker. He was a home support worker himself and explained to me that not only was it easy to get the job, but it was also in line with my course as a student of Disability Studies. So, I obliged and applied.

The application process was easy and straightforward. Most of the agencies at the time advertised the position as an entry-level job with no previous experience required. There were a few others who were looking for candidates with some form of experience working with people with disabilities, who had a reliable vehicle and a valid class 5 full driver’s license. At the time I did not meet all of these requirements, so I only applied to the agencies that advertised entry-level positions. It did not take too long before I was called and scheduled for a couple of interviews.

Finding a job was very crucial because I did not receive any scholarship for my Master's education and my uncle who promised to support me financially lost his job a few months after I arrived in Canada to pursue my education. This meant that I had to work and pay my tuition fees and other expenses that come along with my education and stay in Canada. My wife was also pregnant with our first child. She had just completed nursing training in Ghana and so was unemployed at the time and could not support me financially.

I was quite nervous preparing for these interviews. I had spent my entire life in my home country where I was so accustomed to the environment and now suddenly, I had moved out of my comfort zone. I did not know what to expect in these interviews or what employers expected from me. But perhaps my biggest fear was communication. I kept wondering if I can hear and respond to the interview questions and whether the interviewers can also understand me with my accent.

Facing an interview panel was the least of my worries because I had been teaching very large classes at the high school level for close to seven years in my country before coming to Canada. Within this period, I also attended a couple of seminars and made presentations. So, I had confidence in my ability to express myself in front of a panel, what I was not sure of was whether I will hear and be heard clearly during the interviews.

In the end, it looked like most of my fears were unwarranted. Most home support workers are immigrants from different parts of the world and most agencies are aware of that. So, they consider that during interviews and try to make the process as friendly as possible. In almost every interview I attended, I was reminded several times not to hesitate to ask if any words do not come out clearly and that there were no right and wrong answers. This helped to calm my nerves. So, once I overcame my nervousness, I got better from one interview to another until I finally landed a job as a support worker.

6.1.2 Training and early observations as a support worker

I did not receive much training either at the start or in the course of my work. First aid and CPR training are mandatory. Aside from that, usually, most agencies organize a two-day orientation program for their recruits to explain company policies and the ‘dos and don’ts’ of the job. Staff is then assigned to their respective homes where they are usually scheduled to experience how care is delivered for two days. This is the training I received. All other experiences were acquired on the job as I moved from one group home to another and from one agency to another.

Given my family history with disability and the fact that I had applied to pursue Disability Studies, this was more than just a job for me. The home care program was novel to me and so I was curious to know almost everything about it. I had conversations with residents, staff, and people performing administrative roles under the program to get a better understanding of how the entire system operates. Every day came with a different learning experience as I moved from one home to another attending to people with different needs.

On an average day when I get to work, I go round to say hi to all the people I work with. For some of these individuals, we are the only family and friends they have, so having a good relationship with them is very important to me. But that aside, what I enjoy most about my job is when I go out with these individuals to places where they could not have gone by themselves. Places like malls, parks, and other public places. Assisting them to wear clean clothes, eat good food and go out into the community like every other person gives me great satisfaction. In my line of duty, I keep asking myself this question “Would I be satisfied with the service I provide if I was the one receiving it?” This thought is my guiding principle, and it pushes me to always want to provide the best possible service I can.

I was full of admiration for the program, and I still am because looking back at my home country, most of the individuals in group homes would have been homeless living on the streets. They have food, shelter, and support staff and that is not something I can overlook given my background and the conditions I have seen people in similar situations endure. But some things struck me from the onset as needing some alteration from the onset.

I still do not understand why casual male staff is continually assigned to homes where all the residents are female and require assistance with bathing, clothing, and personal care. The opposite also happens where casual female staff is assigned to an entirely male home. I remember telling a female team lead that if I was a resident receiving home care services, I would not want different people walking through the door to see my nakedness on daily basis. Her response was, "I would not want that either." Most of these people in care homes still value their privacy just like any other person except that they are not in control of hiring and scheduling their staff, so they have to make do with whoever walks through the door to offer them services. Sometimes the resentment is glaring on their faces and their actions at times speak louder than words, but their options seem limited.

The most challenging part of my job so far has been finding a balance between implementing agency rules and the rights and wishes of the people I support. It is easy to go by a person's care plan strictly and do exactly what it says disregarding any concerns raised by them. After all, either they or a family representative signed on to the care plan. But as a student of Disability Studies and also knowing that some of these care plans have not been reviewed for years, I find it difficult to disregard some of the concerns expressed by the people I support.

Some of their demands are so minor that in my opinion, it does not require approval or a review of their care plan to carry out. Sometimes it involves performing an activity an hour early or late, or simply requesting something that was not originally scheduled to be done that day. In my view, these are adults living in places that are supposed to be their home, so they sometimes get bored with their daily routine and want to try something different. They get frustrated when these seemingly harmless requests are denied because their care plan does not permit them to carry out those activities.

I recall an incident that occurred in the early days when I started working as a support worker. One of the residents was entitled to two phone calls a day and so requested to make those calls around mid-day. Unfortunately for him, there was no response from either of the two numbers he dialed. So around half past two (14:30), he came back and requested to make another call as the previous two did not go through. He was met with a blatant “No, you have already made the two calls you are entitled to in a day.” He got angry, grabbed the house phone, and smashed it. The police were called, and the incident was reported to the office.

I must say I was amazed when upon investigation the office found no issue with the conduct of the staff, and instead the individual involved in the incident was suspended from using the house phone for one month. In as much as I do not condone the violent behavior of this individual, I was and still am of the view that if this staff had exercised a little discretion and allowed this individual to make his phone call, the whole incident could have been avoided. This was a postpaid phone, so no additional charge was going to accrue or nothing untoward was going to happen if he had been allowed to make the call.

What I was told after this incident was that once you allow one individual in the group home to perform an activity that is not sanctioned by their care plan, all the others will like to do the same and it will be difficult to maintain any form of order in the house. In general terms, this sounds like a reasonable explanation, but it also explains how restricting care plans and their implementation can be based on how and who is implementing them.

There are several staff who are very comfortable implementing the various care plans to the latter and do not share the idea of using one’s discretion in certain circumstances. But in most instances, it is impossible to meet the needs of the people I support without going against the rules of the agency I work for or drawing a complaint from a colleague staff. The truth is, I do share most of the concerns and frustrations of the people I support, so I try to meet them halfway without overly disregarding the rules set out by the agency. That to me is the best way I believe I can keep my job and continue to support these people to the best of my ability. Hopefully, one day when we have persons with disabilities running home care services, they will better appreciate the needs of people in care homes and provide more flexible rules to meet their ever-changing needs.

While a slight deviation from the rules may be viewed as a policy implementation failure, I still hold the view that some amount of discretion and flexibility ought to be exercised from time to time because most people in care homes are fully grown adults and the policy itself sets out to ensure that these individuals have some level of independence while receiving care.

6.1.3 Challenges and personal experiences as a support worker

Home support work can be very easy and routine. Most of the people I support are very reasonable. They know their care plan and so even if they are not entirely pleased with a decision, they comply to a large extent which makes it easy to work with them. Also, the home environment and having no supervisor around most of the time makes it more relaxing.

In some homes, the people we support can do practically everything for themselves except maybe going to the basement to do laundry or going out on their own. So, there are days I go to work and do practically nothing except stay around in case something comes up. Sometimes to kill the boredom, we just watch a television show, hockey game, or just go out for a stroll around the neighborhood.

But the job can be very challenging at times, not all days are smooth and incident-free. I have been attacked both physically and verbally, I have been racially abused and in some few cases the police had to be involved. Some of these experiences will be shared in a lot more detail in the pages to follow. But the positives certainly outweigh the negatives. Several people are genuinely appreciative of the support I and other support workers offer them and like any other job it feels good to be appreciated.

We indeed get paid for the job we do but home support work is not for everybody. We see people at their best and their worst moments. Sometimes we are required to provide support for people a few moments after they have physically or verbally abused us. It takes a lot of professionalism and self-control to do that and so sometimes I think we do not get all the credit we deserve. Some do not even see support work as a profession because no special training or certification is required. But on the field, the job takes a lot out of you and sometimes you need to dig deep and be at your best to keep up with the demands of the job.

I have had the privilege of working in individual homes, group homes, and personal care homes. But most of my experiences and memorable moments shared in this study occurred in the group homes as this is where I worked the most. The number of participants ranged from two to ten and the number of staff assigned for each home is usually based on the assessed needs of the individuals receiving care.

What I observed working in these three settings is that people in individual homes seem to have a bit more control over their care and how service is delivered compared to those in group and personal care homes. It is somehow understandable if people do not have much autonomy in personal care homes because practices in such long-term care facilities have been criticized by many disability rights activists over the years. I, however, expected better in the group homes but they are run not too differently from the personal care homes, especially those that have three or more participants in one home.

The level of impairment of the people I support varies greatly, from those who can practically do everything for themselves to those who need help with very basic tasks. It is the same with age and gender; I have supported individuals both male and female as young as twelve and elderly people in their sixties and seventies.

There are three main shifts in almost all the agencies I have worked for. Morning shifts start from 7am-3pm or 8am-4pm, evening shifts 3pm-11pm or 4pm to 12am and overnight shifts from 11pm to 7am or 12am to 8am. Staff attending morning and evening shifts have two main responsibilities which are meal preparation and administering medication. All other duties such as attending medical appointments and other outings are done as and when needed. There are some homes, however, where the participants can cook their meals and also need no help taking their medication. In such homes, staff have very little to do and are usually there just in case there is an emergency.

The overnight staff is responsible for cleaning, taking out the garbage, and doing laundry if any. In most instances, these chores can be completed within an hour or two and the staff just occasionally checks on the residents to make sure they are okay until the shift is over. Sometimes as an overnight staff you make no contact with the residents as most of them go to bed before 11 pm and by 7 am when the shift is over, they may still be in bed. I recall working several overnight shifts and making no contact with the residents.

In most group homes, staff may cook and eat with the residents. As discussed above, most support workers are scheduled for eight-hour shifts. Some shifts even go beyond eight hours. I have been working twelve hours every Saturday for close to two years. During this shift, I often eat my breakfast, lunch, and dinner all at work as the shift begins at 7 am and ends at 7 pm. Some agencies knowing this permit their support staff to also eat whatever meal they prepare for the participants while on shift if they wish. The only condition is that we are supposed to eat the same meal we serve the participants. The idea is to avoid a situation where participants are complaining that staff serves themselves better food than what they serve the participants.

This arrangement comes in handy, especially when working longer shifts like my twelve hours shift on Saturdays. Additionally, most persons with disability have either been treated or made to feel inferior by society and sometimes their support staff sharing the same meal helps some participants to feel better about themselves.

There are home care participants in group homes who have been labeled as difficult by staff when it comes to taking them out into the community. These are usually individuals with mobility issues who need assistance to get around public places. Others have the tendency to cause a scene in public if they are upset over something. Most regular staff trying to avoid this responsibility often try to pass it on to new staff. In their minds they have worked in the home long enough, so they have earned the right to take on the easier responsibilities and pass on the more challenging ones to the newly recruited staff.

I recall in my early days as a support worker I was made to take a participant to the shopping mall. Usually, I was told it is the responsibility of the staff working my shift to take him out. This individual is deaf and has cerebral palsy, so he uses a wheelchair to get around. He does not like to be hurried as it takes him a bit longer to get things done and loves to do things on his own. This was unknown to me at the time so I tried to signal him that my shift was almost over so we should return. He freaked out at the mall and jumped out of his wheelchair. I was static for close to two minutes as I had no idea how to deal with the situation. After creating a bit of a scene, he calmed down and we came back to the group home.

Later I came to realize anyone can take him out regardless of the shift you are assigned and that the other staff anticipating the possibility of an accident was merely trying to avoid the responsibility. When there is no one to pass on the responsibility to, they come up with all sorts of excuses. But the truth is, these incidents mostly occur when the staff is new and does not have much knowledge of working with the participants. Ideally, it is the older and more experienced staff who are supposed to take on these duties. But most of them do all they can to pass on this responsibility to new staff some of whom may not have even been trained to work with the participants in that home.

Working alone in a home you have not previously been trained can be very challenging**.** There were a couple of times when I had to work alone in a group home where I had not been trained. It is always difficult because you don’t know what to expect. My agency will normally say ‘we know you have not trained there but we cannot find anyone else’. In their minds, it is the same services; cooking, cleaning and administering medication so it does not matter whether you have been trained in that home or not. At the time, I needed the money badly for my tuition fees and other expenses, so I did not ask too many questions and just obliged. But every support worker will tell you that every home comes with its unique challenges; if you have no one to give you a heads up on certain ‘dos and don’ts’ of the home, things can go so wrong during the shift.

Some of these things may seem very minor and insignificant to a layperson, but in the field these minor things can result in escalations and incidents. I recall a resident whose only brother died after taking an overdose of his prescribed pills. This individual has no problem taking his medication, but if a staff unknowingly or mistakenly mentions the word ‘pills,’ he will not take his medication for close to a week because, in his mind, pills will kill him just like they did to his brother. These are some of the tiny details that can turn a regular shift into an absolute nightmare if the staff is scheduled to work in a home for which he/she has not been trained and has no knowledge of the residents. This probably explains why most participants in care homes prefer working with the same staff to the extent that some are very hostile when a new staff shows up.

That probably explains why some residents +will often wait for particular staff to arrive to perform a certain chore for them**.** From my experience, most home care residents are used to certain routines. For instance, I used to work a 4 pm to 12 am shift in a group home on Sundays and there was one participant who would always wait for me to arrive to do his laundry and take him out shopping if he wanted to go out. Initially, my thinking was that probably the staff working the morning shifts were unwilling to perform these tasks, but that was not the case.

For him, that was his expression of appreciation for my services. He would not let anyone do it for him when I am around. So, it is common to walk into a group home as a new staff and be told the participants do not welcome new staff too well. Some will not even allow you to support them in the early days of being assigned to the home. You must work a couple of shifts before the participants get used to you. That is what makes it very challenging when you are asked to work alone in a home that you have not previously been to.

In my journey as a support worker, I have encountered issues relating to standards and quality of care in the delivery of home care services. Residents in care homes usually blame the staff when services do not meet their expectations. The staff also blame the agency that hired them for not providing them with the right resources and incentives to enable them to deliver better quality services. Agencies also believe both the federal and provincial governments are not allocating enough funds for health care delivery hence their inability to provide high-quality home care services to their residents.

The regional health authority having an oversight responsibility has a standards team that visits care homes from time to time to ensure that care homes in the province meet certain set standards. These visits notwithstanding, there are still care homes that do not meet all the set standards. Shortcomings range from structural deficits to staff shortages.

Currently, when officials from the regional health authority responsible for licensing are visiting a particular home, they notify the agency well ahead of time. I recall being told by my house manager a couple of times to help with some additional cleaning and housekeeping service because our house was due for inspection. This does not happen in just one group home or one agency. So, by the time the inspection takes place, the house is perfectly clean, and every other thing is put in place to meet the licensing requirements.

I believe a different picture would be seen if some of these visits were unannounced. I am not by any means implying that the group homes that I have been privileged to work in are dirty, but even as a layman, it is obvious that some of them do not meet the licensing requirements. For instance, I work in a home with two wheelchair users and one other participant who uses a walker, and yet the walkways are so narrow that even a single wheelchair can barely fit. There is also just one bathroom with just one toilet for all three participants and the two staff on duty during the day shifts. Surprisingly, I have been working in this home for years and have yet to see a licensing team visit this location. My best guess is that the owners of home care agencies probably have a way of steering the licensing team away from the homes that do not meet the licensing standards, or perhaps the licensing team is a bit lenient on some of these agencies.

On several occasions, I have worked alone in homes where licensing regulations require two staff to be on duty at all times. When I call the office, I am told they are trying to find another staff member to come work with me. Sometimes they succeed but other times they do not. Even when they succeed in finding a second staff, it takes several hours before someone arrives. When they do not find any staff, I work the entire shift alone. Many of my colleague workers have also complained about having to deal with similar situations a couple of times.

If anything, the agency saves money when this happens because I basically perform tasks meant for two staff and yet my hourly pay for the shift remains the same. All I get is an apology and a thank you. The same thing happens when staff turns up late for a shift. The staff coming in late is short paid, but the staff on duty gets no additional money.

Ideally, home support workers are required to wait until another staff arrives to take over the shift. But there are instances where for example only one staff is required for an overnight shift and two for the day shift. In that case, when the first staff arrives during the day, the overnight staff is free to leave. And when no one else shows up, then the day staff is on their own though the shift is meant for two staff.

In such instances, aside from the staff on duty not being compensated for being made to do work meant for two staff, it is also against licensing rules for the participants to be assigned just one staff during the day. These determinations are often based on health and safety concerns for both staff and the participants. Several incidents have occurred simply because the right number of staff were not on shift at the time of the incident. The latest I recall was a resident who got upset and smashed a few things in his room because he called for support, and no one showed up on time. Two staff were supposed to be on duty but there was only one present at the time. The staff claimed he was assisting the other resident to get ready for his day program and so could not attend to the other resident at that moment.

Incident reports are written when these events occur but whether they get into the hands of the appropriate authority for the right actions to be taken remains unknown. Some of these reports expose the inadequacies in the delivery of home care services. In doing so, I believe they also expose the agencies pointing out some of the things that are not right including structural deficits, problems with scheduling, and staff training among others. That is why I will not be surprised if none of these reports get to the authorities who can effect some changes by sanctioning agencies whose operations do not meet the licensing requirements.

For the supervisory bodies like the regional health authorities, I believe an alternative and a more effective way to monitor care homes and to ensure that home care agencies are delivering on their mandate is to have CCTV cameras in most care homes if not all and review them from time to time in addition to their routine inspections.

We are all constantly under surveillance by traffic cameras, security cameras at shopping malls and other public buildings, and even our mobile phones. I have worked in a group home where there were security cameras in the walkways and the entrance of the building. But this was an exception as it is not common practice to see security cameras in group homes. I believe this is due to privacy concerns or perhaps agencies do not see the need to have their homes under constant surveillance. But as a support worker, based on the number of incidents I have witnessed and how some of these incidents were reported and, in some cases, not reported, I believe having security cameras installed in care homes would benefit both home support staff and the participants in care homes.

I recall attending a shift and the staff handing over to me was accused by one of the residents of the home of attempting to sell them marijuana. The staff claimed the participant was doing something that is not sanctioned in the house and when he asked him to stop, he came up with that allegation. It got tense and the cops came over to the home. Each of them said their side of the story. There were two residents and one staff. Unfortunately, the second resident could not collaborate on any side of the story as he was mentally unstable. In the end, the police did not have enough evidence to conduct a conclusive investigation as it was the word of the participant against that of the staff. Unfortunately for the participant, he had been arrested a couple of times for various offenses, so no weight was placed on his accusation. At the end of his shift, the staff wrote his log and an incident report obviously in a way that exonerates him from any wrongdoing.

Going home that day, I kept asking myself why this participant would come up with this accusation if there was no truth to it. And of all the things he could have accused him of, why that accusation? From their body language, I am pretty sure the cops had similar thoughts, but they had evidence to collaborate on any side of the story. Up to date, no one knows what transpired that day except the two of them.

There was another instance where a resident claimed he was pushed off his wheelchair in an altercation with his support staff. Though an incident report was written, it did not make any mention of the resident being pushed off his wheelchair. It was in a conversation with his case worker that he mentioned that he feels a bit dizzy at times due to the fall. Several attempts were made to get to the bottom of the issue but once more, it was the word of the staff against that of the participant. In this case, there was a second staff on shift and two other participants, but they all claimed they did not witness the incident and so cannot collaborate on any side of the story. This incident according to the supposed victim occurred in the living room.

I am certain that in both incidents if there were security cameras installed, we would have known what transpired. One interesting thing about having CCTV cameras at work is its ability to prevent incidents from occurring while encouraging others to work harder knowing they are being watched. For instance, it is common to see home care staff use their phones regularly while at work especially when there is no supervisor around. This is because there is a lot of downtime in the delivery of home care services. However, in the only group home I worked where these cameras were installed, staff were very careful with the use of their phones and concentrated more on carrying out their support duties.

I worry that several participants in care homes cannot speak out the way the individuals discussed above did. Even if they can, their views are not deemed credible either due to their medical condition or past criminal record. From my experience, several incidents either go unreported or are not reported accurately in care homes especially if the staff is complicit or at fault in a way. For example, medication errors often come with serious consequences as they can have an inimical effect on the health of people in care homes, some of whom already have precarious medical conditions. So, when these errors occur, they are to be reported immediately to both the pharmacy and the clinical case worker for the necessary action to be taken to remedy the situation. But for the staff, part of the consequence could mean suspension or even termination based on the number of times the error has occurred. So, if the incident is not life-threatening and cannot be easily noticed by the house supervisor, it may not be reported at all.

For instance, a missed medication may be disposed of and signed off on the medication records as though it was administered. Similarly, if a staff administers medication to the wrong participant, they may choose not to report it to save themselves the consequences that may follow. A missed medication or administering medication to the wrong person may not have any serious immediate effect on them. It is therefore hard if not impossible for anyone to notice if not reported.

For staff who have regular shifts such as full-time and part-time employees, these incidents do not happen often. It is usually the casual staff who move from one care home to another who have difficulty remembering the residents and their medication. I recall taking over a shift from a casual staff and the log he wrote for resident ‘A’ was actually for resident ‘B’ and vice versa. The good thing was that he worked an overnight shift, so he was not required to administer any medication. I am pretty sure he would have made the same mistake with the medication. Some agencies have gone the extra mile to put the pictures of each resident in their medication binder to make it easy for staff to administer medication to the right residents.

Items have also gone missing in care homes. Laundry soap, flour for baking and even meat meant for the participants of group homes have been reported missing in some of the homes that I have worked in. Whoever is engaged in this act, once they become aware people have noticed items getting missing from the home, they put an end to it, and no one ever gets caught. It becomes so uncomfortable working in such homes as everyone becomes a suspect from there on.

I am pretty sure some of these incidents and more could have been captured and the perpetrators found and dealt with if these homes had security cameras installed. Better still, some of the incidents could have been prevented altogether if both participants and staff knew they were being filmed.

I have also tried to understand what goes into the pairing of participants in group homes. There does not seem to be any specific procedure. Most agencies use their discretion and usually place people based on the availability of space in their respective homes. I have seen male and female residents paired together in a home, young and old residents as well as severely impaired and those with minimal impairment.

It looks like most agencies try to have a good balance in terms of spreading residents with severe impairments across all their group homes. The idea is that those with severe impairment require more support so putting them in the same home will mean a very heavy workload for the staff working in such homes. I recall a staff telling me during one of my training schedules about the homes I should avoid when I am picking up shifts as in his view there is always too much to do in those homes.

It is not only staff who try to avoid certain homes. Sometimes the residents themselves do not want to be in the same home with some of their home mates. Some have complained of their mates stealing their belongings, making too much mess, doing drugs at the home, and other upsetting behaviour. Sometimes these are not mere complaints. There are records of these incidents occurring multiple times. In one of the group homes, a 65-year-old resident who has been physically attacked a couple of times by another much younger resident has been asking for years to be relocated to another home but to no avail.

Finding a group home that meets all the licensing requirements can be difficult at times. It is probably the reason why most agencies do not head to the complaints of their participants to move them to other locations. There are even some neighborhoods that do not want group homes located around their area. I recall a group of homeowners collecting signatures to have a care home moved from their area because the participant was quite loud when he is having an episode and also had a record of violence and walking out naked in broad daylight. They cited disturbance of their peace and fear for their safety and that of their family members. It took a while, but the participant was eventually moved to another location.

Accessibility is another challenge I have identified in my role as a support worker**.** It is quite ironic that there are a lot of issues with accessibility in many care homes where I have worked. One will have thought that a field that supports people with impairments would make accessibility their number one priority. But that does not seem to be the case. I have made the point that if most care homes were accessible, some of the participants may not need any support services. It ranges from items placed at heights that they cannot reach, ramps at various entrances in the home, stairs to and from the basement where their laundry is done and medication is kept and beds and toilet seats that are either high or low such that they need support to get on and off.

For example, in one of the homes where I have been working for close to four years, even though two out of the three people at the home are wheelchair users, there are bumps at the entrance of the kitchen as well as the bathroom. The third resident also uses a walker to get around the home, but it seems both the agency and the homeowner see nothing wrong with these bumps at the entrances. Even the steepness of the ramp at the entrance of the building is such that without a push it is nearly impossible to enter with a wheelchair.

At the same location, exit through the back door is almost impossible for the participants in case of an emergency. There are two stairs from the kitchen to the exit door and then a big ramp at the exit that is nearly impossible to exit with a wheelchair without tumbling and falling off. There are several such accessibility issues in many of the care homes I have come across and the worst part is that it does not even seem to be an issue the agencies are looking to address.

Another observation I have made as a support worker is the limited access to progressive staff training and a chance to grow and rise through the ranks on the job**.** Home support work may be an entry-level job, but you would be amazed by the qualification of some of the people working in this field. One of the team leaders once jokingly said, “We can have a whole department in this home as we have engineers, scientists, historians, et cetera.” The problem is that most of these certificates acquired abroad cannot be used to practice here in Canada so people either start from scratch or take some top-up courses to be able to practice in their fields of study. During this transition period, bills and other expenses still need to be paid, so people, especially immigrants, look for a job that requires no previous experience and accepts very minimum qualifications. Home support work is one such job that offers a haven for immigrants.

As mentioned earlier in this study, the only certificate required is a first aid and CPR certificate. This can be acquired in a day within eight hours. That aside, there are all kinds of shifts 24 hours a day even on holidays which makes it easy to work even if one has other engagements like schooling, family responsibilities, or a second job. I have met people who were professional teachers, nurses, lecturers, engineers, pharmacists, and others from their respective countries all working as support workers here in Winnipeg. While some were pursuing courses to hopefully get back to their original profession, others had no such plans and seemed content with their role as support workers. In a conversation with some of these individuals, they mentioned age, finance, and other family responsibilities as some of the reasons why they have no intentions of going back to school.

Some have been working for ten years as support workers. There does not seem to be any clear path of progression in the field. A few ambitious ones rise through the ranks from support worker to team lead, to residential operations manager, to the manager of operations, and even director of operations. But these are very rare. Personally, as a student of Disability Studies working as a support worker, if there was any clear path to rise through the ranks, I would have followed it. But there is no training or courses available that would qualify you to move from say support worker to team lead or home manager. You have to wait and hope an opportunity pops up. And when it does, there is no guarantee that you will be selected as it is not based on longevity of service or any form of progressive training on the job or certification.

Usually, when such positions are advertised, it only says that experience working with persons with disability is a bonus. Over 90% of the staff I have interacted with in care homes have at least a high school education or better. I believe if a path is created where they can improve upon their knowledge and skills as support workers, they can perform a very crucial role in reducing the pressure on the mainstream health care delivery system. Some can rise through the ranks to become senior medical officers and those who choose to stay in the field would be better trained and prepared to support residents with complex care needs.

Probably there is the fear of mass exodus from the field one’s people receive additional training and some form of certification. This can create staff shortages a problem home care agencies have been grappling with for years. There may also be concerns about wage increase as all trained and skilled professionals often demand payments that correspond to their skill set.

Home support work is not a well-paying job. That probably explains why the job is easy to get as most people move on once they get a better-paying job. As of 2017 when I started working as a support worker, my agency was paying minimum wage. What is worrying is that the salaries of direct support workers are not properly structured. Depending on the agency you are working for and your status as either a casual, part-time, or permanent staff, you can earn as low as $12 per hour or as much as $22 per hour. As long as agencies are not paying below the minimum wage, they are not breaking any laws. And so, the for-profit home care agencies mostly pay just a little above the minimum wage.

I will be the first to admit that home support work is not the most difficult of jobs, but it also definitely does not deserve minimum wage payment. There are several downtimes when the residents are either sleeping, watching television, or even going out to visit their family and friends. Even on busy days at work, the home environment still makes the work more relaxing compared to other fast-paced work environments such as working in a factory or a grocery store. But having said that, we do support people with very complex care needs such that a single mistake may lead to a life-threatening situation or may even cost them their lives. There are participants in care homes who are epileptic and when they are having an episode and do not receive proper support may choke on their puke or fall and get seriously hurt. Others are on various forms of life support, and they need the help of staff to keep their equipment functioning else there may be serious consequences. Such a job I believe is deserving a respectable salary, not minimum wage.

I have seen support workers come and go. Some move from one agency to another while others join a new line of employment. Many of these individuals made very good connections with the home care residents and seemed to love their job. Even years after their departure, some still call or even visit to say hi to the people they use to support. Yet they had families to feed and bills to pay so they had to move on to better-paying jobs.

The current wage structure for home support workers across several agencies except for a few is such that it is almost impossible to survive working just one job. It is no surprise that most support staff work multiple jobs to be able to meet their financial needs. I recall working for three different agencies simultaneously during the summer of 2019-2020 to be able to raise enough money to pay for my tuition fees and other personal expenses.

This wears you down, stresses you out, and makes it difficult to give a hundred percent in each of the jobs. Lateness, fatigue, and mistakes become very common and sometimes inevitable. For instance, I use to work overnight shifts that ended at 7 am, and yet I was supposed to start a morning shift in another home at the same time. I was always in a rush, I hardly had time to go home and freshen up and have a good meal. Arriving at shifts late and making simple mistakes was becoming a norm and yet it was the only way I could keep up with my expenses at the time.

Luckily for me, this was temporary. My continuing fees as a student were not that much so I no longer had to keep three jobs to meet my expenses. But one thing I realized during this period was that moving from one shift straight to another is very common with home support workers. I recall working an overnight shift and, in the morning, it was ten minutes past the end of my shift, so I called the office to ask who was supposed to take over from me. I was told to always wait for at least fifteen to thirty minutes before calling as most staff drive straight from their overnight shifts to take over morning shifts. So, it seems to be a practice that is known and accommodated in the delivery of home care services. All you have to do is call the home and let them know you are running a few minutes late. It all comes down to salaries paid to home support workers that are simply not enough to meet their basic needs, hence the need to work multiple jobs to make ends meet.

Transportation is one area that posed a lot of challenges to me from my job search to the time I started working as a support worker. Most people in care homes have mobility issues and require various forms of transportation to get around the city. Some agencies do a good job of providing vans for their homes to transport the participants to and from appointments and other activities. During hiring, such agencies ensure that all prospective employees have a valid driver's license so they can operate the company's van if they must. Others liaise with Winnipeg Transit Plus and taxi operators to facilitate transportation for their residents.

Unfortunately for me, at the time of entering Canada, not only did I not have a valid driver's license, but I had also never driven in my entire life. There were several jobs that I could not apply to because a valid class 5 full license and a reliable vehicle were requirements for the positions advertised. After I became a support worker, I came to understand why some agencies made these conditions a prerequisite for hiring. Some agencies rely on the vehicles of their employees. They pay the staff mileage when they transport the residents in the group home to and from appointments and run other errands for the home.

That aside, most agencies rely heavily on a casual pool of staff who normally can pick up and drop shifts as they wish. There are instances where staff is needed to fill up shifts in the middle of the night. In such instances, the job of the on-call supervisor is a bit less difficult if the staff have their means of transportation, especially during winter. Also, because some residents in group homes have a record of either being too loud or violent, some agencies look for homes on the outskirt of the city where there are few settlements in order not to draw too many complaints from the other neighbors. Sometimes there are no bus services to such locations, so it becomes difficult for staff to work in such homes if they do not have their own means of transportation.

The common complaint of most staff using their private vehicles to transport participants in group homes is that, apart from the mileage that is paid by the agency, if the staff gets a speeding ticket or parking ticket or even gets into an accident, the agency does not reimburse them. So, most staff are very reluctant to use their vehicles while on duty unless they have no other option given the circumstance.

One thing that is not common in the delivery of home care services in Winnipeg is a survey of staff and residents in care homes about their thoughts regarding the program and its implementation. It is common practice here in Canada to have customers fill out a survey on their level of satisfaction with the services they receive. From grocery stores, online shops, and even government agencies, customers are constantly asked to share their views on services they receive and what can be done to improve the service if any. I always look up the reviews on certain services if I want to try them for the first time. The views of other customers largely inform my decision to either go in for the service or look for an alternative.

In the delivery of home care services, however, staff and participants in group homes do not get to share their views on the performance of their employers and the quality of services delivered. When I used to work in a grocery store, customers especially aggrieved ones constantly sent in reviews and expressed their dissatisfaction. Based on the gravity of the issue, either the department concerned, or the store manager would take steps to address the issue. I believe if participants in care homes were empowered to publicly share their views on service quality, most agencies and their employees will be on their toes and improve upon their services.

The moral model of disability may not be popular in Canada, but it does occasionally show its face in the delivery of home care services. In my years of service as a support worker, I have come to realize that the way people perceive disability affects the way they relate to people with impairments. It may be right to disregard the moral model of disability in the Canadian context as religious beliefs do not inform the decision-making process both at federal and provincial levels of government. Even among the populace, especially those born and raised in Canada, not many believe in that line of thinking.

But as discussed earlier, direct support work is dominated by immigrants. Home care agencies are almost constantly hiring direct support workers and the minimal entry requirements makes it easy for immigrants, most of whom do not have any Canadian work experience to find themselves a job. Some of these immigrants like me are from countries that can best be described as religious states. My country is democratic, governed by an elected head of state, and yet almost every aspect of life is influenced or shaped in one way or the other by religion. From the head of state to the ordinary man on the street, everyone is religious in some shape or form.

For instance, as recently as 2021, an anti-gay bill was sent to the legislative house in my country (Ghana). The proposed bill could see LGBTQ community members imprisoned for between five to ten years for identifying or advocating for their rights. This bill is influenced by both Christian and Islamic beliefs which frown upon same-sex marriage. Despite the fierce opposition between the two main parties in the country, they seem to agree on this bill, and it is only a matter of time before the bill passes. That aside, the current president of the country is a lawyer who had most of his education in England, and yet he has publicly stated that same-sex marriage will not be legalized during his tenure as president.

This gives you an idea of how deep-rooted religious beliefs inform the decision-making not just in my country but in several parts of Africa and indeed several other countries across the globe. Interestingly, a study conducted by Crabtree (2010) and published by Gallup, a global analytics and advice firm that helps leaders and organizations solve their most pressing problems, found that most religious countries are relatively poor. People from such countries often migrate to other countries to seek a better quality of life. Canada is home to many such people. In 2021 alone, the Minister of Immigration, Refugees, and Citizenship, Honourable Sean Fraser, in a news release announced that Canada welcomed over 401,000 new permanent residents which were the most newcomers in a year in Canadian history (Immigration, Refugees and citizenship Canada 2021).

People indeed try to adapt when they get into a new environment, but there are certain cultural values and beliefs that people do not give up easily. Religion is one of those. So, it may be a mistake to entirely disregard the moral model of disability in Canada in the context of the delivery of home care services.

Personally, when I found a job as a support worker here in Winnipeg, at the initial stages I rejected several shifts especially on Sundays because they coincided with my church schedule. Later my agency adjusted my schedule on Sundays, so I attended my shifts right after church. At the time I needed money badly for my tuition fees, my bills, and to take care of my wife who was a few months pregnant and yet I did put religion first.

I was just a member of the church and yet this was my mindset, so you can imagine the thinking of pastors and other leaders of the church. We are taught to put God first before any other thing, and most religious people do or at least try to.

It is, therefore, logical to think that when it comes to the issue of disabled people who are religious, understand it the way their religion perceives it. Before coming to Canada, I had encounters with persons with disability in my family, at elementary school, and as a teacher at a high school in Ghana. In all these instances I was guided by my religious teachings to help and support people in need and to be empathetic towards their course. Here in Canada, I was getting paid for the job I was doing but I genuinely had the desire to help others. Despite my religious belief at the time, I never believed that the people I was providing care for were in that situation because of wrongdoing by either themselves or their ancestors. This was perhaps because of my previous experiences with persons with disabilities.

But not all support workers have this experience and so may perceive disability purely based along religious lines or any other ideology that they believe in. I have worked with Muslim friends who excused me a couple of times to either go and pray or break their fast during Ramadan.

I do not recall religion interfering with my service delivery or my relationship with the people I support aside from refusing shifts that clashed with my church schedule. But there have been instances where I have personally witnessed religion interfere with the delivery of care. I recall one instance where a participant was having an episode and one of the staff on duty who was a Muslim will not interrupt his prayer to come and help support this individual to prevent him from hurting himself or the other staff on duty. Another staff due to his religious belief will not cook or serve certain meals even if that is what is on the menu.

The question I ask myself is if the person receiving care does, says, and believes in things that the care provider's religion frowns upon, what is the relationship between them going to be like? Can support workers be professional enough to shelve their religious sentiments and deliver the best possible care to their residents irrespective of their religious and ideological differences? These I believe are legitimate questions and answers to which I do not know. What I know is that I have personally sat in a church building here in Winnipeg with several other support workers where practices and behavior very common to most Canadian communities have been preached against and referred to as sinful and evil. I am referring to common practices like smoking, alcohol intake, having a tattoo, ladies wearing short pants, being in a romantic relationship with someone you are not legally married to, nose piercing, and men wearing earrings among others.

I find it somehow irreconcilable to believe in such teachings and not be judgemental of the people around us who engage in those acts and practices. But as it is now, there are no complaints either at the agency or provincial level about people's religious beliefs interfering with their work as support workers.

But the mere fact that the issue is not topical does not necessarily mean it does not exist. We should remember that some people in group homes can neither verbalize nor write their frustration and dissatisfaction with the services they receive, or some bad treatment meted out to them by their support staff. At the very least I believe people should be asked during hiring interviews if their religious beliefs will in any way interfere with their job as support workers and be monitored during their probation period to ensure that they have no difficulty supporting the individuals in the group home irrespective of the difference of thought and ideology they may have.

Another thing that I believe can help to ensure that persons with disabilities enjoy services that meet their needs under the home care program is having people with disabilities or knowledgeable in disability-related issues run home care agencies and services. As discussed under the earlier topic in this study, most home care agencies across Canada today are for-profit. From the hiring of staff to the delivery of home care services, the primary objective is to maximize profit. This is often reflected in the quality of service they deliver. Aside from their profit motives, some owners of home care agencies seem to have very limited knowledge of disability and disability-related issues.

I recall walking into the office of one of the agencies I used to work for to pick up my pay cheque and I was having a conversation with the owner of the agency about an incident that occurred at the group home I was just coming from. The words probably slipped out of her mouth, but she categorically stated that she cannot work in such an environment. Probably realizing that she should not have said that to someone working on the field was quick to add, “This is why I appreciate you guys working on the ground so much.”

From my previous conversations with this individual, she has no history of working with people with disabilities. She had connections with a couple of people who were running home care agencies in the province. All she had to do was to get an office and recruit people as backup staff for these agencies. She gets paid by these agencies for the hours covered by her employees and she, in turn, pays her employees a percentage of the money. After settling her office expenses, every remaining amount becomes her profit for the pay period.

For such an employer, the more hours she gets her employees working, the more money she makes. The main objective, therefore, is to get his staff working as many hours as possible. The suitability of the staff for the job, working conditions for the staff, and the expectations of the people in the various care homes are the least of her worries. I recall one time a new staff was supposed to take over a shift from me and despite the agency providing support staff for the said home for close to two years, the manager had no idea which part of the city the home was located in. The staff was new to Canada and did not know how to get there so the manager called me to direct him to the said location.

I recall many more stories which prove that most people running home care agencies are in the business for the money and care very little about the welfare of people with disabilities in care homes and their support staff. It could also be the case that they just lack the understanding of disability and what people with impairments desire in care homes.

To a layperson, every individual in a care home is suffering from one illness or another. The medical model of disability is largely responsible for this way of thinking. The objective, therefore, is to provide a cure or some form of rehabilitation. It is little wonder therefore that in almost all group homes the most important thing is the participant’s medication, medical appointments, and other medical-related procedures. All other things like accessibility, their social lives, and personal preferences are all secondary.

For instance, I recall a 65-year-old man in a group home who was diagnosed with colon cancer. His treatment required that he takes medication to empty his bowels when he was due for his appointment. The purgative administered to him was such that he gets several accidents as he does not see the stool coming. Despite the numerous complaints he made about his dislike for the procedure, it still went on until the doctors were satisfied that his condition was under control.

Perhaps if home care services were run and controlled by persons with disabilities, they would have a better appreciation of what people with impairments desire at different stages of their disability.

At the early stages of impairment, it is normal for people to seek a cure, especially for those who become impaired in the course of their lives. The general expectation usually is to get back to their normal functioning. But after years of hospitalization, medicalization, and rehabilitation, most people give up and begin to accept their new reality.

The truth is, despite the desire and attempts by proponents of the medical model to find a cure to almost every illness, several medical conditions still have no cure. This is a fact that most people in the medical field do not want to accept so they continue to experiment in the hope of finding a cure to every known impairment.

In a conversation with one of the people I support, he told me he has been taking the same medication for close to seven years and has seen no improvement in his condition. Yet when he tells his case worker, he wants to get off the medication, he is told his condition will deteriorate if he stops taking the medication.

Not everyone complains about the situation in care homes but sometimes when I work with them, their gestures, facial expression, and body language give me a fair idea of how they feel about the services they receive and the things they are either prevented from doing or made to do in the care home.

For some of them, after years of complaining and not seeing any changes, they take matters into their own hands and begin to go against some of the rules that they deem inconvenient. For example, for some participants in care homes, the only way to administer their medication is to mix it with their food or drink as they constantly refuse their medication. Others refuse their medication so frequently that their case workers tell staff not to write an accident report when they refuse their medication because it seems to have become a norm. Some also fail to attend their day program and other arranged outings all as a show of their dislike for the activity.

As a support worker, these acts of resistance simply tell me that some participants in care homes are not satisfied with their care plan and the services they receive. From my experience, the biggest area of resentment usually has to do with medication, medical appointments, and rehabilitation programs. As mentioned earlier, after years of experimenting with several medical procedures and seeing no improvement in their medical condition most participants prefer to move on with their lives embracing their new reality.

I am positive that if home care agencies were run by persons living with disabilities, they would most likely better understand the needs of people with impairments. This would make our work as support workers easier as we would no longer be required to implement care plans that participants object to.

Sometimes it is very difficult to implement certain decisions made by the agencies I work for as a student of Disability Studies. I understand that people should not be discriminated against or treated differently because they have a disability. But total disregard for the rules is not an option and strict implementation brings about a lot of resentment and sometimes resistance from the people I support. The dilemma of trying to satisfy both sides is perhaps the most challenging part of my job as a support worker. Hopefully, one day when home care policies are formulated, implemented and supervised by persons with disabilities, I will no longer have such difficulty trying to find a balance between meeting the needs of the people I support and implementing rules set out by the home care agencies I work for. I am convinced disabled people would better appreciate the needs of people in care homes and would not force on them care plans and rules that they resent.

6.2: Home care culture in Winnipeg

The culture of an institution can be defined as institutional policies, practices, beliefs, and traditions affecting the careers and lives of faculty, staff, administration, and students (Bingham & Nix, 2010). Every institution or program has its methods or processes of carrying out its duties daily. This can be referred to as the culture of the institution. In simple terms, a particular set of rules and norms that govern an organization. In most group homes in Winnipeg, there seems to be a certain pattern in the delivery of home care services. This is what I refer to as the home care culture in Winnipeg. From one agency to another, there are slight differences in the methods employed to deliver home care services, but there are several practices that seem to cut across almost all the agencies in Winnipeg, some of which are discussed below. Some of the points may have already been touched on as part of my experiences as a support worker.

6.2.1: Pairing of people in care homes

The needs of home care residents are classified into three levels. Level one is low-level residents who require very limited assistance with activities of daily living. Most of them are almost independent except for a few chores that they cannot perform on their own. Level two is intermediate and they require a bit more support with their daily activities. Those in level three are classified as needing a high level of care due to their condition. They may need help with bathing, clothing, feeding, etc. This categorization helps to determine the level of care, the type of staff required, and the equipment needed to carry out care.

Most residents in levels one and two can be adequately supported by home support workers. It is those in level three that require the services of healthcare aids with transfers, bathing, feeding, and other hands-on services which workers have been trained to undertake. Most agencies often pair residents from each of the three levels depending on the number of residents in a home. What they do not do in most instances is hire the right staff according to the level of care required. With WRHA, home support workers are made to perform basic housekeeping services and health care aides take on the hands-on services and are duly paid for that. But most agencies leave all these duties to home support workers who do not have the right training to perform these functions.

There is also the issue of residents who have a history of violence being paired with other residents who are considered 'vulnerable,' putting them in harm's way almost on daily basis. It appears to me that it is less costly to run a group home compared to individual homes. Two staff can be assigned to four residents in a group home whereas if all four residents were living in their separate homes, four staff would be always required. But these pairings do not always work out well for some residents. There are privacy concerns too as they sometimes share the same bathroom, kitchen, dining area, and living room. Yet this seems cost-effective, so most agencies prefer having multiple residents in one home.

6.2.2: More casual employees than full-time staff

According to Mighty Recruiter (2022), an online job recruitment platform, casual employment refers to a situation in which an employee is only guaranteed work when it is needed, and there is no expectation that there will be more work in the future. During periods when the employee is not working for the employer, the two parties have no active relationship, and neither one has any obligation toward the other. This seems to work out well for most agencies, especially the for-profit ones, as it relieves them of a lot of financial responsibilities toward their employees. It is however not ideal for scheduling as casual staff can choose to stay away from work whenever they feel like doing so, resulting in staff shortage. There is also no consistency in the delivery of care as different staff can be assigned at any time. But most agencies in Winnipeg seem to be more concerned about cutting costs, hence their reliance on casual staff.

6.2.3: Transportation

For some agencies, vans are assigned to their houses to transport residents to and from appointments and other outings. Others depend on Winnipeg Transit Plus and taxi. It is usually expensive for residents who rely on a taxi for their outings as their weekly allowances may not be enough to take them on two outings. I am unaware of what entitles a group home to a van or other means of transportation, so I am unable to say what some agencies are not doing right in that direction. But if some are doing it for their residents, I am pretty sure the others can do the same. It is curious as to why in some agencies, just a single resident has a car at their disposal and yet with other agencies there could be as many as four residents living in a house and yet there is no transportation to facilitate their movement. Sometimes they rely on staff to use their private vehicles to transport residents to and from appointments and pay them mileage.

6.2.4: Weekly allowances and other finances

Most people in group homes receive either weekly or monthly allowances through their public trustee for their upkeep. This is different from the monies assigned to the house for groceries and other house supplies. These monies are kept by staff and given to residents when they request to buy something. Sometimes there are disagreements between staff and residents as to how these monies should be used with residents wanting to buy one thing and staff suggesting another. It is only the few who can handle their finances who do not have to deal with such situations. Even with them, if they require assistance with transportation or anything that must be arranged by staff, then their purchases are sometimes subjected to auditing and approval by staff before they can spend their money.

6.2.5: Staff training

Aside from the mandatory first aid and cardiopulmonary resuscitation (CPR) training, for most of the agencies I have worked for when mass recruitment is made, an orientation is held to explain the company’s policies and general rules. Aside from that, the staff is scheduled for at least two training shifts at the house or houses he will be working. At these shifts, the staff is shown around the house and mostly made to observe as the regular staff provides care. Depending on the house, staff may also require Non-Violent Crisis Intervention (NVCI) training if one or more residents in the house have a history of causing harm either to themselves or the staff. With this training, the staff is thought de-escalation techniques as well as restrictive and nonrestrictive interventions. Ideally, staff should not be scheduled to work in such a house until they have received this training, but that is not always the case. I worked in several of such houses for months before I received my training. Almost all the agencies require their staff to take first aid and CPR training every two to three years to refresh their knowledge. Most agencies bear the cost of this training if the staff has been working with them for all that period.

6.2.6: Reliance on incident reports

Agencies rely on reports from their field staff to arrive at decisions regarding care delivery. The field staff is their eyes on the ground and they rely on their feedback to evaluate the effectiveness of the various care plans and possible changes that could be made in the delivery of care. It is not wrong for owners of home care agencies to rely on their field staff for information regarding what transpires in the various homes. What they should realize however is that no one will write a report to indict him/herself. From what I have observed, agencies overly rely on accounts of their field staff in arriving at decisions regarding care planning and the delivery of services without making any effort to verify some of these reports. There are indeed several residents who cannot express themselves verbally or otherwise due to their medical condition, but there are many others who if asked could give a pretty good account of what transpires at the various care homes and what their needs are. Alternatively, home supervisors can pay routine visits to the various homes to get first-hand information as to what transpires on the ground. The problem is, aside from the duties they perform at the office, most home supervisors are assigned four to five houses scattered across the city. It becomes difficult for them to make regular visits to the houses due to their workload. They are forced to rely on field staff for information on what transpires at the various homes and can only hope that the information provided is accurate as they are unable to verify this information most of the time.

6.2.7: Medicalization and documentation

Most residents in group homes take regular medication. It is very rare to find a resident in a group home who does not take any medication. The general assumption is that these individuals are sick and must be cured. After their assessment and admission into the home, pharmacies drop off their medication on a weekly basis. Medication administration and documentation form a very important part of staff training during orientation and in-house training. Missed medication and medication errors are treated with much seriousness. In some agencies, staff would be dismissed if he/she commits medication errors twice a year. Depending on the severity of the error, either the pharmacy, clinical case worker, or the on-call supervisor (or all three) is notified immediately.

From the beginning to the end of every shift, the staff is required to log whatever transpires. Additionally, incident reports are written anytime something out of the ordinary happens. In the context of home care, out of the ordinary can mean minor things such as refusing to eat dinner, taking medication an hour early or late, going to bed early, or waking up late. All these are recorded on every shift and either kept at the home or sent to the office for appropriate action to be taken.

6.2.8: Home care staff have multiple jobs due to pay and other conditions of service

The first agency I worked for started me off with minimum wage. The same is true for many other agencies. So, most support workers find themselves having to work multiple jobs to make ends meet. In fact, from my interaction with friends on the job, I am yet to come across anyone who does not have a second job, myself included. The salary and other conditions of service make it impossible to meet all financial needs. Wadehra (2021) is right when she says there is no time like now to start prioritizing the mental and physical well-being of migrant caregivers by removing barriers to permanency, ensuring their access to basic services and supports, and protecting them from abusive and exploitative working conditions. These are basic human rights (Wadehra, 2021). The downside of home support workers working multiple jobs is that they often arrive at shifts already tired or stressed which sometimes affects the services they deliver. This seems to be the norm among home support workers in Winnipeg.

6.2.9: Variation in salary and care delivery

Unlike other jobs and professions, it is hard to tell exactly how much the starting pay is for home support workers in Manitoba. It differs from one agency to another and even within the same agency based on the status of the employee as either full-time, part-time or casual staff, even when the staff is delivering the same services. I have personally worked for four different agencies delivering the same services. For each of them my start pay was different. The difference can be as much as $10, which brings into question the profit motives of some of these agencies. They are smart enough not to pay below the minimum wage to risk lawsuits and other litigations. It amazes me how in the same province, and in this case in the same city, some agencies pay their staff around $23 per hour and others pay just a little above $13 for the same services.

Winnipeg may be a big city, but word does get around very fast. Most people like me have worked and continue to work for multiple agencies. Several others work for one home care agency and their spouse or other relatives work for another. So, it is easy-to-get information on the working conditions that prevail in various agencies.

When staff is not properly paid and motivated it reflects in their output and unfortunately it is the innocent people in care homes who bear the brunt. When you are paid just about half of what others delivering the same services are, it is hard to find any form of motivation to deliver quality services. It appears to be the general trend across the country. A recent Ontario research report on Personal Support Workers (PSWs) attributed the shortages of Personal Support Workers in Long Term Care (LTC) Homes to low wages and poor working conditions. The onset of the pandemic has only made it worse (CCPA, 2020). With several infections and deaths recorded in care homes across the country, even those already on the job are trying to find new jobs because the wages do not seem to match the risks involved.

6.2.10: Assigning staff

Due to staff shortages and over-reliance on casual staff, it is common practice to have male staff work in an entirely female home even if the residents require assistance with bathing, dressing, and using the bathroom. Some of these individuals in care homes care about their privacy but they also need these services to enable them to live safely in the various homes. As uncomfortable as it may be for them, it seems that is the price they must pay for the service they require. It gets a bit too much for them when the agency depends heavily on casual staff as is the case with most agencies in Winnipeg. It is amazing the number of staff these people encounter in their lifetime. Staffing in care homes is very fluid. Due to the variations in salary and generally poor conditions of employment among agencies, support workers are always on the lookout for better opportunities either with other agencies or a different field altogether. So, different staff come and go all the time and this becomes quite uncomfortable for some care recipients.

Chapter 7: Conclusion

This chapter looks at the shortcomings of the study, draws conclusions based on the researcher's observations and experiences of how the home care program is implemented, and makes recommendations to address the current challenges facing the program and for future studies.

7.1: Limitations and evaluation

Variations in the delivery of home care services among the different agencies I worked for made it difficult to make definite conclusions on certain issues relating to service delivery. There were even huge differences from one home to another within the same agency which made it extremely difficult to generalize. From pay structure to recruitment and training of staff, service delivery and record-keeping, all vary greatly from one group home to another. In most cases, it comes down to the commitment of the home support personnel and the level of supervision. It is hard to tell which agencies are effectively implementing the policy on the ground and which are not.

Confidentiality and privacy concerns did not permit certain fine details to be included in the study. Names of residents and agencies for instance were consciously left out due to fear of breaching privacy protocols. There were times when I felt my study could have been more detailed if I could name the agencies, the specific home, and the individuals I was referring to in my research.

There was difficulty getting information outside the agencies I worked for due to bureaucracy and in some cases unwillingness of some individuals to give out information. On issues such as care planning and staffing, I wanted to be able to come to a generalization or a sort of conclusion as to how it is done across the various agencies in Winnipeg. To do this I wanted to speak to as many agencies as possible in the form of an informal interview to see where they diverge and converge on the issue. While some were simply not forthcoming with information, others gave me contacts that never responded to my calls or emails. In the end, I had to make do with the sample I got from the agencies I worked with and the few informal conversations I had with friends working for other agencies across the city.

The onset of COVID-19 changed so much in the delivery of home care services. Care homes were one of the hardest hit by the COVID-19 pandemic across the country. For this reason, several new protocols and practices were introduced to help curb the situation. It is hard to tell if all these new protocols are going to be maintained post COVID-19. It was a dilemma for me whether to praise the various agencies for their enhanced cleaning, disinfecting, and general hygiene protocols or not knowing very well that they were not like that before and were only introduced to help stop the spread of COVID-19.

Also, with outings and most recreational activities suspended due to the pandemic, it would be unfair to criticize any agency for not organizing such outings. The truth is, even before the pandemic some of these agencies were not doing much in terms of organizing outings for their residents, but now they can mount a solid defense and blame it all on the pandemic.

Though the actual study was conducted a little over eight months, it is an account of the implementation of the home care program over three years as a home support worker. So, there is the possibility that I cannot recall some of the fine details of incidents and occurrences within the entire period. Also, my understanding of issues then as a newcomer to Canada and now are different, so there are some important facts and issues that I may have overlooked entirely in the early days of my work as a support worker.

Again, given my background as someone from a country where resources are relatively scarce and where the government has very little responsibility if any at all towards persons with disabilities, it was hard for me to be overly critical of the home care policy in Manitoba and its implementation. For instance, having one bathroom for three residents and two staff may seem inappropriate to someone born and raised here in Canada, but not for me. Also due to cultural differences, there are things that may be very important to a Canadian that may be irrelevant to me. So, there are events and occurrences that I probably should have mentioned or critiqued, but I saw nothing wrong with them and ignored them.

In all, I believe the study is reflective of my four years of experiences and observations as a home support worker examining the home care policy, methods of implementation, and effects on recipients of home care services in Winnipeg, Manitoba.

7.2 Conclusion

The purpose of this study is to look at what the home care policy states, how it is implemented on the ground, and its impact on the beneficiaries of the program

The study delves into what the home care policy states about staffing and care planning under the home care program and what transpires on the ground. Regarding staffing, the study looked at recruitment and training of staff, staff shortages, and ways to motivate and retain staff on the job. It identified disparities in salaries, over-reliance on casual staff, and generally poor conditions of employment as some of the possible causes of staff shortages. The profit motives of home care agencies and general cuts in healthcare expenditure by both federal and provincial governments were also identified as other possible causes of the poor conditions of service leading to staff shortages. There is also a deficit in staff training. Agencies do not take into account the diverse background of both residents and staff and the peculiar needs of each resident. The training is seen as generic and not individual-centered. The inability to motivate and retain staff on the job is attributed to poor salaries and unfavorable conditions of service.

The policy is not clear on staff salaries and emoluments, a grey area that most agencies are exploiting to their advantage by paying their employees minimum wage to maximize profit. The profit motives of these agencies affect the conditions of service of home care staff and the quality of care delivered in care homes to residents. Canadian Center for Policy Alternatives in a 2020 study in Ontario notes that about 58% of long-term care homes in Ontario are for-profit facilities, and evidence shows that for-profit homes have poorer quality of care than not-for-profit homes. Private care providers must make profits, and to boost those profits they cut costs (CCPA, 2020).

The study also discovered that generally, residents do not have much say in the care planning process. It all comes down to the expert opinion of medical professionals running the program and the resources available in the community to support their care. The quality of care provided largely depends on the agency and its ability to motivate and supervise its staff to deliver good quality services. The regional health authority that oversees the program seems to be preoccupied with agencies meeting the licensing requirements and not the quality of care delivered in the various homes on daily basis.

The home care policy itself seems to be modeled along the lines of the medical model which views people’s impairments as the reason they are unable to fully participate in society. It does not focus on offering an enabling environment for these individuals to thrive in their various communities and possibly live independently despite their impairments. Most of the focus is on providing rehabilitation and other medical interventions. Future studies on the home care program should focus on how the program can empower people with disabilities by creating the right physical and social environment that is inclusive and permits persons with disabilities to live independently in the community despite their impairment.

I believe through this study it has been established that the home care program is poorly supervised hence some of the program’s objectives are not met. According to Roos et al. (2001), since 1997 the RHAs have been responsible for the assessment, coordination, and delivery of home care services and maintaining standards, with Manitoba Health retaining responsibility for overall policy and program standards. Agencies seem to be taking advantage of the poor supervision to deliver sub-standard services by cutting costs and maximizing profit at the expense of recipients of home care services.

The program does not also consider other disabling conditions in the various group homes and the community that makes it impossible for residents to live independently. So, from my experience and observation during this study, I conclude that most home care residents in Winnipeg are not satisfied with the quality of services they receive under the Manitoba home care program.

7.3 Recommendations

Unannounced visits by standards and licensing teams to various group homes. The average Canadian from my observation is polite and would not go into somebody’s house unannounced or uninvited. This is true with home supervisors, licensing, and standards teams under the home care program. They usually give at least a day’s notice if they intend to visit a group home. This may seem the right thing to do but it gives team leads and support workers all the time to put things right at the home before the visit and then things go back to the way they were after the visit. 24 hours is a lot of time to put things right so usually, supervisors turn up and find almost everything perfectly in place only those things are not that perfect before and after their visit.

An alternative to regular visits is having CCTV cameras at the homes of most residents, especially those severely impaired, to deter possible physical or emotional abuse and other disorderly conduct by staff. It may even protect the staff in case they are falsely accused of something they did not do. I used to work at a grocery store and the only place you are not filmed in the store is the bathroom. It may seem that the purpose is to check on shoplifters, but most of the time managers can check on their staff to make sure they are performing their duties accordingly. Staff knowing that they are being filmed also go about their duties diligently to ensure that they do not get themselves into any kind of trouble. There may be privacy concerns, but I believe fixing a security camera in the living room with the consent of the residents may go a long way to ensure better service delivery as staff would be fully aware that they can be in trouble if they misconduct themselves whiles on duty. A few group homes already have these cameras installed and as uncomfortable as some staff are with this development, I can confirm that it does make a difference.

Good mix or pairing of residents in group homes is vital. Some residents have post-traumatic stress disorder (PTSD) and as a result, get either agitated or scared when there is excessive noise or any disturbance at the house. Others have a history of violent behavior and yet are kept in the same space with old residents who cannot defend themselves if they were attacked. It seems to be the plan that agencies want at least one resident who they consider to be needing a high level of care in each house and not all of them in one location. In their view, spreading them across the various houses may reduce the number of incidences compared to housing them under one roof. This may seem logical, but it puts other vulnerable residents in harm’s way. Some agencies merely fill up vacant spaces at their group homes with new residents and do not take into consideration the well-being of the other residents. Sometimes it takes several incidences before a resident is moved to a new location. Moving forward, I believe resident safety and compatibility should be considered when putting people together in group homes to prevent incidents that may cause further harm to individuals who already have impairments.

More effort should be geared towards accessibility rather than cure and procedures that residents object to. For most residents, after years of treatment and daily intake of medication, they have come to accept the fact that their condition is not curable. They would rather appreciate measures and an environment that would make life easier for them in their current condition rather than the numerous unsuccessful attempts to cure them. Some of these individuals would probably require no home care services if their home environment and other conditions around them suited their situation. Some residents cannot climb up and down stairs due to their age or disability and yet the only way to their basement and other parts of the house is by stairs. It makes it impossible for them to get around their own home without the help of support staff. Others are wheelchair users, and yet their closets, kitchen cabinets, and other storage spots are at heights that they cannot reach. If these little but significant factors are considered in housing persons with disabilities in group homes, some may not require support staff.

Staff training should be progressive and resident-centered, not taking anything for granted. A lot of things are taken for granted and the training is so generic as though all residents require the same services. The nature and background of staff should be taken into consideration. For instance, the polite Canadian way of saying ‘please’ and ‘thank you’ when making a request and after the request is granted is not part of the vocabulary of most support workers, most of whom are immigrants from different cultural backgrounds. Also, things like adjusting the heat in the house, using a washing machine, dryer, electric oven, dishwasher, microwave for instance may all seem pretty simple to anyone born and raised in Canada. Unfortunately, most of the home care staff are neither born nor raised in Canada. Most of us are from countries where all these household appliances are luxuries that only the rich can afford. Even for those who can afford it, a poor supply of power and electricity connectivity makes it difficult to use these appliances at home. So, it is possible to have a fully grown adult who cannot operate any of the appliances mentioned above. For someone who was born and raised here in Canada, it would be very irritating and frustrating if the person who is supposed to support them cannot operate their household appliances. Yet none of the agencies seem to recognize this fact. They assume a lot of things wrongly which makes things very tough for both staff and residents at the early stages of their relationship.

Also, after several years on the job, staff could be taken through some additional training instead of the regular biannual first aid and CPR training. If home support staff are taken through some enhanced clinical training every year or two on the job, they could perform several other functions. A pathway could even be created where home support workers could be trained annually and rise through the ranks to work in mainstream hospitals as nurses. This would not only build the capacity of home support workers, but it would also help solve the problem of the acute shortage of nurses in the province.

Staff salaries and emoluments should be properly structured and attractive enough to pull in new staff members and keep those already on the job. Aside from not being able to pay workers below the minimum wage which would be against the law, home care agencies in Manitoba decide whatever they want to pay their staff. While some pay as much as $22 per hour, some still pay their employees $12 for the same services others are getting paid almost twice as much for. It is worth noting that the quality of care often reflects how well the support staff is motivated or otherwise. For most of the agencies who are paying their staff good salaries, they ensure that the staff is delivering better services worth the money they are being paid. Others are quite demanding of their staff to provide quality services and yet do not remunerate them adequately, resulting in staff agitations.

As by Sethi (2020) notes, there is an urgency for policymakers to prioritize personal support workers’ working conditions and wages if they hope to sustain a robust healthcare system. Sadly, it has taken COVID-19 to highlight the significant contribution to our collective well-being made by personal support workers and other healthcare workers. However, the voices of racialized personal support workers remain at the margins of care discourse. They are indeed the unsung heroes (Sethi, 2020). I believe streamlining the pay structure of home support workers and other conditions of service would solve the discrepancies in salaries and prevent home care agencies from taking advantage and paying their employees minimum wage to maximize profit for themselves.

It should be mandatory for agencies to acquire vans to facilitate transportation of residents to and from appointments and other outings. Some agencies are doing remarkably well regarding transportation. There are homes where there is just one resident and yet a van is assigned because most of these residents as a result of either their age or disability have some difficulties with mobility. I also know of other agencies who have as many as three residents in a house all requiring transportation to get out into the community, yet they have no van to aid their movement. In my view, unless there are binding rules, some of these agencies would only concentrate on maximizing profit and do very little to enhance the comfort and safety of both their residents and staff.

A regular survey of staff and residents by an independent body to determine their level of satisfaction with the program. Policymakers and the regional health authority can also rely on routine surveys from both staff and residents to evaluate the home care program. From my interactions, both staff and residents have a lot to say about the program, they just do not seem to find the right avenue to channel their grievances and suggestions. Most of them end up keeping their views to themselves and the few who make the effort to speak up find themselves talking to the same operators of the agencies responsible for their predicaments.

The best evaluation of the home care program for me is the sentiments expressed by the beneficiaries of home care services. Just like grocery stores and other establishments, the sentiments and ratings of employees and customers are the measure of the efficiency of the company, not the views of the managers or owners of the company. Owners of agencies and managers may say nice things about the program to make them look good in the eyes of their paymasters to keep them in business, though that may not be the reality on the ground. Staff and residents on the other hand have no such commitments. They experience the program on the ground and are therefore better placed to offer a more accurate assessment of the program.

The bulk of home support workers in Winnipeg are immigrants from countries where religion is very pervasive, so their attitude toward persons with disabilities may be a problem. Certain religious groups perceive disability as punishment for a person’s wrongdoings or that of their ancestors (moral model of disability). Garland-Thomson (1995) states that, according to this position, disability is a disadvantageous state, usually a visible impairment, visited upon individuals (and their families) as retribution (see Garland-Thomson, 1995; Silvers et al., 1998; Stiker, 1997/1999). If someone holds this view and is providing care, they might blame the resident for being the cause of his/her predicament and may have no empathy whatsoever. Most staff are on the job for the money to pay their bills and to acquire some experience, not because they desire to assist persons with disability. Sethi (2020) in her article states that personal support work has low requirements and allows immigrants to quickly find employment, enabling them to gain Canadian experience, one of the most significant barriers for immigrants. I believe agencies should be interested in knowing how people perceive disability before hiring them to work in group homes and other care settings. This would serve the interest of much of the population in Manitoba because according to Sethi (2020), the Employment Outlook (2019-2021) notes that along with those who leave school, a significant number of new immigrants belong to the personal support work occupational grouping. Considering that many of those workers will inhabit Black, Brown, immigrant, and/or refugee bodies, one of them will be taking care of each of us or our family members at some time in our life (Sethi, 2020). It is therefore in everyone’s interest that people who have a negative posture towards disability and people with disabilities do not end up being the ones providing support services in care homes.

Having persons with disabilities in charge of home care and other support services would better serve the interest of recipients of home care services and other disability-related services. There are owners of home care agencies and managers who do not have any form of disability and also have not worked or provided care for persons with disabilities. For this reason, they do not fully appreciate the needs of people in care homes, so their methods and processes of delivering care, even if well-intended, may not be what the people in care homes desire. Most institutions and organizations across the world are run and managed by people who are experienced and knowledgeable in that discipline. I do not think it should be any different when it comes to the formulation, implementation, and delivery of home care services.

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