

**"I Didn't Know Where to Go, Who to Meet":
The Work That Young Disabled Adults Have to Do to Gain Access to the Social Services in
Waterloo-Wellington Region**

Victoria Ikeno

Department of Social Development Studies, Renison University College, University of Waterloo

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Dr. Meg Gibson

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Abstract

The purpose of this thesis was to investigate the experiences of the young disabled adults who were accessing social services in the Waterloo-Wellington Region. This project used Institutional Ethnography (IE), a research method developed by Dorothy Smith to investigate how institutions work starting from people's everyday activities (Deveau, 2016). Interviews were conducted with 10 participants who were 23-30 years of age, had lived in the Waterloo-Wellington Region for at least two years, had accessed or attempted to access social services, and had lived experiences with disability. Findings identified the work people did to access services, including relying on networks of family and friends or on providers who help them navigate what is available.

Participants also summarized what is and what is not working for them, including the impact of racism and income disparity, and offered suggestions on how things can be improved. This study adds to the current limited literature on the perspectives of young disabled adults, and can provide insight into how services can be more accessible, equitable, and effective.

Keywords: social services, disability, young adults, institutional ethnography, lived experiences

Introduction

Problematic: Disabled young adults engaging with social services

Consistent with Institutional Ethnography practice, this thesis research begins from a series of everyday disjunctures between official accounts and what happens— that is, from moments that show the need to investigate further (Smith, 2005). This project proceeds from the standpoint of disabled young adults in the Kitchener-Waterloo area, and is rooted in experiences I have had or have heard about from other disabled young adults in the region.

One problem I have experienced personally within the social service system is that often people do not hear about programs that they are eligible for. There is a lot of uncertainty and luck as to who gets this information. For example, I am associated with Lutherwood through their Achieve Competitive Employment (ACE) program which is for individuals who are on either Ontario Disability Support Program (ODSP) or Ontario Works (OW) to help them find employment or assist them with gaining meaningful employment. Through this service, since I have had jobs off and on since being with them, I have discovered that there is a program through the government that is called Exceptional Work-Related Disability Supports (EWRDS) Fund which can help the person with funding for something that allows them to be successful at their job. It has a wide variety of possibilities to access it. However, from what I have discovered when talking to people who are also disabled and do sometimes have employment, is that they do not know about this funding. Everyone who is disabled and able to work deserves to know about this program.

I have also encountered problems for individuals who are going to post secondary education and require Ontario Student Assistance Program (OSAP) for their tuition but are also on ODSP or OW. It seems that there is an ODSP/ OW policy that individuals are not allowed to

receive any income that is labeled “non-educational” on the OSAP assessment form. However, the problem with this is that if the individual only gets grants but there is still “non-educational” funding listed, then ODSP/OW will deduct the total amount the individual will receive by how long the school program is (e.g., \$4,000 divided by 33 weeks). When I discovered this last year, I felt like I was being punished for going to school as a disabled person. I do not have a strong desire to stay on disability/ government income forever if I do not have to, which is why I am in school. ODSP/OW does not really give individuals enough money to live on per month. Furthermore, if I were to apply for awards and bursaries, it is possible that they can also be deducted from my cheque which to me is unfair since ODSP does not give me enough. The third problematic area I find is housing. Housing is crucial to anyone but definitely challenging for those who are disabled. In my experience, different organizations vary in who can help with housing, and how much they can help. I have both positive and negative experiences when it comes to housing in the Kitchener-Waterloo area, but I still had to pretty much do everything without any assistance to find a place.

Through these experiences, I have discovered that I have been fortunate to be able to gain my advocacy skills before coming in contact with my problems and knowing how to properly ask questions to certain individuals. I recognize that not everyone has the ability to know how to be resourceful or properly advocate for themselves however, there is some onus on the service to be able to provide the information that is relevant to the issues which sometimes I feel there is a lack of. All of the issues I have experienced, both positive and negative, and the solutions that I have found or were told, should be more public knowledge instead of secretive. One thing that needs to be investigated is other people’s lived experiences with these services, and why service providers are not more willing to provide the relevant information with undue hardship on behalf

of the client. Lastly, why service providers are not providing more support and doing more advocacy on behalf of their clients, instead of making clients support themselves, is unanswered. I plan on doing this through using semi-structured interviews to try to see what other individuals' experiences are when trying to access and gain support from the social services in the region.

Background

Existing research has shown that early adulthood can be a challenging time for disabled folks, particularly since many youth-focused services end. The World Health Organization (WHO) has recommended in several policy analyses that health and social services should progress from youth-friendly projects to 'adolescent-responsive health systems' by developing national quality standards, training an adolescent-competent workforce, and moving beyond sexual and reproductive health to address a wider range of needs (Barker et al., 2015). Furthermore in Lindsay et al., (2019), researchers found that disabled youth often have a hard time with transitions from secondary school into employment, or further education, as community engagement decreases greatly. There is often a lack of coordination between youth services and adulthood care services once the youth leaves school as some adulthood care services are not suitable for the disabled youth (Lindsay et al., 2019). These youth are often left to fall through the cracks of the social service systems as they age out of the previous system they were once in (Lindsay et al., 2019).

Lindsay et al., (2019) talks about work that has been done by Furlong and Cartmel (2007) and Côté (2000), and about how it can be hard for youth to successfully transition into adulthood. Furthermore, disabled youth are being treated the same way as their non disabled counterparts which is only causing issues for the individual. Depending on what limitation the young disabled person needs, they may need more support in certain areas however, in the Lindsay et al., (2019) paper, individuals who have a combination of disabilities, for example someone with a mental *and* physical impairment, can have a more challenging time navigating social services and their everyday lives, which might be impacted by their disabilities. This can delay the process of

gaining support, as there might still be a sense of dependency on certain systems or social supports (Morris et al., 2022; Nguyen, 2016; Lindsay et al., 2019; Pearson et al., 2021).

A common issue across the literature is the lack of adequate funding for services to provide sufficient care for disabled youth who are in need of them. Barker et al., (2021) discusses how transportation costs and long wait lists to seek out care can often affect a person from wanting to continue to seek out support for their disability. Potchek (1986) found that there are discrepancies between where funding goes for services that are meant to help people and their demand. For example, a church who helped with emergency pregnancy issues had enough funds to support their clientele, but a peer job counseling service that was aimed to help women ultimately had to close its doors due to lack of funds (Potchek, 1986). There were high demands for the job counseling service, but low demands for the pregnancy program, which both served women, however the funding was not able to adequately meet demands of each service. In another example, shelters have also faced similar struggles with discrepancies with demands and lack of funding to keep their doors open for the clientele (Potchek, 1986). Thus, social services can often face funding problems, as certain programs or services need more funding, but struggle to gain access to the appropriate funds, whereas other services have too much funding and there is lower demand for it. Similarly, new programs can experience troubles in securing adequate funds for their programming. On the other hand, services that were older and better established were not facing the same levels of challenges in terms of funding troubles (Potchek, 1986). This may be because older programs have the knowledge and experience on how to properly use the funds that they are given or can access to spread across their services, while newer programs can struggle to properly budget for services that they are providing to their clientele (Potchek, 1986). Likewise, Gibson (2019) interviewed parents of disabled children and found that there was a

reported lack of adequate funding for the needs of the child. Furthermore, in one interview, a parent of an adult child who was trying to find community housing was put on a long waitlist in order to access housing that would be best suited for them (Gibson, 2019). Gibson (2019) noted that waitlists such as supportive housing can be troublesome and leads to a margin for error for individuals who need the support and services to go about their daily lives. Finally, the existing literature speaks to some issues regarding funding problems and waitlists for social services. However, there is still a limited amount of literature specifically talking about disability related services that help individuals and the barriers they can face in regards to funding or long waitlists.

Drake et al., (2021) noted that most people who are disabled want to work, but often struggle due to their health and lack of appropriate work conditions and suitability. Townley et al., (2013) echo this by saying how there are limited employment opportunities for the disabled population. Some of the literature has noted that people with mental illness might lack motivation and the ability to achieve competitive employment which was hypothesized by mental health professionals (Black, 1988; Mackota & Lamb, 1989; McFarlane et al., 2000; Spaulding & Sullivan, 1992, as cited in Abraham, & Stein, 2009). Furthermore, clinicians may discourage their clientele who suffer from mental illness to gain employment as they believe that it may cause their client to relapse in their struggles dealing with their illness (Gill, 2009, as cited in Abraham, & Stein, 2009). A study by Casper and Carloni (2007) found that participants who were dealing with mental illness had a desire to be referred to employment services to help them gain employment (as cited in Abraham, & Stein, 2009). However, the study found that case managers would use the current status of the participant's mental health as a primary factor of if they would refer them on the employment services or not (Casper and Carloni 2007, as cited in

Abraham, & Stein, 2009). Likewise a study by Rogers (1995) found that participants often experienced a lack of professional support when it came to gaining employment, as the barrier was agencies making the participants feel like they were incapable of working, which in return was a self-fulfilling prophecy (as cited in Abraham, & Stein, 2009). Lastly, individuals who suffer from mental illness have said that it is hard to gain equality in the workforce, which often leads them to be at home for long hours alone, which further promotes exclusion from society and community surrounding them (Granerud, and Severinsson, 2006). In sum, individuals who have disabilities, especially those with mental illness, can often find it challenging to gain meaningful employment in their community, because professionals can often stand in the way when it comes to referring them to appropriate services.

Drake et al., (2021) stated that in the United States, since healthcare is not standardized across all domains, if a disabled person is able to work they would lose their Social Security Disability Insurance, which helps them gain access to health care that could be crucial to their impairment. In Ontario, for people who are on the Ontario Disability Support Program (ODSP), individuals can receive health care and dental coverage. As long as they remain eligible to receive income support, it is possible for them to get extended health benefits, if the person or family health care costs are too high. However, this is not guaranteed by any means which can lead to individuals who may depend on the support of government programs to help pay for their health care and dental needs a difficult decision whether or not to work or not (MCSS, 2022).

Geographic and national context can be an important factor to consider when looking at the experiences of disabled young adults. For example, Edie et al., (2015), discuss how in some countries in Africa (Sierra Leone, South Africa and Namibia), people who are disabled struggle to access appropriate services due to transportation and economic costs (Barker et al. 2015;

Morris et al.,2022; Lindsay et al., 2019; Pearson et al., 2021; Townley et al., 2013). Additionally, there are not enough adequate services to help them address their disability-related needs (Edie et al., 2015).

In Morris et al., (2022), the researchers comment on how there are limited resources available for people who come into the hospital that are looking for stable housing. The social workers say how they feel like they have failed the client, because they sometimes have to discharge them from the hospital, leading them back to homelessness. The literature is currently limited on stable housing for disabled youth and young adults. However, in Toronto, Sheppard et al., (2022) discusses how social service agencies and the housing providers are capable of working together to help provide adequate support and resources for their clients. For instance, in Toronto, the social service agencies come in to assess the senior citizens to see what sort of care support they may need in order to keep their stable housing. These services ranged from psychiatric care to helping ensure that rental payments are being made on time, or coming up with a plan if there are past rental payments that have been missed. Lastly, it's important for housing providers to give their clients the ability to exercise their choice in housing, as it allows people to have more autonomy, which helps to promote a greater sense of well-being and belonging in their community (Hendryx, et al., 2009).

Another issue that has come up in Barker et al. (2015) is that youth may have a hard time trusting service providers. For example, in their past, the youth may have faced discrimination and judgements towards possible drug use or other issues that the youth was going through. Service providers can often judge youth for some of their issues or ways they choose to live their lives, which can make them feel hesitant towards wanting to access services and talk to service

providers. This may include ones that may have not caused any discrimination or judgements towards the youth.

In Townley et al., (2013), the authors noted that a person who was previously hospitalized for a psychiatric episode may receive less support from different services, which can lead the individuals to feel isolated and withdrawn from the community as a whole. Similarly, for people who suffer from mental illness, when a social network is smaller in size, rehospitalization tends to go up whereas if the social network is bigger, rehospitalization tends to go down (Cohen & Sokolovsky 1978; Fraser et al., 1985 as cited in, Eklund & Hansson, 2007). People who suffer from mental illness disabilities can often avoid social contacts and conceal their true selves due to the stigmatization that they could receive for having mental health problems (Johnstone, 2001 as cited in Granerud & Severinsson, 2006).

Additionally, Ramon (2001, as cited in Granerud & Severinsson, 2006) states that poor health and low income can often create barriers for people to participate in social activities, further making the individual feel like a devalued member of their community. Low income can affect a person's overall well being because they might feel like they are not able to entertain people either at their home or able to go out to a restaurant or cafe to socialize with individuals (Granerud & Severinsson, 2006). In Gottlieb (1985, as cited in Lam, & Rosenheck, 1999), people need basic health and welfare services so they can feel like they can be an active member in the society around them as this can correspond with formal and informal support.

Townley et al., (2013) mentions how social and emotional support are crucial for a person who is living with disabilities. Social support can be defined as one feeling accepted, despite some of their disabilities (e.g., mental health diagnoses), or one having help with day to day (e.g., transportation to appointments or other errands). Social support can help reduce the

amount of times a person might need to be hospitalized, the amount of support services that the individual may use and overall mental health recovery for the individual who is dealing with severe mental illness (SMI) (Lam & Rosenheck, 1999; Albert, Becker, McCrone, & Thornicroft, 1998; Chou & Chronister, 2012 as cited in Chronister et al., 2013). Likewise, Dudley (2000) found that greater amounts of social support is related to less internalized stigma, and Adewuya and colleagues (2010) found that if a person does not have much social support, then their internalized stigma is more presented (as cited in Chronister et al., 2013). Furthermore, Hogan (2003) found that even though mental health treatment has managed to make improvements in the recovery for a person suffering with SMI, treatments often have a hard time addressing issues around social support, which was identified as a key aspect in overall recovery for the individual (as cited in Chronister et al., 2013). Emotional support can include a person being able to actively listen and provide empathy for a disabled individual, or just in general if a person is having a hard time coping with something going on in their life and they need someone to lean on for support. Correspondingly, the more emotional support an individual who suffers with SMI has, the less the societal stigma affects the individual and their overall coping abilities (Chronister et al., 2013). In contrast, if a person is more likely to conceal their mental health struggles from people in their life, then the stigma they might feel or interpret from society is more predominant (Chronister et al., 2013). Finally, one type of social and emotional support that has been shown to have success in helping with individuals who SMI is peer support as individuals are able to seek out advice and validation from their peers that can bolster mental health recovery in an individual (Chronister et al., 2013).

Community integration is defined as individuals who have opportunities to be able to work, live, and engage with their peers around them regardless of disability status (Townley et

al., 2013). In order to achieve a good quality of life, and allow the disabled individual to feel like they are a valuable member of the community, they need adequate support. Pearson et al., (2021) notes that people who are able to be more mobile through either monetary or other discretionary means are able to take part in more community activities which can further promote community integration and social support for the disabled individual. Furthermore, individuals who are able to successfully take part in community integration feel less lonely and greater sense of acceptance by their fellow community members (Townley et al., 2013). In Boydell et al., (2002), researchers found that individuals who had close friendships in their lives, that they considered to be like a family to them, were very important to their emotional support needs (as cited in Townley et al., 2013). In contrast, Brown (1996) states that when individuals are hospitalized for severe mental health related issues, it can often decrease the number of social supports that the person may receive (as cited in Townley et al., 2013). If an individual is continuously hospitalized, they might become withdrawn and isolated from the community, which leads to the person experiencing decreased motivation to engage with community members and activities (Beels 1981; Schwartz and Gronemann 2009, as cited in Townley et al., 2013). However, mental health nurses can help promote community integration by facilitating conversations between the patient and community members (Granerud & Severinsson, 2006). Community integration is important for a disabled person, so they can feel like they have some level of social support that would be outside of their familial links.

Family members can be another example of social support for individuals who have disabilities. Padgett et al. (2009) found that family members could be both a benefit to the disabled individual but also detrimental to the individual (as cited in Townley et al., 2013). For example, during a crisis, family members are able to provide sources of warmth and nurturing,

but they can also make a person feel rejected due to their disability (Padgett et al., 2009, as cited in Townley et al., 2013). In Nguyen et al., (2016), researchers reported that family members, such as parents, can be a big benefit for the disabled person when they are still in the youth system by handling the “behind the scenes’ activities. This can include things such as scheduling appointments, managing medications, and providing emotional support through potential hard times relating to the disability (Nguyen et al., 2016). In Nguyen et al., (2016), there has been an increasing amount of research regarding how parents and youth have to work together to allow the youth to become more independent and be able to handle their own healthcare needs as they enter into adult services. Comparably, Ragins (2008) found that parental support can make a huge difference when their child is dealing with self-esteem dealing with their disability. Parents can help facilitate their child to be more open and accepting of their disability to others instead of the child feeling like they need to hide their disability from everyone (Ragins, 2008). On the contrary, individuals who struggle with disabilities such as mental illness can struggle to meet their family obligations or roles which can make them look like a failure, which can cause negative interactions between the individual and their family (Chang & Chen, 2021). Negative family interactions can affect the person with disability quality of life and can affect one’s internalized stigma about their disability (Chang & Chen, 2021). In sum, family support can be both positive and negative in terms of how it can affect the individual with disability and how they are able to cope with the demands of everyday life.

British and Irish researchers have documented how disabled young people struggle with transitioning from child care to adulthood care (Lindsay et al., 2019; Pearson et al., 2021). Pearson et al., (2021) state that policies have failed to address common issues around social, psychological, education and economic support, leading many young disabled individuals to fall

through the cracks of the systems that are supposed to be helping them. The transitions that youth face when transferring between systems are rendered more complex and difficult due to discrimination, inequalities, and disadvantages (Lindsay et al., 2019; Pearson et al., 2021). Pearson et al. (2021) further mentions how children and youth who are making the transition from child services to adulthood care often experience discoordination when making the transition.

Another notable issue that the literature talks about is how age limits or age cut-offs for certain types of services can vary depending on what the young disabled person might need for assistance or help (Barker et al., 2015). For certain types of services, such as addiction or mental health treatments, there can be a lot of variability in someone who was receiving youth services, and then all of a sudden having to go to adult care. This might be more dangerous and problematic depending on the age of the young person and the recipients of the service, who would be older and possibly more experienced.

One major gap that exists in the literature was participants struggling to get access to funds to help them achieve a better quality of life. Furthermore, another gap in the literature is waiting lists to receive support and services for participants who might need help with something in terms of quality of life or care. The present study will attempt to address these gaps through semi-structured interviews with individuals accessing services in the Waterloo-Wellington region.

Methods

Institutional Ethnography

Dorothy Smith is the pioneer of Institutional Ethnography (IE). She developed the research method to be able to discover the discourse of how institutions work and how the people who work in and access them experience them in an everyday setting (Deveau, 2016). IE is used to help address oppression and inequality that people can face when dealing with institutions (Campbell, 2016). Furthermore, IE emphasizes the fact that people who are facing challenges are active actors in their story, and assists in honoring their experiences when dealing with the institutions (Campbell, 2016). It deals with people's knowledge and handles the ruling relations that are being coordinated by the institutions at hand (Campbell, 2016). Dorothy Smith states that anyone who is able to speak in a sensible and coherent manner, is able to speak about their experiences with social relations (Campbell & Gregor, 2002). Individuals who are able to talk about their experiences with the institutions know how their efforts and work are applicable to the institutions that they are coming in contact with (Campbell & Gregor, 2002).

IE often uses semi-structured interviews to collect data. The questions in the interview examine people's experiences – both positive and negative – when dealing with the institutions. For example, the questions could involve asking what a person's experience is like when trying to access a service that does with income support, and find out what a person might have to do to gain knowledge about how the process works. Additionally, Campbell (2016) talks about when using IE for research, individuals need to immerse themselves into the research by walking aside the individuals who are being interviewed. For example, when using IE, researchers should try to put themselves into the shoes of the people they are talking with. Institutional ethnographers

need to take the standpoint of issues that they are discovering within the research itself (Campbell, 2019).

In Deveau's (2016) article, they say that people are experts of their own lives which means people are knowledgeable about how their way of being is in relation to everyday life. Furthermore, institutions help shape how people are able to live and conduct themselves into society by using their power to help dictate how they are supposed to operate in the local settings (Deveau, 2016). IE's overall goal is not to study the experiences of random individuals; instead, it is used to investigate a certain type of setting or experience that individuals may have or encounter when dealing with ruling relations (Deveau, 2016).

Procedure

First, I started with applying for an ethics protocol through the University of Waterloo Ethics Board (REB #44479). I received the first ethics approval for my study on August 19, 2022. Then I started sending out my recruitment post via Reddit subreddits: Guelph, Cambridge, Kitchener, and Waterloo along with some relevant facebook groups that would allow respondents to my post (see Appendix A). I had to make an amendment to my ethics protocol to include a \$10 (CAD) honorarium for either Starbucks or Tim Hortons which was proved ethics on September 1, 2022 (Appendix B).

As the Canada Jobs/Employment program states, youth participants are from ages 15-30 however, I am focusing on the age ranges between 18-30 as services tend to change their mandates and terms of services once an individual is considered to be a legal adult. Individuals who turn 18 are no longer provided with the same level of care or services that they might have been accustomed to growing up. The services that are being asked focus on the

Waterloo-Wellington Region so the individuals interviewed will need to have adequate lived experience of 2 + years in this region.

I sent participants who contacted me the screening questionnaire for them to fill out via email (See Appendix C). Participants had to be over the age of 18, have lived in the Waterloo-Wellington Region for at least two years and have lived experiences with disability. Disability was defined in my study as one or more of the following: physical disabilities, chronic illness, learning disability, mental health, neurodivergence or other.

Participants were asked when they would be available within a two week time period to schedule an interview. I then sent the consent form and study information within the scheduling email (See Appendix D and E). Participants sent back the signed and completed the consent form. All participants were given the option of completing the interview via Zoom or Qualtrics which was a written format however, only one participant opted to do the Qualtrics format due to the limitations of their disability. I also obtained additional verbal consent before beginning the interview and gave participants a chance to ask any questions before recording.

Interviews were scheduled with eligible participants, and were conducted over the course of 2 weeks between September 7, 2022 and September 25, 2022. The interviews were semi-structured as that is what the literature suggested doing for IE (Campbell & Gregor, 2002). I followed the interview guide, and asked some additional probing questions that were not always in the interview guide (e.g., such as could you explain more about your experience with that specific service) (see Appendix F). Interview questions were based around people's experiences with dealing with the social service agencies in the Waterloo-Wellington Region. Questions had a mixture of both positive and negative prompts to get a wide view of how people who identify with having a disability are experiencing the services in the area. The interviews

lasted no longer than 25 minutes, and the recording was done via Zoom function. Midway through the interviews, I started to ask participants more specifics about the social services they were accessing such as names of the organizations or the type of services they were gaining help from to have a better understanding of which services people were utilizing the most.

All participants opted to receive a \$10 (CAD) Starbucks gift card that was sent via email, along with the feedback and appreciation letter following the end of the interview (See Appendix G). I put all the interview recordings with the participant number (1-10) onto a secured password protected USB drive. Lastly, I put all the interview recordings into Otter.ai with those transcriptions onto the same USB drive too.

Analysis

Zoom recorded interviews were de-identified and put into Otter.ai for transcription. I then reviewed and corrected these transcripts, and received additional assistance from another member of the research team working with my supervisor, and from my supervisor as well.

When analyzing the transcripts, I put all the quotes and ideas from the transcripts into tables that have similar themes in terms of the work that people did in order to access services. For example, I put participants who were getting help from friends in one table, and help from family into another table. Furthermore, I put quotes into two separate tables that were pros and cons of issues that participants experienced in the social services. Then I did another level of analysis to reflect on what I learned about how social services are organized from this work that participants described.

Results

Participant Demographics

I recruited 10 participants (8 males, 2 females) from a recruiting call posted on Reddit, Twitter, Facebook, and on the research supervisor's website. All participants were between 18-30 years old, had lived in the Waterloo-Wellington Region for more than 2 years, and identified with having a disability. Participants self-reported on their racial ethnicity. 30% identified as Black, and 70% identified as White. Participants also self-reported on their experienced disability. 2 identified as Mental illness, 4 identified as Physical Disabilities (such as spinal cord), 2 identified as Learning, 1 as Deaf and 1 as Unknown. All participants had some level of post secondary education.

Work that the disabled young adults have to do to gain access or figure out to services

Networking with friends

There were a large number of participants who reported being able to find out and access support via friends' insights about how the services in the region work and operate. Furthermore, the participants who leaned on their friends for support and information often helped guide them with what supports would be best suited for their needs relating to their disability.

For example, Participant 3 said that he suffered from a spinal cord injury from playing sports and was dealing with financial issues. He was struggling to find support and resources to help ease the burden but with the help of his friends, he was able to: "...because I couldn't stand up to look for service by myself. So my friends helped me the process for looking for social services in the region". Similarly, Participant 7 said, "But I actually made a friend, actually made a friend. And actually, it was the friend that led me to services. And when I got the, the guy linked me home with somebody else, and the relationship would go with." Participant 10 also

reported that she gained help from a friend who was dealing with similar issues when it came to looking and accessing the relevant social services in the area. Participant 1 said that he got help from a friend when it came to looking for and gaining access to the supports in the region. Participant 6 mentioned that a friend of his gave him a number to try to call when it came to trying to access the services in the region.

These are all examples of how friends are important and crucial to individuals who experience disabilities. Friends can lend a hand to their peers by helping to figure out what support would best help them with the situation that the individual is dealing with. Furthermore, friends can help give valuable insights to what a certain type of service might be like from a client perspective if their friend deals with similar types of disabilities. Friends are able to help alleviate the burden that a disabled person might have to endure when it comes to dealing with social services by giving the individual an upper hand with getting them the support they need to best assist them. Finally, by sharing the wealth of their own knowledge about the services in the region, friends were able to assist their peers by giving the information they needed to gain access to support.

One participant in the study moved to the Waterloo-Wellington region because their friends told them about how the services that were operating in the region are adequate. For instance, Participant 6 said, “When I first came to Waterloo my friend told me that is a very nice place to live and also your main social service you enjoy.” In conclusion, friends are able to provide helpful insights and knowledge about how to help the individuals access the social services in the area.

Networking with Family

Much like friends being able to help the participants gain access to the social services in the region, family members are able to provide the same level of support. Participant 1 said: “So I made an inquiry. I told my dad to help me talk to these, this particular organizations that would make the study very easy for me. I got played like a football because of my color.....my dad tries to help me with some of the basic information”. A few other participants reported gaining help from their family members when it came to figuring out the social services in the region and how to best get services for the related disability needs.

When individuals utilized children's services for their disabilities, oftentimes the guardian or family member would be the one who was talked to when it came to getting support and the services needed for the individuals:

...the child support services were actually pretty easy because I wasn't making the effort myself. My guardian was actually making the effort for me....Be it all from where my guardian was actually helping me. The services were quite a bit better, they visit me from time to time, they pay attention to my mental health. Because sometimes, what you actually need is no physical things. You actually, you need someone... to understand how you feel. Yeah, so the ... provider for me, they helped me to slow my pace. Like, I could actually do some steps, even [with] my [disability] challenge. When it goes [to a] new year [and I was an adult], like I said, I had to fend for myself.

Participant 7 talked during the interview about what it was like to transition from children services to adult services. There was no sense of continuity to ensure they would be successful as an adult when it came to getting help from the similar services in adult care, since the service providers were only interested in talking to their guardian instead of them as they were growing up. In sum, family was a pivotal pillar in the young disabled adults' life when it comes to networking the different services that are offered in the area.

Networking with other people

Individuals who were not able to lean on family and friends were able to get help with accessing or figuring out the services in the area from other individuals in their lives. For example, after a not-so-great encounter at first with a social service in the area, Participant 2 got assistance with the social services from a service provider the second time around when it came in contact with one:

I was actually thinking of going somewhere else. [It] was fortunately that particular day I met with someone else. And this person was [like], Come with me. And she offered me attentiveness and offered me everything I wanted.

Participant 4 was helped by a religious leader when it came to getting access for services and figuring out their way around the area: “It's my religious leader....Yep, yep, he guides me? And he puts me in the way I should go about it... an organization that...guides me on assessing the social services.” In short, when individuals lack support from family or friends, there are other people in the community who are able to assist with figuring and navigating the social services, and some could even be the service providers themselves.

What did we learn about how services are organized from the work that people have to do?

Some of the participants reported that the work they needed to do to figure out how to get help and access to the service was understanding how the service works as a whole, such as who was the best person to go to talk to when it came to getting help for the needs that needed to be met. I personally have experienced this when it came to accessing the support needed for my related disabilities. I had to figure out who was the best person to talk to make sure that I was receiving an equitable experience with the social services too. Participant 2 said that:

I understand that... one of the major things I learned is the chain of events... or the process or who to meet at that particular point. You know, at first, I did not know

who to meet, where to go to, I just know, 'this place, this office is for social service.' ...I don't know how to meet. So but one of the things I understand and one of the things I learned is like a chain of command, who to meet for assistance.

Some participants talked about how the paperwork that was needed to be filled out for getting help and support for the services can create barriers for them, such as challenges due to their learning disabilities, and just overall feeling overwhelmed.

Participant 4: Um, I learned that there was a lot of paperwork to fill. The amount of forms I had to fill just to get the service was a little much in my perspective.

Victoria: So do you feel like ...all the forms you had to sign were a bit of a barrier, in some sense?

Participant 4: Yep. Yep. I feel so because I believe if you had to fill the form, then they'll have to go through to start again. I believe it's taken more time than it needs to take or it should have taken.

Victoria: And that's completely fair. That's what I've heard ...from ...some other people. So did you ever feel like some of the problems you were experiencing were your fault or [feel] blame that you didn't get the proper support? And if so, can you think of examples when that happened?

Participant 4: Nope. ...I almost always get support, what I need.... My only issue with my own program is paperwork.

In conclusion, people often have to do some level of extra work when it comes to getting help and support from the social services. Being able to learn who to talk to in the service can be important when it comes to making sure that you are getting properly supported. However, it may be hard to figure out who the correct person is due to the lack of information provided. Furthermore, the paperwork that an individual might have to fill out might grow tiresome or seem daunting if it seems like it neverending, all for just gaining assistance from the program.

Positives about the social services in the Waterloo-Wellington Region

A number of participants reported that they were satisfied with the services that they accessed and level of care they had received. When asked if they felt like their needs were being

met with the services they were seeking help from, a vast majority of them felt that their needs were met.

For example. Participant 4 said that: “Yep, there are medical services, my needs are always granted .. quite quickly.” A few participants reported that the services they were gaining help from helped them with financial services, food services, and one even said housing assistance when they needed assistance. When Participant 7 needed a new mobility aid such as a wheelchair, they said the following, “Yeah, when they actually noticed ...my condition and realized I needed help. They actually stepped up and they provided help. They got me a better wheelchair”.

Participant 8 had to seek help from counseling services in the area and this is what they would say about the level of care and experience they had with the counseling services:

...the counseling sessions, which have been actually helping me to maintain a proper state of health... has been really having a positive effect on me as a person, because it tells me to be encouraged that I'm not alone. And also to keep up with my medication. And also to try to be happy as much as possible. So that's kind of when they actually get in... my locality.

While many of the participants that I had interviewed reported good things about the services they had accessed, some said not so good things. Additionally, some of these participants noticed some discrepancies in the services in the region when it came to getting help from the services in the region.

Problems with the social services in the region

Racism

Two participants in my study had reported how race can play a factor when it comes to getting help from the services and how privilege is something that individuals need to keep in mind in terms of how oppression and marginalization can affect someone's level of care and

equitable treatment when talking about needing assistance. First I would like to talk about how being a BIPOC individual can cause discrepancies when it comes to trying to get help.

Participant 1 recounted:

I got played like a football because of my color.....Um like some institutions' biases are trying to tell me... it would have been better if I'm white and then I'm disabled I believe. I don't want to [get]... more discrimination as such. But then [I'm] black skinned and then I'm in trouble ... some of these places are inaccessible for me.....Yeah, basically, this should be equity....There should be some form of sensitization on the form, or a seminar.

Another individual reported how being a white individual provides them some level of privilege when it comes to getting access to the social services, and that they can empathize with how BIPOC individuals might struggle gaining the relevant support from either same or similar services in the region. While there was more than one person who reported being a BIPOC person and only one did report issues, the other individuals who identify themselves as BIPOC did not report themes of racism in terms of their experiences with services. However, this does not mean they do not exist as a whole.

Financial Supports

Participant 8 noted during their interview that there were some issues regarding financial support in the region. When asked if there were any types of support that were lacking in the Kitchener-Waterloo region and why that might be, they said:

Yeah. Yeah. By the person or the government. Yeah, that's true. And, you know, I know, ... some states are more financially stable than the rest. So it's not something we can actually compare. Why is the state doing better than the other? You know, it has to do with the financial subsidies available to them.... You know, there's something I know for sure, there's an uneven distribution of income... But I just pray things get better with me as a person. So I just wish I can actually, you know, achieve my goals, do things that I want to achieve as a person. I think that's what really matters to me now.

Victoria Ikeno: Why do you think this change hasn't happened to come along? Why do you think the change that you suggested ...just adding more money, hasn't happened yet?
Participant 8: Yeah. Because, so, I seem to be having so little financial aid... So I actually wish for a better life and I'm actually working towards it. So I just pray everything works as planned.

Psychological Supports

A few participants noted that there was a lack of support for people with intellectual or learning disabilities in the region. Two participants in my study identified themselves as having learning disabilities and challenges that went along with them. For example, Participant 6 said that they thought they were treated worse because of their learning disability. Another participant said that they wished that there was a service in the area that could assist them with learning about their disability. They struggle to understand how to be able to identify their challenges and what sort of support would make them be successful in the world due to lack of knowledge and expertise of their learning disability.

In the region, while one participant noted that their emotional support/mental health supports in the region were adequate, another participant said the opposite in terms of the lack of emotional connections they were able to find and access for the region, “I think that's still lacking. Because sometimes, I actually feel very dumb. And I don't... get the emotional support.” Based on these participants, services in the region are not able to fulfill the needs of people who need assistance with learning about their learning disabilities or have a desire to have some level of emotional/mental health support in the region.

Other recommendations

There were a few other notable findings during the interviews that did not really fit any subcategory but I felt like it was important to highlight. The first one that I will be discussing is having a service for individuals who are new to the region to help the disabled individuals around the region and what sort of support and services that they can access to help them with their disabilities. They probably would want to have similar types of services that they were

receiving in the place to live but if a person is new to the region, it can be hard to be able to navigate and figure out where to go, especially if they have no contacts when it comes to family or friends. Participant 7 said this,

Well, as I said, when I got into the area, I had to look for help. I had to look for somebody to actually show me around and link me up with those social services. So if there's a way we can actually connect with them without so much stress, I think that will be good. That might not be for me, it could actually be for somebody else.

The second important recommendation came from Participant 6 talking about issues that their friend experienced:

I have a friend of mine who has a spinal cord disability. Yeah, you're thinking of suicide because of many things... and [I'm] like checking them from time to time and also making their lives like comfortable for them. Like give me the support they need... anytime.

Based on this, it seems like there is a lack of service that would be checked up on those who might need both physical and potentially mental health based support. Due to lack of quality in their care, the friend might have wanted to end their life. This is an important thing to address as I am sure there are other people in the region who might be struggling with similar issues and not getting the level of care that they require in order to be able to function in an everyday life setting and be comfortable too. It might not be possible to fully cure the disability that the person is dealing with, but services should do their best to boost quality of life for the disabled person.

In conclusion, while some participants felt like their needs were being met and the quality of care was good, others found the opposite depending on what sort of services they needed. As mentioned above, some services might judge a person based on their skin colour or their type of disability and treat them differently which is not good when it comes to trying to serve the disability population, who already face inequalities as a whole. Participant 6 said this when being asked how they found Waterloo-Wellington Region versus the region they onced lived in: "Okay,

your service is not as good... The reason I say that is that I don't enjoy the services because they normally delay Yeah, normally delay.” The services in the region can always do better and improve their overall approach to the clients they are hoping to help with issues they need assistance with. That is what the aim of the thesis was meant to be.

Discussion

The purpose of this thesis was to investigate the experiences of the young disabled adults who were accessing social services in the Waterloo-Wellington Region. We aimed to get the individual's perspectives of what is and what is not working for them in the systems they encounter in hopes of identifying barriers and possible improvements to service delivery.

Based on my findings, it was discovered that disabled individuals rely on their friends, family, and other members in the community to assist them in gaining access and navigating the social services in the region. Friends were able to help by connecting the individuals with social services that they might have used before or knew someone who has been successful in obtaining service for their relevant needs. Family members were able to assist them with similar things, but also were able to help take on the burden by intervening and get better, adequate and equitable support for their child, even when they were an adult.

What this finding tells us is that the current systems are not operating in a fully accessible and equitable way. If everyone had ready and equal access to social services as disabled young adults then they would not need to rely on their networks of friends and family members. They would not need to identify and work with individual providers who go beyond what others do. Not everyone has friends, family members, and providers who can offer the same level of support. As long as services rely on people's networks or specific individuals who work in these organizations, then there is going to be unequal access to crucial supports and services. Both my background section and my study findings discussed themes around community integration and receiving help from friends, family and community members. Townley et al., (2013) found that individuals who were able to be successfully integrated into their community

were successful in being able to live, work, and engage with their peers around them. Many of the participants reported being able to rely on their friends for support and being able to network and navigate the social services in the region. The participants were able to use their friends to find out which kinds of services were beneficial to their related disability needs and learn how to best work with the services. Other community members (e.g., a religious leader) were also helpful for one disabled individual when it came to navigating the social services in the region. In contrast, when a person is not able to be successfully integrated into the community, it could lead to unreputable harms to the individual (Gottlieb 1985, as cited in Lam, & Rosenheck, 1999; Townley et al., 2013). One individual noted how their friend who had a physical disability was on the verge of almost committing suicide because no one was checking in on them on how they were doing or helping them manage their disability regarding the social services.

Overall, individuals reported being satisfied with the level of service and care they were receiving from the social services they were accessing. However, there were a few reports of individuals not feeling like they were not getting great support or equitable support due to racism or the type of disability the individual had. Two individuals reported saying that they felt like some of the services they were using would discriminate based on the colour of their skin. This came from an individual who was identified to be BIPOC and an individual who was white, but could see how a person who was BIPOC might have issues with trying to get support and acknowledged their privilege as a white, cis, heterosexual male. Another individual reported that they felt like the services they were accessing would not treat them properly based on their learning disability as they felt like the services they were accessing would treat them differently as opposed to others accessing the same services. Additionally, financial aid support and

psychological support was something that participants felt needed to be improved in the region, as two participants felt like there were not adequate services for their two areas of need.

Both Nguyen et al (2016) and Lindsay et al., (2019) discussed how it can be hard for disabled individuals who were previously in the children/youth system, transitioning to adult services can be difficult. One of my participants made this point as they said when they were in the children services sector, the service providers were only interested in talking to their guardians and not them. However, when they aged out of the children services in the adult services, they struggled to navigate the services as the services were no longer interested in talking to their guardian, instead just them. The transition for this individual was rocky because they did not know how to properly advocate for themselves due the the service providers never talking to them when they were younger. This finding suggests that services need to attend to transitioning people across programs that are based on age.

Nguyen et al (2016) stated how family members can individuals when they are trying to access social services, especially as youth. My study would support this part of the literature as one individual, when in the children's services, did lean on their guardian for support when accessing the social services. Similarly, Padgett et al. (2009) showed that family can be both a benefit to the disabled individual but can also cause harm to them, however there was no harm reported in my study when discussing family. An individual reported how they had to get help from their father when it came to figuring out and navigating the services in the region, even though they were an adult at this time.

Pearson et al. (2021) suggests that policies often fail to address the young disabled individuals psychological, economic, and education supports. The participants in my study spoke to all three of these issues: one noted that they had problems with gaining access to education

funding to further support their studies to become successful in the working world, another individual spoke of how there was lack of psychological support for them and wished that there were more services or supports in the region that would address this discrepancy, and lastly, another individual said how financial aid supports were hard to access and figure out and sometimes that lead to issues when it came to overall quality of life.

This study has implications to add to the bodies of literature for both critical disability studies and IE. One participant said during their interview that just because a person is disabled, it does not mean they can not make it in life. Goodley's (2013) article further supports this as they said that having an impaired body does not equal disability, but disability in itself is a problem of society. The participants who took part in my study had a range of different types of disability, stemming from learning disabilities to physical disabilities. In Shakespeare's (2006 as cited in Goodley, 2013) book he noted how some disabilities could be static and others would be more episodic, which holds true to the participants in my study as someone would be more static in nature and others be more episodic.

A few participants in my study noted that they did not feel like they had troubles finding support for tangible about resources that would help promote personal enhancement such as lack of emotional and psychological supports, having someone check in on them to see how they are doing with coping with their disability, and being able to gain insight about their learning disability to assist in knowing combat the impairment.

Disability studies can use the experiences of what the disabled individuals experience in their day to day lives which is something that I was investigating when it came to talking to the participants in my study (McKenize,2009 as cited in Goodley, 2013). The focus of the study was to investigate how the individuals in Waterloo-Wellington experience the services that they

access to seek care and support for their related disability. Being able to use the disability studies in the context of learning about the experiences of people's everyday lives fits well with how IE researchers conduct their work, as they want to figure out the disparities and issues that individuals have to deal with when trying to access institutions. Meekosha and Shuttleworth (2009; as cited in Jóhannsdóttir et al., 2021) said as researchers who are trying to investigate issues around the experiences of the disabled individuals should not shy away from asking difficult questions or trying to discover an issue that may be harder to uncover due to people not wanting to talk about it. In my study, while it did focus on the what positive experiences the participants had, it also tried to uncover and investigate what might be difficult for the participants when trying to seek and access services by asking questions that would help draw a bigger picture to what individuals have to experience when trying to find help and resources in the region.

These findings suggest that the social service system would be more equitable if they were able to treat individuals equally who come through their doors, despite the colour of their skin or the type of disability that they are experiencing. Additionally, they should treat the individuals like they are a valuable member of society and can effectively contribute to the region once they are able to gain access to resources and support that they need to help improve their quality of life. Lastly, developing more services or supports that address psychological issues such as providing emotional support to individuals who need it outside counseling services and other types of psychological issues such as learning disability issues surrounding being able to understand the disability in a better frame of context.

Limitations

While these findings demonstrate issues of experiences of individuals who are disabled and experience services in the region, there are limitations to consider. One of these limitations would be that interviews were only conducted in English which may not be the first language of every individual that participated in the study, and this language choice could cause communication challenges. Another limitation would be that interviews were done over Zoom which at times caused connection problems which could make it difficult on both sides to hear and understand what the person was saying or asking. Thirdly, another limitation of the study was possibly the types of questions that were being asked during the interview. If participants did not have a negative experience with receiving support, it was difficult to get answers to questions regarding change they may want to see for the social services in the region. Sometimes people might not know how things could be different without specific examples. Furthermore, questions about employment and other issues that may affect a disabled person's experience with quality of life were not explicitly asked during the interview. Next, for accessibility purposes and in compliance with the ethical review process, I used a Qualtrics questionnaire for one participant who required a text-based approach for accessibility purposes. However, my questions were designed for a live interview, rather than an online form, which was difficult to properly format in Qualtrics. Lastly, the sample size that was used in this study was small, as there were only in total 10 participants. Therefore, it was a small exploratory study to investigate issues that some young disabled adults experience but may not identify important issues that others face.

Future Research

Future research should investigate the side of the service providers in terms of their experiences when trying to give support and care to individuals that walk through the doors. It is important to understand the service providers' side of the story, because they may have the

similar frustrations as their clients as they have a mandate they need to follow in order to continue to gain access to funding through places such as governments. As identified in Morris et al. (2022), the service providers felt like they had failed their duties to provide help and services to the clients because they had to send their clients back onto the streets to remain homeless. In the article, they did want to help, but struggled to do so given the rules and regulations of what they can do to support the participants; they were restricted by what they could realistically do for the clients. Next, there is currently a limited amount of literature talking about funding issues when it comes to trying to receive or provide services to individuals. As a disabled young adult myself who has accessed the social services myself in the region, the service providers have told me that funding can often be a problem when trying to help. Funding is an issue when it comes to receiving services, as there is a major power imbalance when it comes to clients receiving funds, but also services being able to get the funds from places like the government. If a service is applying for a grant to a level of government, often they have to follow strict guidelines or criteria of who can receive those funds and what those funds can be used for. Furthermore, as identified in my limitations about the types of questions being asked to participants, if were to replicate the study and build on it more, it would be recommended to ask participants about employment in terms of possible struggles in obtaining it and also healthcare related issues such as getting access to medication or assisted devices. In my background section, it was identified in the literature that individuals had a hard time obtaining meaningful and high-quality employment due to sometimes their own limitations or what social services could provide for support. Furthermore, if individuals were able to obtain some level of employment, they had to then worry about still being able to receive certain medical care and benefits such as reduced or free medication that would help them be successful in job and overall life. Additionally, my original

idea for my study was to see if young disabled adults in the Waterloo-Wellington region experience the feeling of needing to go around in circles in terms of going from one service to another. Future research can try to ask more targeted questions to address these possible issues, and potentially talk to service providers about the experiences that they have been hearing from the participants to see if changes can and need to be made. Lastly, it would be recommended to recruit a large number of participants to take part in the study to see a better idea of what the population of disabled young adults in the area experience.

Conclusion

This study investigated the experiences of young disabled adults in the Waterloo-Wellington region, and how they felt and interacted with the services for support and help. I used IE to help develop the design for my data collection and analysis. I found that there were participants that did have good experiences with services in the region, but also participants who identified having issues with services such as dealing with discrimination of disability and racism. There were also some recommendations from participants of what they would like to see in the region as improvement for services such as psychological care for both emotional and learning disability issues. This study adds to the current limited literature as groundwork of what some young disabled adults experience in the region in terms of services. In conclusion, this study can help provide insights of what services can do more of or what additional services they need to add to make their services more accessible, equitable, and effective for those in need.

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Appendix A

This is the first recruitment post that I had sent out among the social media avenues including Reddit, Twitter, and Facebook, as well as linked onto my supervisor's research website.

PARTICIPANTS NEEDED FOR RESEARCH IN ACCESSING SOCIAL SERVICES

I am recruiting for a study that involves individuals who have lived experiences with disability (e.g, physical disabilities, chronic illness, learning disability, mental health, neurodivergence or other), who have accessed social services in the Waterloo-Wellington Region, are between the ages of 18-30, and have lived in the Waterloo-Wellington Region for 2+ years.

Participation will involve a one-on-one interview that will take 30-60 minutes of your time. Interview questions will focus on your experiences with accessing social service agencies in the Waterloo-Wellington Region.

Please feel free to contact me at vikeno@uwaterloo.ca

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board.

(For reddit purposes, you are allowed to contact me through private or direct messages.)

Appendix B

This is the second recruitment post I had sent out on the social media avenues as I had made an amendment to my ethics protocols.

PARTICIPANTS NEEDED FOR RESEARCH IN ACCESSING SOCIAL SERVICES

I am recruiting for a study that involves individuals who have lived experiences with disability (e.g, physical disabilities, chronic illness, learning disability, mental health, neurodivergence or other), who have accessed social services in the Waterloo-Wellington Region, are between the ages of 18-30, and have lived in the Waterloo-Wellington Region for 2+ years.

Participation will involve a one-on-one interview that will take 30-60 minutes of your time. Interview questions will focus on your experiences with accessing social service agencies in the Waterloo-Wellington Region.

Participants will receive a \$10 gift card to Tim Horton's or Starbucks in acknowledgement of their time.

Please feel free to contact me at vikeno@uwaterloo.ca

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board.

(For reddit purposes, you are allowed to contact me through private or direct messages.)

Appendix C

This is the screening questionnaire that I used for participants who responded to the recruitment post.

Name:

Email:

Are you between the ages of 18-30?

How long have you lived in the Waterloo-Wellington Region?:

Do you have lived experiences with disability (e.g. physical disabilities, chronic illness, learning disability, mental health, neurodivergence or other)?: Y/N

Have you accessed social services in the region?: Y/N

Appendix D

This is the consent form that both the participants and I signed for my study.

CONSENT FORM

By agreeing to participate, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the information letter about a study being conducted by **Meg Gibson and Victoria Ikeno** of the Department of **Social Development Studies** at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that I have the option of allowing my interview to be audio recorded to ensure an accurate recording of my responses. If you would find a written interview more accessible, we can send you a link to the questions in an online survey format I am also aware that with my permission, excerpts from the interview may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous.

I was informed that I may withdraw my consent at any time without penalty by advising the researcher.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB #44479). If you have questions for the Board contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or reb@uwaterloo.ca.

For all other questions contact **Victoria Ikeno** vikeno@uwaterloo.ca

Meg Gibson margaret.gibson@uwaterloo.ca

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

YES

NO

I agree to have my interview audio recorded.

YES

NO

I agree to the use of anonymous quotations in any thesis or publication that comes of this research.

YES

NO

Participant's name: _____

Verbal consent was obtained.

Participant's signature: _____

Researcher's signature: _____

Date: _____

Appendix E

This is the study information that I had sent out to the participants.

Study Information Form

You are being asked to participate in a research study. To help you make an informed decision regarding your participation, this letter will explain what the study is about, the possible risks and benefits, and your rights as a research participant. Please take your time to review this study information form and discuss any questions you may have. You may take your time to make your decision about participating in this study and you may discuss it with your friends or family. This study information form may contain unfamiliar words. Please ask the interviewer to explain any words or information that you do not clearly understand.

This study is being conducted for a senior honours thesis in the Social Development Studies Department through the University of Waterloo, supervised by Dr. Margaret Gibson. This study is being used to investigate what disabled young adults'/ young adults with disabilities' experiences with social services in Waterloo-Wellington Region. There has been some preliminary work done on relevant topics to this study, but none that have targeted the Waterloo-Wellington Region, specifically.

Participation in this study will not provide any personal benefit to you.. The benefit to society is that the social service agencies will be able to see where there are potential pitfalls in the services they provide, and possibly improve how they approach individuals who come through their doors.

You are being invited to participate in a research interview about your experiences – both positive and/or negative – of accessing services in the Waterloo-Wellington Region as a young adult who has lived experience with disability. For this project, disability is defined broadly to include any combination of physical disability, learning disability, mental illness/ psychiatric/ Mad identity, sensory disability, deaf/ Deaf identity, intellectual disability or neurodiversity.

The interview will take about 30-60 minutes. You can stop at any time or take a break and come back, or ask for clarification. The interview will focus on your experience accessing services, and your suggestions on how things could be improved. I will also be asking some questions regarding demographics such as race, gender, age, etc. These questions will allow me to describe the sample of people I interviewed and to put experiences into context (e.g., if people say that gender is an important part of their experience).

This interview will be conducted using video call platforms (e.g, Zoom) or phone calls.. If you would find a written interview more accessible, we can send you a link to the questions in an online survey format (e.g., Qualtrics). Transcription will be done by me or an online transcription

program (e.g., Otter.ai) who will not know your identity. Once the audio recording has been transcribed, this recording will be deleted.

In order to participate, you must be between ages 18-30, identify as having a disability, have been living in the Waterloo-Wellington Region for more than 2 years, and have had lived experiences with social service agencies in the region.

This study is voluntary and participants are able to leave the interview whenever they want if they feel uncomfortable answering the questions pertaining to the interview. Participants are allowed to choose not to answer a question if they wish to. In acknowledgement of your time, we will send you a \$10 gift card to either Tim Horton's or Starbucks, per your choice. We can contact you with the findings of the study.

There is always a risk that speaking about your personal experiences might bring up uncomfortable or unpleasant emotions and thoughts. If you think that this might be the case for you, you can ask to see the questions in advance and determine if you need any additional support with you at the interview. You can decide against answering particular questions, or against participating at all. It is okay to take a break or end the interview at any time.

The interview will be conducted over an online platform, Zoom (or Qualtrics if the interview is conducted in a written format). Zoom and Qualtrics have implemented technical, administrative, and physical safeguards to protect the information provided via the Services from loss, misuse, and unauthorized access, disclosure, alteration, or destruction. However, no Internet transmission is ever fully secure or error free.

Your participation in this study will be considered confidential. Identifying information will be removed from the data that is collected and stored separately. Your name will not appear in any paper or publication resulting from this study, however with your permission anonymous quotations may be used. Collected data will be securely stored for a minimum of one year on a password protected external hard drive. You may withdraw your consent and request that your data be deleted by contacting me up until my thesis draft is submitted in November 2022.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB #44479). If you have questions for the Board, contact the Office of Research Ethics at 1-519-888-4567 ext. 36005 or reb@uwaterloo.ca.

If any questions arise please contact myself, Victoria Ikeno, at vikeno@uwaterloo.ca, or the principal investigator, Dr. Margaret Gibson, at margaret.gibson@uwaterloo.ca.

Thank you for considering participation in this study.

Appendix F

These are the questions that I asked during the interview.

Thank you for meeting with me. As you know, this project is about the experiences of young disabled adults who have used social services in Wellington-Waterloo county. I'm interested in knowing about the kind of work that people have to do to learn about services, find the right services, deal with gaps, and generally get their needs met. I have a series of questions but this can also be a flexible conversation, so we don't have to follow the exact questions in order. You can also let me know if you have questions about what I am asking and I can clarify things.

- 1. What can you tell me about your experiences with the social service agencies in the area?
 - Do you have an example/ story of a time that things went well?
 - Do you have an example/ story of a time when things didn't go well, or you couldn't find what you needed?
 - Had you received children's services before? If so, what was the transition to adult services like?
 - Did you receive social services in another region? If so, what did you notice about the shift to W-W?
 - Has anyone helped guide you or given you tips as you went?
- 2. Did you feel like your needs as a disabled young adult/ young adult with disabilities were met with the institutions that you accessed?
 - Did you feel the need to go somewhere else if you felt like your needs weren't being met? If so, how did you figure out that plan?
 - What kind of things have you had to learn how to do in this process of looking for support?
 - Have you ever felt like you were being told some of these problems were "your fault" or blamed when you didn't get supports? Can you think of an example of when that happened?
 - Is there a certain kind of support or service that is especially tough to find? Any thoughts on why this is so hard?

Have you found that who you are affects how service systems interact with you? (E.g. gender, race, sexual orientation, type of impairment/ disability, class background)

3. Are there any policies or other changes that you think would make your life easier in the region?

- Why do you think this change hasn't happened yet?

- How can others help make this happen?

4. Is there anything else you want people to know about being a disability-identified young adult using social services in the region?

Appendix G

This is the feedback and appreciation letter that was sent after the interview.

Feedback and Appreciation

I wanted to thank you for your participation in this study. This study is being used to investigate what individuals' lived experiences have been like with the social services that are in the Waterloo-Wellington Region. Your contribution will be part of informing researchers, service providers, educators, and policy makers. This work will also contribute to larger conversations about community, inclusion, justice, and support. As we discussed, I will be emailing you a \$10 gift card in acknowledgement of your time. Please let me know if you do not receive this within 2 weeks.

The full information about the project is available on the information and consent letter you received at the interview. Here are some highlights:

How can I learn more about the study's findings?

Findings from the study will be presented in a thesis paper for the Social Development Studies department at Renison University College, University of Waterloo. Findings may also be presented in a policy brief, community report, and/or outreach presentations to local organizations. All findings will be presented anonymously and participants' identities will be strictly protected. Project summaries and documents may also be posted on the faculty supervisor's research website: <https://uwaterloo.ca/scholar/m23gibso>.

Please contact the researchers listed below if you would like to receive updates or have any questions.

The anticipatory date of finding to be published will be January 6, 2023.

Who is funding this study?

This study is not funded through any organization.

Has the study received ethics clearance?

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB #44479). If you have questions for the Board, contact the Office of Research Ethics at 1-519-888-4567 ext. 36005 or reb@uwaterloo.ca.

Who should I contact if I have questions regarding my participation in the study?

If any questions arise please contact the lead student researcher, Victoria Ikeno, at vikeno@uwaterloo.ca, or the faculty supervisor, Dr. Margaret Gibson, at margaret.gibson@uwaterloo.ca