

**TRANSNATIONAL NARRATIVES OF ACCESS: VISUALLY IMPAIRED
ACTIVISTS IN CANADA AND CUBA IN CONVERSATION**

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Table of Contents

Acknowledgements.....	p. 3
Becoming Disabled.....	p. 4
Theoretical Underpinnings of my Research.....	p. 10
Methods: Conversations in Cuba.....	p.16
Autoethnography, Qualitative Interviewing and Focus Groups.....	p. 16
Preparing for Cuba.....	p.21
In Cuba.....	p.24
Themes from Blind and Visually Impaired Activists in Cuba.....	p. 26
Overview.....	p.26
Community, Support and Belonging.....	p.28
The Right to be Included.....	p. 33
Independence.....	p.38
Stories.....	p. 40
Discussion.....	p.45
The Cuban Revolution and Grassroots Movements.....	p. 45
Education.....	p. 49
The Rights of Cubans with Disabilities.....	p. 51
Gender Dynamics.....	p. 56
What I Learned and Where I Want to Go.....	p.59
Conclusion.....	p. 60

To my dad Toby, this project and degree are for you. You found out I was accepted into this Masters program a few months before you passed away and you were so proud. You taught me to seek out adventure and live in the moment. To be curious and push the boundaries of possibility. I love you.

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Becoming Disabled

I woke up in the dark and looked around. Nothing. The doctors and nurses were whispering. What happened? Be patient, your vision will come back soon. They didn't say anything about losing my vision from the surgery. What happened? Be patient, your brain is inflamed from the surgery. It will come back soon. Waiting,

waiting, nothing. What happened? We don't know. Whispering confused darkness. What happened? A stroke, you had a stroke. You are blind.

Oct 24, 2014

My interest in disability activism began in 2015. I lost the majority of my vision suddenly at the end of 2014 when I was 19. Overnight, my identity changed. I spent a month in multiple hospitals, where doctors and hospital staff struggled with how to treat me, a newly visually impaired person. Eleven days after the stroke, I regained a small window of central vision.

I sat at a table, Mom on my left, Dad on my right. Dad put a cardboard package of soap in my hands and asked me what it was. I sniffed it and figured out it was soap. My parents went back to their phones. I twisted and turned the package. Nothing. Focus. Twist and turn, twist and turn. A glimpse. Focus. Twist and turn, twist and turn. "Hey, does that say two times nine zero gee?" My parents looked up and asked me to repeat what I had just said. "It says 2 x 90 g." I looked over at my arm and saw a faint patch of freckles. We burst into tears. Some of my vision was back.

November 4, 2014

I have learned to navigate the world in a new way as a visually impaired person. I have taught myself to use screen readers and learned to walk with a white cane. I quickly

found out that the public treated me differently as a visually impaired person. Many people spoke loudly and slowly while interacting with me, or they ignored me when I asked for help. Strangers would often grab, pull, or push me, instead of using verbal directions or instructions.

In order to acquire a guide dog, I had to first become skilled at traveling with a white cane, which proved to be challenging. My body was always bracing in anticipation of hitting obstacles in my travels. Every time I encountered a crack in the sidewalk, my cane stabbed me in the stomach. These factors were even greater catalysts for me to acquire a guide dog.

Eventually, in mid-2015, I received the call that there was a guide dog waiting for me. I travelled to The Seeing Eye in Morristown, New Jersey, where I met and trained with my first guide dog, Grainger. Grainger was a wiggly black lab whose front end did not always communicate with his back end. He changed my life. I remember the lump in my throat as we walked our first route together. The sense of freedom, of possibility, was palpable. I returned home a month later with a new partner, a new friend, and a boundless sense of freedom.

My sense of freedom and boundlessness shrunk soon after I returned from training with Grainger as I faced access denials to everyday businesses who did not want a dog in their store. I also experienced public interference from strangers wanting to interact with Grainger. I had a new, extraordinary aide to help me get around, yet society's ignorance prevented me from moving with ease.

I went out with some newfound friends during my first year back after losing my vision. We wandered away from the University of Victoria towards downtown and beyond. We walked and walked and walked. The sun was shining and we were laughing by the ocean. We explored the city and ended up at a hot dog joint to get lunch. As we all walked in, the owner singled me out and demanded that I prove my dog was working. We were all stunned. Grainger had just guided me through traffic, along busy streets, steady and consistent. Prove to whom? Who was this man? Why was I the only one being called out for being in a restaurant? Did the man want to see everyone else's ID? Or do a test to see if everyone wearing glasses actually needed them? I shrunk. I didn't have Grainger's ID on me. The man refused service and told me to leave. Kicked out.

September, 2015

Throughout my time as a visually impaired person, I have found that I am more disabled by the actions of people around me than by my visual impairment. This has led me to wonder about the experiences of other visually impaired people around the globe.

In 2018, I traveled to Cuba for an anthropology field school. I spent a month traveling around the country with the help of another person to guide me. I noticed that Cubans treated me differently than people in Canada. In Canada, people are often looking down at their phones and don't take the time to help me. In Cuba, I had the sense that people were looking out for me. Strangers in the street would call out "be careful" in Spanish when I was approaching an obstacle with my guide. Bystanders would tell me to

take my time while I was guided up some stairs. Some would reach out and take hold of my other elbow as my guide was leading me off a curb or over an obstacle in the street.

The bus carrying our anthropology field school arrived at a beach. We made our way along a street above the ocean and arrived at the top of a staircase leading down to the sand. My guide and I paused. My guide explained that the stairs were steep and uneven. Some steps were deep, some shallow, and there were no railings. As we began our descent, a passerby stopped what he was doing and came to take hold of my other elbow. He assisted me until we reached the sand. I said thank you and he went back up the stairs and on his way.

May, 2018

I experienced a difference in how people are with their personal boundaries in Canada compared to Cuba. It seems that in Canada, many people value individuality, autonomy, and personal space. But in Cuba, it was not out of the ordinary for a stranger to reach out to help me by holding onto my elbow as I stepped off a curb or guiding me to a safer path. I found that many Cubans seemed to understand that there are physical barriers everywhere in their country for people with disabilities, and they seem to try to help when they can. For example, in Santiago de Cuba, a man set up a makeshift wheelchair ramp outside of his store to help a customer in a wheelchair. There were also signs on some buildings in Havana that contained Braille. In the years following my visit, I learned that Cuba has a school for the blind in every province and that all children learn about disability, no matter what school they attend (Monteagudo, 2001).

I have pondered quite a bit the idea of people grabbing or taking hold of me in an effort to help. In both Canada and Cuba, I have experienced this. After visiting Cuba for the second time, I realized what makes the two countries different. In Canada, I find the grabbing is jarring and unwanted. I am often going about my business when someone stops me by holding my arm and tells me I am doing something wrong. Often when I am grabbed like this, people will also say something like, "You're in the way." Throughout my travels in Cuba, strangers and people I had just met grasped my arm to assist me in achieving my goals, whether that was stepping off a curb or going down a set of stairs. I found their actions comforting.

My experience in Cuba in 2018 left me wanting to learn more about what it is like to be a blind or visually impaired Cuban citizen. I had my own experiences as a visitor. I wondered whether my experiences were similar or completely different from people who reside in the country. Overall, I have found that as a visually impaired person living in Canada, I may be treated as an outsider in any given situation. I don't know how I will be received. This contrasts with my experience in Cuba, where I felt taken care of, and looked out for.

In this Major Research Paper (MRP), I will explore my own experiences as a visually impaired person navigating the world. I have included autobiographical vignettes of points in time that stand out for me since acquiring my disability. The MRP will also

explore the experiences of eight blind and visually impaired Cubans. I traveled to Cuba in late April 2023, and I interviewed participants over the span of a morning.

Theoretical Underpinnings of my Research

I entered this degree program and MRP with an open mind, wanting to learn about disability through different lenses. I have learned that there are many theoretical frameworks that work in conjunction with Critical Disability Theory, and I have drawn from aspects of Critical Legal Theory, Critical Race Theory, and Feminist Theory to better understand my own experiences and the experiences of blind and visually impaired Cubans. I also acknowledge the importance of taking an intersectional approach throughout my research and reflections. Above all, I aim for my work to be emancipatory and empowering for both the participants and for me.

First and foremost, I drew upon Critical Disability Theory throughout my work. In their paper *Stories of Methodology* (2016), Margaret Price and Stephanie Kerschbaum write:

... critical disability studies (CDS) is itself a methodology, one that involves scrutinizing not bodily or mental impairments but the social norms that define particular attributes as impairments, as well as the social conditions that concentrate stigmatized attributes in particular populations... it is about studying broken systems, broken attitudes, broken gazes. (p.19)

Critical Disability Theory emerged in the 1970's as part of the disability rights movement (Meekosha & Shuttleworth, 2009). Advocates fought and continue to fight against the use of the medical model for disability. The medical model puts forth that disability is a problem within an individual; people are disabled by their own impairments and not by any other factors (Marks, 1997). Critical Disability Theory offers numerous approaches to disability, all of which diverge from the medical model. Using a critical disability framework is imperative for the advancement and improvement of all systems that impact the lives of disabled people.

Critical Legal Theory contends that the law impacts every system in society and is not applied equally to all citizens. It separates the law from all other aspects of life.

Tammy Bernasky, author of *Working to End Gender-Based Violence in the Disability Community* (2022) states:

... law itself is not applied in a vacuum: legal outcomes are determined by political and social contexts and, frankly, the people operating within these systems. This framing is important because it takes power dynamics into account, understanding that the law reflects class interests and relations of power. (p. 20)

Throughout my time as a disabled person, I have interacted with the law numerous times. I have encountered laws that negatively impact disabled people and

learned of laws that are outright ignored. It seems to me that being aware and knowledgeable about the law is necessary for disabled people to advocate for themselves.

I was trying to get breakfast in Vancouver before attending a long, demanding medical appointment. The closest cafe was a block away from the appointment. When my dad and I walked into the cafe, a man behind the counter, the owner, said, "No pets allowed, take it outside." When we explained that Grainger was my guide dog, the man disappeared into the back. He resurfaced a few seconds later, saying again that "the dog is not allowed." We went back and forth and he again disappeared into the back. A woman behind the counter began to take our order when the man returned, claiming that he was allergic to dogs and did not want us in his restaurant, even after we told him it was illegal to deny service to a guide dog team. We left. My dad filed a human rights complaint on my behalf because the process is onerous, and I was feeling overwhelmed. In the filing, we asked that the owner acknowledge that he discriminated against me and commit to not doing it again. He has evaded all attempts to be served on this human rights issue. It's been three years. In the middle of all of this, my dad passed away. Now the open case rests solely on my shoulders. Right before the human rights tribunal had planned to have a hearing without the café owner, he decided to respond. This incident and process has made me question the idea of justice. How is it that a café owner can discriminate against a patron, avoid all attempts

to be served, and then decide to participate three years into the matter? What at the end of all of this will be justice?

November, 2022

Feminist Theory seeks to understand how gender plays a role in inequity.

Rodriguez et al. write that there are some key characteristics of feminist research. These include a goal to conduct empowering research and an emphasis on alternative ways of conducting research (2011). Feminist scholars have been at the forefront of conducting research with marginalized populations and I intend to follow this tradition (Rodriguez et al., 2011).

Feminist Theory and Critical Race Theory posit that gender and race respectively are socially constructed and used as a way of oppressing certain groups of people in all aspects of life. Adrienne Asche, author of *Critical Race Theory, Feminism, and Disability: Reflections on Social Justice and Personal Identity*, believes that both Critical Race Theory and Feminist Theory include groups of individuals who are marginalized. These groups “... must be better understood by the larger society, and that the law should look not to wrongs of perpetrators but to helping those who have been victims of discrimination” (p.394).

Using Feminist Theory and Critical Race Theory throughout my research allows me to better understand the complexities of how I live as a disabled person. It also allows me to better understand how the people I met in Cuba live with their blindness and visual impairments. Every aspect of an individual must be considered when looking at how they

experience life, and this is why I am working from an intersectional approach. Audre Lorde, a prominent Black feminist activist, wrote, “There is no such thing as a single-issue struggle because we do not live single-issue lives” (1983, p.138). This statement resonates with me and with the concept of intersectionality. Carbado et al (2013), authors of *Intersectionality: Mapping the movements of a theory*, believe that intersectionality is a continuous entity that can and must change as new issues arise.

Hankivsky, author of *Intersectionality Based Policy Analysis Framework* (2012), identifies eight guiding principles to consider when looking at intersectionality. These principles are:

- 1) Recognizing intersecting categories: It is important to consider how different conditions interact with one another given the time and place in which they occur.
- 2) Multi-level analysis: It is critical to consider all levels of intersectionality within society, including, “macro (global and national-level institutions and policies), meso or intermediate (provincial and regional-level institutions and policies) and micro levels (community-level, grassroots institutions and policies as well as the individual or self)” (p.35).
- 3) Power: Power is socially constructed and exists in all societal interactions. A person can simultaneously experience power in some areas and oppression in others.
- 4) Reflexivity: Practicing reflexivity requires that a person commits to ongoing dialogue with participants who are historically marginalized. It challenges the power dynamics that exist and forces the researcher to be aware and conscious of their actions.

5) Time and space: “Time and space are not static, fixed or objective dimensions and/or processes, but are fluid, changeable and experienced through our interpretations, senses and feelings, which are, in turn, heavily conditioned by our social positioning/location” (p.37).

6) Diverse knowledges: It is imperative to know about the power dynamics in terms of knowledge production in academia. Often, the people being cited are people with a lot of power. This is why it is essential to know who is creating knowledge and being cited in order to change the power dynamic.

7) Social justice: Practicing intersectionality is inherently social justice.

8) Equity: Equity, “... exists when social systems are designed to equalize outcomes between more and less advantaged groups” (p.38).

This thorough analysis of intersectionality provides a solid foundation for my work, both in reflecting about my own experiences and while inquiring about the experiences of blind and visually impaired Cubans.

I chose to include my own experiences in my MRP because I believe that storytelling is an effective way of engaging people. Jijian Voronka (2019) argues that, “individual storytelling practices now get processed through resiliency and recovery meta-narratives that continue to position both the problem and its potential solution at the level of individual bodies” (p.8). I provide narratives that engage my audience and help me explore my feelings about these experiences. It has at times been difficult to relive experiences that are painful or uncomfortable, but I have tried my best to take breaks and deep breaths. This work is important. I believe that by sharing my own experiences,

others can either relate to or learn about my experience as a visually impaired Canadian activist. Adams & Ellis (2013) write that telling one's story, "... creates a space for a turn, a change, a reconsideration of how we think, how we do research and relationships, and how we live" (p.21).

Methods: Conversations in Cuba

Autoethnography, Qualitative Interviewing and Focus Groups

I use two methodologies in this MRP: autoethnography and interviews. This section will go into detail about both methods. I will also explore focus groups as a way of gathering information from a group of people. I did not know before arriving in Cuba whether I would conduct interviews or a focus group with the participants, therefore I investigated both possibilities.

Autoethnography uses personal experience to critique or prove a point about the circumstances in society. Autoethnographic research is used to, "(1) purposefully comment on/critique practices; (2) make contributions to existing research; (3) embrace vulnerability with purpose; and (4) create a reciprocal relationship with audiences in order to compel a response" (Adams & Ellis, 2013, p. 22).

To learn more about the lives of blind and visually impaired Cubans, I set out to connect with blind and visually impaired activists specifically. An activist is someone who takes social or political action to improve the lives of a specific group (Bobel, 2007). In this case, I wanted to find people who, either through their actions or words, were working to educate the public about what it is like to live as a blind or visually impaired

person. I wanted to speak with activists because I identify as one and wanted to learn from people trying to improve the lives of blind and visually impaired people. I traveled to Cuba to hear directly from individuals. This MRP will explore themes that arose from my conversations with people connected to The National Association of the Blind (ANCI) in Cuba and connect these themes with my own experiences as a visually impaired Canadian.

Ayesha Vernon (1997) writes about how to conduct research when you yourself are a part of the group you want to research. The following is an excerpt from her article *Reflexivity: The dilemmas of researching from the inside* (1997): “...my research is as much about my own experience as it is about others” (p.158). Vernon emphasizes that research that includes the researcher in the group being studied can never be free of bias. She states, “... the closer our subject matter to our own life and experience the more we can expect our own beliefs about the world to enter into and shape our work, to influence the very questions we pose and the interpretations we generate from our findings” (p.159).

I have taken care in all my interactions throughout this project. I tried my best to avoid making assumptions about anything and made sure to clear up questions I had and clarify any issues that arose. It is important to note that no matter my intentions, bias will always exist. This project is subjective and the themes that arise from it cannot be generalized to all blind and visually impaired activists. I was aware throughout my time in Cuba that the blind and visually impaired activists I met had their own stories; my purpose was to listen.

As I embarked on this project, I was aware of the power imbalance between the participants and me. As someone from the North interviewing people in the South, I made sure that my interactions were intentional. According to Barbara Heron, author of *Gender and Exceptionality in North-South Interventions Reflecting on Relations*, the North-South connection is, “usually cast in terms of an economic analysis that has been critiqued as a form of neo-colonial economic exploitation... Implied in such discourse is a mutually constitutive and unequal relationship of power which is fundamentally raced” (p.118). I was also aware throughout this project that two truths can exist at the same time. While there was a power imbalance between the participants and me, in terms of birthplace, we were also all visually impaired. Bernasky says that, “We may experience oppression in some aspects of our lives while simultaneously experiencing privilege in others” (2022, p.9).

In preparation for meeting with blind and visually impaired Cuban activists, I researched the best way to gather qualitative information from this population. I did not yet have an idea of the number of people who would participate, so I kept my options open. My two best options were to conduct a focus group with all the participants, or to carry out interviews with each individual participant. Breen (2006) writes about the difference between focus groups and one-to-one interviews. They say that focus groups are, “...far more appropriate for the generation of new ideas formed within a social context. In contrast, one-to-one interviews ought to probe individual experiences,

encouraging self-reflection on issues that could be distorted if social pressure were placed on the individual” (p. 466).

I first look at focus groups. According to George Balch and Donna Mertens, authors of *Focus Group Design and Group Dynamics: Lessons from Deaf and Hard of Hearing Participants* (1999):

Focus groups are particularly well suited to identify and describe in depth issues that are not well known or understood by the researchers. Focus groups are guided discussions among a small group (6–12 participants), in which the interviewer serves as a moderator. Participants are the experts on the topic, since the topic is what they think, feel, or do. (p.267)

A focus group would allow the participants to have conversations with each other instead of just the researcher. This could mean that, given the participants would be familiar with one another, they would be more open to an in-depth conversation. A focus group could allow participants to explore in detail the topics they like and take a lead role in directing the conversation. Balch and Mertens found that focus group members encourage each other to take the conversation beyond the “rhetorical or habitual” (1999, p.267). The focus group discussion, “may reveal important material that would not have emerged in direct questioning” (p. 267).

While focus groups appear to be an effective way of gathering rich qualitative data, there are a few practical reasons why this method may not be easily implemented.

Focus groups can be time consuming, and it can be difficult to find an appropriate space to host them. Another consideration for this research project was the need for translation between English and Spanish speakers. It could be difficult to translate and transcribe the recording of the focus group afterwards, especially if people are talking over each other. During the focus group, it could be challenging for the translator to translate simultaneous conversations. Additionally, there could be unintended noises that make it difficult to hear the recording if the recording device is not close to each participant.

One-to-one quantitative interviews were the other option I considered for gathering stories from blind and visually impaired Cuban activists. Carol Warren, the author of *Qualitative interviewing. Handbook of Interview Research: Context and Method* (2002) says, “The purpose of most qualitative interviewing is to derive interpretations, not facts or laws, from respondent talk” (p.2). This is fitting for the information I wanted to gather from participants: personal accounts of living as a blind or visually impaired Cuban. Interviewing participants would allow everyone to recount their own experiences without being persuaded or pressured by other participants in the room. At the same time, participants may not open up to me as much because I am an unfamiliar person.

Depending on the size of the space provided, interviewing could be the best option. If there is limited space, separate interviews with each participant would be a likely option. There are pros and cons to focus groups and one-to-one interviews and it was important that I fully considered these factors ahead of conducting either form of information gathering.

Whether I conducted a focus group or individual interviews, I wanted the process to be culturally responsive. In this case, culturally responsive alludes to the “instructional strategies which center equitable social power or cultural wealth within the learning environment” (Rodriguez et al., 2011, p.401). For my research in Cuba, it was important that I consider the backgrounds and needs of the participants, as they gathered to share their stories with me. In addition, Rodriguez et al. state that a culturally responsive approach, “acknowledges how dominant culture paradigms limit the ways in which knowledge is created and provides an alternative framework as to how knowledge can be constructed and understood” (2011, p.401). As a Canadian who has been primarily exposed to Western literature and scholars, I was keenly aware of my limited knowledge as a researcher. This is why I approached this research with an open mind and reached out to experienced scholars for help. I approached this research with care and respect.

Understanding that people’s realities are varied is essential when orchestrating a focus group or conducting interviews. Rodriguez et al. argue that “People’s ways of knowing come from their own mental derivations due to their particular experiences and contexts, and, as a result, acknowledging multiple realities is essential in the interaction between the researcher and Participants” (2011, p. 402). There is more than one way of knowing and looking at the world.

Preparing for Cuba

My first step in completing my MRP was to submit my proposal, the MRP Protocol Form, the Consent Form, and a script to the Critical Disability Studies Ethics

Committee at York University. The Consent Form and interview script were roughly translated into Spanish using Google Translate for participants to read ahead of time. The general questions for participants to consider were:

1. Where have you found the greatest sense of community as a blind/visually impaired person?
2. How has being blind/visually impaired impacted your life?
3. Who/what have you found to be the most helpful in your life as a blind/visually impaired person? Who/what have you found to be the least helpful?
4. Tell me about your activism work to improve the lives of visually impaired/blind people.
5. Are there any other stories or thoughts you want to share?

I submitted all of the necessary documents for approval at the beginning of April, 2023. Once my research was approved by the Ethics Committee, I used my connection with the spouse of a late blind friend in Victoria, B.C. to contact a blind man in Cuba. For the purposes of this paper, I will refer to this man as Luis, though this is not his actual name. To maintain anonymity, all participants will have pseudonyms. Ensuring anonymity is important, especially within a marginalized group (Balch & Mertens, 1999).

Luis was excited about meeting me and he was eager to help in any way he could. Using his connections, Luis reached out to blind and visually impaired colleagues in his

network to see if they wanted to participate in my research. This type of recruitment is known as snowball sampling. It involves a researcher connecting with a small number of people (for example, Luis), who then reach out to their contacts. This is one of the most popular ways of sampling in qualitative research, especially when investigating a specific population such as blind and visually impaired people (Parker, Scott, & Geddes 2019).

Through snowball sampling, Luis reached out to several of his colleagues at ANCI and seven of them agreed to meet with me. The participants had a breadth of expertise in different fields, from music to gender equity to sports and psychology.

Undertaking this research required strong advocacy, both on my part and on the part of my supervisor and advisor. There is no clear path to obtain funding for students with disabilities who need extra help, but my supervisor was steadfast and determined to help me find answers. I am so grateful for the support I have received. A large part of meeting with blind and visually impaired Cuban activists was determining how to navigate safely in the country as a visually impaired person. Given the uneven and unfamiliar terrain as well as the high temperature, I opted to bring a friend to guide me, rather than bring my current Seeing Eye dog, Maggie. My long-time friend, Nora Loyst, is an experienced guide. She flew to Toronto, Ontario, from Victoria, B.C. and accompanied me to Cuba. A Cuban friend of my supervisor named Jorge organized our trip to Luis' town. Jorge also served as the translator for our trip.

In Cuba

Luis offered his house as a meeting space for Nora, Jorge, the driver, the other participants and me. Jorge, the driver, Nora and I left at 5 a.m. in a 1960's Cadillac for the three-hour trip to Luis' house. We arrived ahead of schedule and Luis greeted us with enthusiasm. He took hold of my hand and guided me up a tight spiral staircase to his apartment on the second floor of the building. I was amazed at how easily Luis moved in his environment. He navigated with ease. As a visually impaired person, I find it difficult to climb up and down stairs. Luis, on the other hand, flew up and down the steep steps. Luis' sisters, mother, and niece all greeted us inside and then served breakfast. Once we'd eaten, Luis showed us around his place, which included a living room and kitchen on the main level and a bedroom and bathroom up another tight spiral staircase.

I quickly realized that the space where I would talk with blind and visually impaired Cuban participants was Luis' bedroom. This area had a cool breeze coming through the window and was relatively quiet compared to the rest of the house. The room had enough space to fit four people comfortably, so I decided to do individual one-to-one interviews. I sat on the bed and asked questions of the participants, who sat on the same bed facing me. Jorge sat on another bed and translated while Nora took notes at a desk at the other end of the room. The interviews were recorded.

Though I was speaking to one participant at a time, I tried to add my own relevant experiences if they made sense with the participants' answers. This made the conversation flow more easily and I believe it made participants more comfortable. I

wanted participants to gain something from participating in the interview, rather than simply telling me their experience.

I interviewed Luis first. Once we finished, Luis brought each participant up the stairs, one at a time, and helped them get situated. Luis had a way of making people feel comfortable, something that was clear throughout the whole visit. After every interview, he'd ask Nora, Jorge and me if we needed water and he offered us many snacks. I sensed that Luis was a leader in his community and a mentor to the people around him. He told me, "My house is actually a center for rehabilitation. On Saturdays, people come here and we gather and we teach them how to cook, do laundry, do their beds, and put their clothes on. We also teach them mobility." It was clear that Luis' house was a good place to host the interviews because the participants felt comfortable there.

Once all the interviews were completed, we congregated downstairs in Luis' living room. Some of the interview participants sang a lovely song for the group, and then we had a mini dance party. I was giddy with excitement. The people I met were so generous with their time and kindness. Luis offered to serve us lunch, but unfortunately, we had to begin our journey back to our lodging. Nora, Jorge, and I left Luis' house with grins on our faces from the people we met.

Upon my return to Canada, my main goal was to find someone who could transcribe the recording of the interviews and then translate the Spanish into English. I wanted to do this because, although Nora took notes and Jorge translated the conversation live, reviewing and translating the recording would be the best way of getting the most

detail from the interviews. My friend from Colombia, Felipe Camacho, agreed to transcribe and translate the recording, which took about two weeks.

Once the interviews were written in English, I read the transcription and identified repeating themes and ideas from the participants. Sometimes the participants said precisely how they felt, and other times they told stories or anecdotes to illustrate a feeling. When they did the latter, I interpreted what the participant said and created a label for it. For example, if a participant said that they met often with people from ANCI and found comfort in the ANCI programs they attended, I would label this as “strong sense of community.” As I progressed through the transcription, reoccurring themes emerged. From my analysis, I created the following categories: Community, Support, and Belonging; The Right to be Included; Independence; Stories.

Themes from Blind and Visually Impaired Activists in Cuba

Overview

I began this quest to learn about the lives of blind and visually impaired Cubans and see how these experiences compared to my own, as a visually impaired Canadian. The information I garnered from the eight interviews I conducted confirmed that my experience as a visitor to Cuba in 2018 was similar to that of the everyday lives of blind and visually impaired Cuban activists. In this section, I will first introduce each participant. I will then explore common themes that emerged from the interviews. I will also include some of my own experiences regarding these themes.

Luis helps children with low vision succeed in school. Throughout our interview and visit in general, Luis' enthusiasm for helping people was apparent. In our interview, he described how excited he becomes when one of his students succeeds in their passions. These passions can be something they love doing or find life affirming. Luis is a mentor for blind and visually impaired people. I sensed throughout my visit that the people around him, both sighted and not sighted, had a great deal of respect for him. Luis lost his sight when he was nineteen and has been a part of ANCI since then.

Alfonso is a retired member of the cultural board at ANCI, where he helped people pursue both their personal and professional interests.

Ernesto is involved with ANCI through sport. He plays many sports including chess and judo. ANCI reached out to him while he was in the hospital after he lost his vision. They asked him what he was eager to pursue, and when he told them sports, they helped him achieve his goals.

Maria works in public relations at ANCI. She has always been with ANCI because her father used to be the president of ANCI. She is studying communications in university and loves to educate people about blindness and disability through media. This includes print media, film media, and social media.

Valeria helps people who are blind and visually impaired learn to use iPhones and other forms of technology through her role at ANCI.

Benita is the vice president of ANCI for the province she lives in. Before she was vice president, she taught teachers in regular schools how to teach and best support blind and visually impaired students.

Lucia is with the gender equality commission for her province at ANCI. She also works in a special school, teaching music. Lucia teaches students music, using Braille, and helps them learn to play all sorts of instruments. She also offers voice lessons.

Diego is a psychologist who works at a hospital, tending to patients on the orthopedic, urology, and angiology wards. In addition, he has his own practice, where he works with adults and children. Diego is also an announcer for the events that ANCI hosts around the province.

Community, Support and Belonging

The main theme from the interviews was the sense of community and support that the participants have, particularly within ANCI. Luis informed me that “... each province has a provincial headquarters, and within the province, each municipality has their own municipal headquarters as well. They tend to visually impaired people across the entire country.”

Several participants talked about how they felt lost and depressed when they initially lost their vision. They worked through these emotions with the help of people from ANCI. Ernesto said:

After losing my sight, almost everything I have and all my achievements has been thanks to ANCI. I was hospitalized and they came to visit me. As soon as you start losing your vision, you go through a process that includes a psychological evaluation, especially when the sight starts degenerating too quickly. During that process, ANCI was there to help me, and asked me which activities I wanted to do, so I signed up for sports. Through sport, I have been able to travel both inside and outside the country.¹

Similarly, Alfonso spoke about his love of dance and theatre. He said that being able to develop cultural activities for ANCI members means a lot to him. He believes that his dance and theatre programs allow participants to feel included and work through whatever issues they are facing.

Maria spoke about the importance of ANCI in providing her with the skills to live with her visual impairment. “The change of being able to see a bit and then turning

¹ Después de mi pérdida de visión, casi todo lo que yo tengo, los logros que he tenido, ha sido vinculado a la ANCI con el deporte. Yo estaba ingresado, y allí fueron de la ANCI. Cuando uno pierde la visión, pasa por una etapa con psicólogo, porque es una pérdida de visión muy rápida, muy brusca y entonces ellos fueron allí, me ayudaron y desde ese día, ejemplo, me apuntaron que es lo que yo quería, me apuntaron al deporte y gracias al deporte he recorrido el país.

completely blind, impacted me a lot. My family's support and ANCI were vital for me, but most importantly, rehabilitation.”²

Benita also shared this sentiment. Before she became a vice-president at ANCI, she worked as a rehabilitation expert. She sought out blind and visually impaired people and encouraged them to get out of the house and into the community. She would take them to events to engage them in the community. I found this concept fascinating because it means that ANCI relies on the greater community to help inform them about people experiencing vision loss. If a member of the community learns that their neighbour or someone they know has lost their vision, they can reach out to ANCI.

Benita further states:

ANCI provides an integral rehabilitation. They accompany kids from a young age, when you start school, and you end up with a career as a professional, all the time with ANCI by your side. Once you're a professional you remain a part of the organization, linked through the different activities that they organize. ANCI gives people all the tools so that people with disabilities can become a part of society.³

² A medida que fui creciendo, al morir mi papá, me subió la presión de los ojos y fui perdiendo la visión poco a poco, es decir que ese cambio de ver algo y no ver, me impactó mucho. Y realmente, para mí fue importante el apoyo de mi familia, de la Asociación y fundamentalmente, la rehabilitación.

³ La ANCI te brinda una rehabilitación total. Abarca todo. Abarca desde, te acompaña desde las edades tempranas. Inicias la escuela, terminas con una carrera, siendo un profesional, Te va a acompañando todo ese tiempo y cuando ya eres un profesional pues sigues vinculado a ella, participando en las actividades. La ANCI te brinda todas las herramientas para que tú como persona con discapacidad visual logres tu plena inclusión social.

Benita provided the following anecdote about how ANCI has helped her:

I was born with this disability. As I grew older and realized I had a disability, it impacted me negatively. It was very difficult, as my family was over protective of me. When I became a teenager, I was approached by the then directors of ANCI, and they slowly motivated me to join the organization. It was a positive change, as I was able to join society. ⁴

Lucia says that all blind and visually impaired people, through hard work, are involved in society. “A lot of us will manage to be fully included into society, but it requires a greater effort from us than it would from someone who can see.” ⁵ Lucia also speaks about the activities ANCI organizes, including sports, recreation, and cultural events “... that help us be included in regular activities, as people with disabilities, but at activities usually aimed for sighted people.” ⁶

Lucia said that the most difficult part of being visually impaired for her is raising her children. With the support of ANCI and others in the same situation, she has been able to cope with the fear she experiences.

⁴ Nací con la discapacidad. Cuando fui creciendo, cuando ya tuve noción de que tenía esa discapacidad, me impactó de manera negativa. Fue difícil, por la sobreprotección que tenía por parte de mi familia. Fui una niña muy sobreprotegida. Cuando empecé la etapa de la adolescencia se acercaron a mí los dirigentes de la Asociación en ese tiempo y poco a poco me fueron motivando para incorporarme a las actividades de la ANCI. Y ahí sí fue diferente, fue ya positivo, porque pude incluirme y fue distinto. Tuve un cambio.

⁵ Mi punto de vista, no. Creo que hay personas que vamos a alcanzar la plena inclusión, pero tenemos que esforzarnos más que los videntes.

⁶ ... que nos ayudan a incluirnos en las demás actividades como personas con discapacidad y en las cosas de los videntes.

It is always scary, not because children cannot take care by themselves, but because we can't see them all the time in their environment. Like when you take them out to a park to play, that is scary, but thanks to what I've been taught, I can now control my own fear.⁷

Some participants also expressed a sense of well-being when helping others. Three participants spoke about the sense of happiness and pride they felt when the people around them succeeded. Luis said, "... I feel satisfied every day that people get to join everyday activities within society."⁸

Similarly, Valeria said, "I really like helping others. I feel a lot of joy when I manage to teach something new to others and help them achieve a feeling of self-improvement. That makes me really happy."⁹

Maria spoke about this pride in terms of growing as a person. She said, "One of the things that has moved me the most is self-realization. It motivates me to continue growing as a person and to be of service to society."¹⁰

⁷ Siempre hay un poco de miedo, no es porque los niños no se sepan cuidar, es porque uno no los puede ver en el ambiente en que van a estar. En el sentido que vayan a jugar, que tú los lleves a un parque, pero eso también lo he podido controlar, lo he podido controlar, ese miedo, ese impacto, ese miedo de hacer eso, lo he podido controlar.

⁸ ... me siento satisfecho cada vez que las personas pueden incluirse cada día más a todas las actividades de la sociedad.

⁹ Porque me gusta ayudar a otras personas. Me siento muy feliz cuando logro que otras personas adquieran un conocimiento, se sienta realizada. Aprendan cosas nuevas, eso me hace muy feliz.

Losing my vision was alarming and confusing, and it has taken me many years to figure out how to navigate as a visually impaired individual. With the support of my friends and family, as well as the (limited) funding of the provincial and federal government, I have been able to get back to a point where I feel that I am able to live a fulfilling life. Many of the doctors and medical staff I interacted with during my hospital stay had no awareness about the services available to blind people, the lives of blind people, or even how to interact with a blind person. One hospital administrator told me of her efforts to find resources to help me, saying “I have been working hard to find answers. It’s not the blind leading the blind here.” She realized right away that her comment was inappropriate. The way I was treated when I lost my vision was quite different from the stories told by the research participants in Cuba.

October, 2014

The Right to be Included

Luis spoke at length about how blind and visually impaired people have the right to be included in society. “It is a state policy to include people with a visual impairment in the workforce. People first need to study, and then they’ll get a job. You have the right to study any career at a university...”¹¹

¹⁰ Y para mí además, un motor impulsor para mí bienestar como persona con discapacidad ha sido la superación. Realmente, el superarme me ha motivado muchísimo a continuar mi desarrollo personal y de inclusión en la sociedad.

¹¹ Es política estatal. La persona estudia y luego tiene un empleo. Tienes derecho a estudiar cualquier carrera universitaria.

Luis believes that inclusion is paramount for blind and visually impaired people to succeed. He describes inclusion as blind and visually impaired people getting an education, working in a job, and participating in cultural activities.

Luis also explained that Cuba had signed a United Nations initiative regarding the rights of people with disabilities. The Convention on the Rights of Persons with Disabilities (CRPD) will be explored in greater detail later in this research paper. The Convention is an international agreement that lays out the rights of people with disabilities. I could tell that Luis was proud that Cuba signed this document because he smiled when he said “...when people start learning that they have certain rights, they realise they can demand for those rights to be fulfilled.”¹²

Maria emphasised that she feels at ease in her environment and in the places she travels throughout Cuba:

As a member of society, I feel very comfortable. I believe that in this country we have a great culture regarding people with disabilities, though we still need to keep working towards sensitizing society to understand how to treat and how to behave around people with disabilities. I feel included into society. But I still feel better with people from the blind and low vision community since they share

¹² a medida que las personas van conociendo que tienes derechos, puedes exigir más el cumplimiento de esos derechos.

similar experiences with me. But in general, I feel included and well treated by society.¹³

Luis explained that there are many types of schools for blind and visually impaired Cuban children. He said that there are specialized schools specifically for blind and visually impaired children in each community, as well as specialized schools for other children with disabilities. If parents do not want to send their blind or visually impaired child to a specialized school, they can send them to public school, where supports will be put in place to help the child succeed. Maria said that ANCI has representatives who teach public school teachers how to treat and help blind and visually impaired students who attend their schools.

The final person I interviewed, Diego, told me about his experience working as a psychologist. I was curious to learn about Diego's experience working amongst and with sighted people given some of my own negative experiences trying to find employment. What Diego shared surprised me and made me realise that Cubans, in general, have inclusive attitudes towards blind and visually impaired people. He said that he has had no problems in the 12 years that he's worked at the hospital. He reported that it took him awhile to learn how to navigate the hospital, but with the help of time and his co-workers,

¹³ Yo en la sociedad me siento muy cómoda, porque aquí en este país, se ha alcanzado un gran nivel cultural con las personas con discapacidad, aunque hay que seguir trabajando en sensibilizar a las personas para con nosotros: el trato, la forma, y que aprendan que esta persona con discapacidad como tratarla y todo el trabajo que deben de hacer con ella. Aquí me siento muy incluida, aunque para mí en lo personal yo me siento mejor con la comunidad ciega y de baja visión porque son las personas que saben... Que tienen los conocimientos de qué es una persona [con discapacidad]. Nos sensibilizamos los unos a los otros, compartimos experiencias, me siento mucho mejor ahí, aunque en la sociedad yo me siento una persona incluida y bien tratada.

he has been able to succeed. I asked Diego how his patients react when they learn that he is visually impaired. He answered:

So far, I haven't had any problems with my patients. At the beginning I thought that it would be too hard working with kids, but no, so far it has been good. I'm a father, I'm an uncle, and my patients, I see them as my own kids. During sessions I tell them to play and paint. As soon as you graduate, every professional has trouble working in the field they studied, whether you are blind or not. But with time you acquire the skills to perform better, and things become easier.¹⁴

I found what Diego said about his experience as a visually impaired psychologist fascinating and in direct contrast to some of my own experiences with employers. The following is a recount of an experience I had when looking for a summer job.

I met a potential employer for a trial-run as an afterschool care provider. I worked well with the other staff, handing out snacks for the kids and helping them settle in. We went outside and played in the forest, on the field, and throughout the playgrounds. It went well. At the end of the shift, the manager said I did very well but that she would not hire me because I was visually impaired.

May, 2018

¹⁴ Hasta ahora la relación con los pacientes ha funcionado sin ningún problema, incluso yo pensé cuando me gradué, que los niños me iban a dar trabajo, pero no. Soy papá, spy tío, y yo los niños que tengo en consulta, los veo como si fueran mis hijos y juego con ellos, los pongo a dibujar... A principio de graduado, todo profesional le da trabajo ejercer lo que estudió, al ciego y al no ciego, al vidente. Pero en función de que vas adquiriendo la experiencia, las destrezas, pues se va facilitando el trabajo.

Luis and Diego spoke about their perceptions of the inclusion of blind and visually impaired people in Canada. Luis had the perception that the Canadian government gives blind and visually impaired people everything they need which makes them stay at home and be less visible in their communities:

Canada, despite everything the government does for people to do well at home, it is not enough for them to feel included in society. In order to do so, you need to be employed, you need to be able to move, and be an integral part of society. It can't just be limited to be at home with your computer and having a phone to communicate with the pharmacy, or the supermarket. They'll provide everything so that you don't have the necessity to go out to the streets, but that is not inclusion.¹⁵

Similarly, Diego said that Cuba, unlike Canada, encourages its blind and visually impaired citizens to join the community:

... no one, nor the government nor our families prevent us from joining society.

You can travel to other provinces, to other countries, you can get married and

¹⁵ Quizá pueden, dirigirla más a la inclusión. Porque la investigación que ella está haciendo, a ver, la investigación es sobre inclusión. Es decir ella quiere comparar la inclusión de las personas en Cuba, con la inclusión de las personas ciegas en Canadá. Ella quiere demostrar que aún en Canadá es insuficiente lo que hace el estado. Porque el Estado te da todo lo que tú necesitas para que estés en la casa. ¿Entiendes? Pero eso no es suficiente. Eso no es suficiente, tú necesitas, para que haya inclusión, necesitas empleo, necesitas moverte, necesitas ser parte del todo. Eso es lo que es inclusión, ¿entiendes? Entonces cuando tú hablas de ser parte del todo no puede ser estar en la casa con una computadora, con un teléfono que tú puedas comunicarte a la farmacia, al mercado, que todo te lo traen a a la casa, como para que tú no tengas necesidad de estar en la calle.

move out of your house, and it'll be ok. And it's important for people to know this.¹⁶

Independence

Many of the participants spoke about independence in their interviews. Whether they talked about losing their independence when they lost their vision, or regaining their independence when they became a part of ANCI, it was clear that independence was something they valued. Luis described losing his vision at the age of 19:

It's like starting to live again, since you have to transition from a life being able to see, to a life based on your senses of touch and hearing. I have always been very independent, which made me feel like a prisoner when I started depending on other people to walk or to do anything at home. I wasn't able to do anything until I managed to overcome my impairment. I had to switch from writing in ink to braille. But now, after 35 years of being blind, I consider myself happy. I have achieved my professional and social expectations, and I believe I have achieved my full potential. What has helped me the most is having a strong will and the desire of being independent.¹⁷

¹⁶ nosotros, ni la familia, ni el gobierno, ni nadie, nos impide que nos podamos incluir a la sociedad, ¿ve? Usted puede viajar a otras provincias, a otro país, casarse irse fuera de su casa, vivir donde usted quiera, no pasa nada, y eso es algo que es importante que se conozca.

¹⁷ Es volver a vivir, porque es pasar de una vida de vidente a una vida totalmente táctil y auditiva. Siempre he sido muy independiente. Y entonces, me sentí preso de depender de otras personas porque necesitaba trasladarme o hacerlo todo en la casa, no podía, hasta que me rehabilité. Y bueno, pues, ahora, después de 35 años ciego, soy feliz, soy una persona realizada profesionalmente, socialmente y realmente me siento una persona realizada.

Many participants stressed that they wanted to be as independent as possible. In his interview, Luis said, “I’m completely independent. I do my laundry. I cook, I clean. I do everything by myself. My family supports me with those things that I can’t do by myself.”

Valeria emphasized how rehabilitation through ANCI has helped her to live an independent life. “It has been through rehabilitation that I can be independent. It has allowed me to be included in sectors like sports and culture. It has granted me access to new technologies, access to information and entertainment, without having to rely on other people’s help.” ¹⁸

Lucia described how, through her work with blind and visually impaired women, she is amazed by their strength and determination to be independent:

The will they (women) have to empower themselves in everything they do. Blind women, or those with low vision like myself, we struggle more while doing house chores, or when we go to work, so that requires us to be stronger. ¹⁹

¹⁸ La rehabilitación. Porque gracias a ella, he logrado tener autonomía. Además, incluirme en los diferentes sectores, como el deporte y la cultura. Además de tener el acceso a las nuevas tecnologías, tener el acceso a la información, al entretenimiento, sin tener que contar con la ayuda de otras personas.

¹⁹ Me ha sorprendido la capacidad de las mujeres ciegas para hacerse autónomas. O sea, el poder, las ganas de empoderarse sobre las cosas que hacen. Porque las mujeres ciegas o de baja visión profunda, como yo, pasamos mucho más trabajo a la hora de realizar las labores del hogar, de ir al trabajo, volver y hacer las cosas y entonces tememos que ser mucho más fuertes.

Stories

The final question that I asked, “Do you have any other thoughts or stories that you would like to share with me today” produced some surprising answers. I did not know what to expect from this question and I was struck by the sincerity of some of the answers, the humour in other responses, and the relatability of most of the comments. I will share some of the highlights here.

Luis said that when he became blind, he wanted to have a blind child. As someone with firsthand experience with blindness and a teacher himself, he felt that he was the perfect person to raise a blind child. “For me, there are no limits to my blindness.”²⁰ Luis has a stepson and grandchildren.

Alfonso had a measured and calm voice when he spoke. He told me about his difficulty in identifying people:

At the beginning I used to get easily confused and mix people up. Sometimes at parties I would approach a man, thinking he was a woman. And I have made mistakes while recognising people. I have suffered because of that, but like the old Cuban saying goes: “Hágale” (Let’s keep going).²¹

²⁰ Porque para mí no hay límites. Es decir, para mí no hay límites en mi ceguera.

²¹ Al inicio me confundía con muchas personas. Al llamar, ver un hombre, pensando que era una mujer. Así en fiesta, un ejemplo. Y me he equivocado unas cuantas veces y he sufrido. Pero bueno, como dice el Cubano, “pa’lante.”

Ernesto described one of his greatest accomplishments. “As an anecdote would be that I climbed the highest mountain in Cuba, Pico Turquino, while being visually impaired. That has been the most difficult thing I’ve done.” ²²

Maria spoke about her hope for the future and the progress she has experienced:

When I was little, I wanted to do whatever new thing I learned. So, during art school I wanted to become a violinist, and at the time, there were no one to teach about reading music in Braille. It was very hard for me to abandon that dream, as I truly wanted to become a violinist, or play the piano. And there were no books or teachers with the knowledge to teach me how to read music in Braille. But nowadays, I feel very proud that there is a kid at art school who can play the drums and you can see how much the country has advanced in that topic. And, even if I couldn’t do it at the time, I know that kids nowadays can follow that dream. ²³

²² Las anécdotas, sí, es subir así como ciego que subimos la elevación más grande que hay en el país que es subir el Pico Turquino. Es lo más difícil que yo he hecho.

²³ Decir que yo cuando pequeña que veía algo, yo estudié en la escuela de arte. Quería ser violinista. Y aquí, cuando, en ese momento no había una preparación, profesores, sobre la musicografía braille, por lo que para mí fue muy difícil abandonarlo, por, lo que yo digo, ese era mi sueño, ser violinista, tocar piano. Y en ese momento lo tuve que abandonar porque quedé ciega. Es decir no había ni libros, ni profesores preparados para impartirme musicografía en braille y en ese momento no estaban dispuestos a enseñarme. Pero, en el día de hoy me siento muy orgullosa porque hay un niño, ya hoy, en la escuela de arte que toca percusión y realmente se vio el avance y el desarrollo de nuestro país y sé que yo no lo pude hacer en un momento, pero sé que ya hay otros niños que van a tener esa posibilidad.

Valeria, and Benita separately told stories about crashing their bicycles. Both women laughed as they told these stories and by the end of each account, everyone in the room was giggling. I was laughing because these stories were so relatable to my own experiences. Nora was laughing because she is my friend and knows what being visually impaired is like, and I think Jorge was laughing in surprise.

Valeria was first: “When I was a little girl, I was learning to ride a bike, and I couldn’t see a man standing in front of me, so I ended up crashing into him.” ²⁴

Benita recounted her experience in detail:

... the last time I rode a bicycle, I don’t ride a bicycle anymore, because the last time I did I crashed into a man who was on a motorcycle. I was on my bicycle and, well I’m near-sighted so I can’t really tell if things are far or not, so I thought I was not going to crash into him. But the man does realize that I was about to hit him and he starts yelling “Niña, niña!”, but I didn’t understand. I end up hitting him. I fell to the ground and I hit my head against the side walk. I was so scared I promised I wouldn’t ride a bike anymore. ²⁵

²⁴ Cuando era niña, estaba aprendiendo a montar bicicleta y no me di cuenta y choqué a un señor que iba pasando por la calle.

²⁵ Y bueno, la última vez que monté bicicleta, ya no monto bicicleta, porque choqué a un señor en una moto. El señor, yo iba en mi bicicleta... A ver, yo tengo miopía y los miopes no distinguimos cuando las cosas están lejos cuando están cerca. Yo pensé que no lo iba a chocar, yo iba en mi bicicleta, y el señor parece que si se percata y é “niña, niña”, pero yo... Cuando choco al señor, me caí con bicicleta y todo para la acera y la cabeza me cayó en... ¿Has visto que afuera en las acera hay cisternas? Me cayó ahí. Me di un susto de la vida que juré que ya no monto más bicicleta.

Lucia told a story about falling down because of miscommunication. Her tale also had me in stitches by the end because it was so relatable:

At my first job, my coworkers were over protective of me, since it was not at ANCI, but at a library. Everyone tried to take really good care of me, and once they were guiding me through the building, but I tripped with a step and fell down the stairs. I landed next to a manhole and was really lucky to not just go in it. Instead of me telling them how I should have grabbed them, they were the ones grabbing me and leading the way. And that's not how it's supposed to be. I'm supposed to hold onto someone's elbow. It's called a "fork grip". But since they were the ones leading, my foot tripped with the stairs. ²⁶

Diego told a story and after he was finished, there was a pause. I then looked over to Jorge, the translator, who had a look of shock on his face. After a moment, Diego insisted to Jorge that he translate what he had just said. Jorge did and we were, once again, cackling:

I was working at the hospital and had to take the elevator. When we got to the first floor, I told the man standing next to me: "We have arrived" but it turned out to be a dead person in a coffin. I felt there was someone standing there. I thought

²⁶ Que la primera vez cuando comencé a trabajar las personas querían cuidarme mucho, porque era en un centro de trabajo donde no era de la ANCI, era donde biblioteca, entonces querían cuidarme mucho y guiándome me zafé de un escalón por ahí pa'abajo y cuando vine a ver había una boca de una cisterna que no me fui vaya de milagro.

it might be a patient on a gurney or something. But apparently, they put him there for someone to pick him up.²⁷

After telling this story, Diego followed up by saying that his blind friend had asked a man for the time only to find out that the man was a horse.

Some of the participant's stories and the feelings that arose from them were relatable to my own experiences as a visually impaired person. The stories about participants running into bicyclists, failing to recognize the people around them, and mistaking a corpse for a person all reminded me of the countless times I have found myself in odd situations because of my visual impairment. The following is one story that stands out among many:

I got off the elevator in my dorm and made my way to my room. I put my key in the door. It didn't go in all the way. I tried again a couple more times. Nothing. At a loss, I asked Mary the maintenance woman if she could let me in for now because Grainger needed to eat. She agreed and used her master key. I walked inside my room, put down my backpack and bent over to pick up Grainger's bowl. It wasn't there. I looked closer at the bedding on the bed. It wasn't mine. To my horror, I was in someone else's room. The elevator had passed my floor and dropped me off on the fourth floor instead. I moved quickly, re-leashing Grainger, and swinging his harness over my head. As soon as I heard the door click behind me, I realised that I had left my backpack on the stranger's bed.

²⁷ Yo me encontraba en mi sala trabajando y tomo el ascensor del hospital y cuando llegamos al primer piso, le digo al que está al lado mío "ya llegamos" y era un muerto en una caja lo que estaba.

Mortified, I had to wait for the stranger to come back to their room and awkwardly explain to them why my backpack was in their room.

November, 2018

Discussion

To understand how blind and visually impaired Cuban activists live today, it is important to consider how Cuba's values were shaped. As part of the discussion, I will explore the Cuban Revolution, and the resulting grassroots movements, and educational and legal systems that grew out of the revolution. Cuba has a rich history of providing aid around the globe and working closely with allies, including Canada. The country has a strong emphasis on education, and teaching about diversity and about people with disabilities. Laws declaring and protecting the rights of people with disabilities are written into Cuba's Constitution. This discussion will also consider gender dynamics between men and women who are blind and visually impaired in Cuba.

The Cuban Revolution and Grassroots Movements

The Cuban revolution concluded in 1959, with Fidel Castro as the new head of state (Chomsky, 2015). With a new leader came increasing socialist ideals. Nino Pagliccia, author of *Cuba Solidarity in Canada: Five Decades of People-to-People Foreign Relations* (2014) states that, "The purpose of a socialist society is captured in the subordination of capital, in calls for fair income distribution, and in ensuring general access to social security and the provision of basic necessities..." (p.147). A socialist

society is focused on meeting citizen's needs, not making a profit through private ownership.

Along with Cuba's socialist ideals came a strong sense of being a force for positive change in the world. Since the time of Fidel Castro, Cuba has sought to be a force for global aid, offering help wherever and whenever it can. "Cuba has not been shy about enlisting international solidarity not only of governments but also more importantly of people around the world" (Pagliccia, 2014, p. 93). I believe that this willingness to help is reflected in how Cuba treats people with disabilities, including blind and visually impaired people. During both trips to Cuba, citizens observed that I had some sort of impairment and tried to ensure that I was well taken care of. In my experience, Cuban's aid at a global level mirrors what's happening at the local level.

Cuba's history of organizing at a grassroots level began decades ago. Grassroots movements happen when groups of people come together with the goal of creating change, either politically or economically (Smith, Fressoli & Thomas, 2014). Pagliccia states, "Post revolutionary Cuba has a firm tradition of seeking people's involvement as principal actors in building a socialist society, city block by city block, in urban and rural areas... popular participation is valued as an antidote to bureaucratic tendencies" (p.20). Pagliccia (2014), contends that organizing and working collectively has enabled Cuba to thrive on the world stage despite being cut off from dominant countries like the United States.

During my time in Cuba, I was struck by the ingenuity of the people who live there: they work with the limited resources they have. The infrastructure is difficult to

navigate for blind and visually impaired people, with uneven sidewalks and streets, potholes, and a lack of Braille on signage. Despite this, sighted citizens, including friends and family of blind and visually impaired people, are there to help disabled people navigate everyday life. Interestingly, all the interview participants used smartphones with text-to-speech capabilities. This surprised me because I did not notice many Cubans with smartphones during my 2018 trip. Nora and I asked Luis if ANCI supplies smartphones to members and he said no, though he did not elaborate. I suspect that blind and visually impaired people received smartphones through many different avenues, including international and grassroots connections. Pagliccia (2014) provides an example of international grassroots successes in the past:

The full cruelty of the U.S. blockade was observed early on by Canadian-Cuban Friendship Association members during a visit to the Abel Santamaría School for the Blind in Havana in the early 1970s. The visitors realized that the school could not buy Braille machines, as they were manufactured in the United States.

Immediately the organization raised funds to buy the machines that cost about \$200 each from a supplier in the U.S. and one by one they were brought to Cuba with delegations and friendly tourists. (p.52)

Canada has played a large part in connecting with Cubans at the grassroots level. The main goal of these relationships is to talk directly with citizens from both countries and to learn about one another. Pagliccia states:

Canada-Cuba solidarity has tried to mobilize Canadians around the cause of Cuba: from opposing U.S. aggression against the island to supporting Cuba's right to self-determination; from advocating that Canada-Cuba relations remain based on mutual respect and equality to upholding the goals of the Cuban Revolution. (p. 171)

One organization that started at the grassroots level is ANCI, which was founded in 1975 (Reed, 2011). Its goal from inception was to come together as blind and visually impaired individuals to advocate for rehabilitation services to be able to participate fully in society. Today, the organization oversees two main areas: the National Center for Culture and Recreation and the National Rehabilitation Center for visually disabled persons (Reed, 2011). The first area focuses on providing accessible reading material and teaching computer literacy and culture. The second area offers many different courses, including orientation and mobility, Braille reading and writing, specialty math courses, and classes in everyday skills such as gardening.

ANCI also plays a role in advocating at national, provincial, and municipal levels. According to the past president of ANCI, Jose Blanch, ANCI is part of the National Commission for Attention to Persons with Disabilities (CONAPED), which involves, "high-level representatives from all ministries and sectors responsible for designing and coordinating a national action plan to address the needs and concerns of disabled persons" (Reed, 2011). In addition to this, ANCI is consulted about many national laws

that impact the lives of blind and visually impaired Cubans. Examples of past work include advocating for bills that protect the rights and improve access of people with disabilities and protect the jobs of blind and visually impaired people in trades shops (Reed, 2011).

Education

In addition to the education offered by ANCI, blind and visually impaired Cuban citizens have several other options for accessing education. The Cuban revolution has led to arguably the most inclusive education system in the world (Shelton, Kelly, & Sanchez Valdes, 2021). The construction of a socialist and communist society allows for the inclusion of all schoolchildren. Eddy Marco Vives Pupo (MSc) teaches blind and visually impaired school children in Cuba. He is the author of *Science Presentation, Technology and Society* (2011), in which he states:

Cuba and the State, since the triumph of the revolution in 1959, has been fundamentally aimed at the creation of a National Education System so that it would be conceived as a complex of elements or subsystems characterized by integration, interaction, links and relationships that condition its structure with a focus on systems as a single whole, not separated in isolation. (p.3)

Interview participants spoke about the number of schools that exist, not only for blind and visually impaired children, but for children with many other disabilities. The

Cuban National Education System provides four different streams for students with disabilities. These include general schools, special schools, at-home education provided by a certified teacher, and classrooms set in pediatric hospitals (Sánchez Valdés et al., 2018). All the schooling options are free. With numerous options available to children with disabilities, families can decide the path that works best for them. I believe that the flexibility within this education model sends the message that children with disabilities, including those who are blind and visually impaired, are valued in society. Pupo (2011) states:

In Cuba, special attention is given to blind schoolchildren, it is considered that there is no other educational model in the world equal to the Cuban model, in terms of equity, the level of quality, uniformity, and personal help for those who need it most; without marginalization of any kind. Today it can be said that the Revolution has equalized the real possibilities of knowledge and opportunities for the development of all schoolchildren and for citizens in general regardless of their social origin. (p.3)

I found it interesting that, for the Cuban participants who lost their vision as adults, ANCI approached them immediately. ANCI contacted Ernesto in the hospital. Luis was approached after he became completely blind at age 19. For those who were born blind or visually impaired, ANCI has been a part of their lives for as long as they

can remember. It is impressive that ANCI is available to provide immediate service to people who are blind and visually impaired. This has not been my experience in Canada.

My dad called the Canadian National Institute for the Blind. That was the first number that popped up on Google for blind resources. The woman who showed up talked and talked and talked. She said she knew everything about Orientation and Mobility. She talked about one time when she organized a full-day outing for a group of blind children. They made a list with all the ingredients to make pizza, bussed to the store to purchase the ingredients, and then cooked the pizza. She then told us about the kayaking and other outdoor activities she had participated in with the children. I asked her where I could sign up for these programs. She said they had not been running them for years.

January, 2015

The Rights of Cubans with Disabilities

Many of the interview participants spoke about the importance of knowing their rights as people with disabilities and advocating for them. This made me curious about how disability rights in Cuba compare to those in Canada. Luis spoke about the Rights of Persons with Disabilities (CRPD). In this section, I will provide an overview of this treaty and examine the differences and similarities between the Constitution of the Republic of Cuba and the Canadian Constitution as they relate to people with visual impairments and blindness.

The United Nations created the CRPD in 2006, “to promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (United Nations, 2006). The Convention is a global treaty, meant to provide checks and balances for the countries who ratify the rules. Cuba ratified the CRPD in 2007 and Canada followed suit in 2010 (United Nations, 2006). The CRPD states that, “Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others” (United Nations, 2006). The Convention was created by the lobbying of grassroots disability organizations around the world.

The CRPD is a landmark treaty because it brings together numerous disability organizations that have different priorities and policies. “Their successful participation is clearly reflected in the application of the social model of disability to identify obstacles to the expression of human rights and in the formulation of specific recommendations on how these can be overcome” (Mittler, 2015, p.80). Despite the ratification of the CRPD, it has seldom been cited in Canadian court or Human Rights Tribunal rulings (Hoffman, Sritharan & Tejpar, 2016). Judges and Tribunal members cite national and provincial laws instead. In Canada, there are frequent battles over provincial and federal jurisdiction. Hoffman, Sritharan & Tejpar (2016) state, “There are challenges with implementing international agreements that are ratified by one level of government and which require changes at another level of Government” (p. 2).

I had trouble finding English-translated scholarly articles about the impact of the CRPD on the lives of Cubans with disabilities. Most of the reports I found were formal

documents showing that Cuba met all the requirements laid out by the CRPD upon inspection. It is difficult for me to know how readily the CRPD is used in the Cuban justice system based on these official reports.

Both the Constitution of the Republic of Cuba “the Cuban Constitution” and the Canadian Charter of Rights and Freedoms “the Canadian Charter” have similar categories protecting the rights of people with disabilities. However, the wording of the translated Cuban Constitution is more detailed and explicit compared to the wording contained in the Charter, which is more vague. Section 7 of the Canadian Charter (1982) states, “Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.”

Section 15 of the Canadian Charter (1982) states:

Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

In contrast to the Canadian Charter language, the Cuban Constitution contains more forceful language: it states that people who discriminate against people with disabilities will be punished. Article 43 of the Cuban Constitution states:

The State establishes the right, won by the Revolution, of its citizens, without distinction based on race, color, sex, religious creeds, national origin, or any other type offending human dignity to:

- have access, in keeping with their merits and abilities, to all positions and State and administrative jobs and of production and services;
- reach any rank of the Revolutionary Armed Forces and of Security and internal order, in keeping with their merits and abilities;
- be given equal pay for equal work;
- have a right to education at all national educational institutions, ranging from elementary schools to the universities, which are the same for all;
- be given medical care in all medical institutions;
- live in any sector, zone or area and stay in any hotel;
- be served at all restaurants and other public service establishments;
- use, without any separations, all means of transportation by sea, land and air;
- enjoy the same resorts, beaches, parks, social centers and other centers of culture, sports, recreation and rest.

The Cuban Constitution also states that people with disabilities have the right to work, have rest periods, and take vacations. For me, the most surprising part of the Cuban Constitution is this clause: “The State’s institutions educate all, from the earliest age, in the principle of the equality of human beings.” This statement shows that Cuba considers education about equality important enough to enshrine it in law. By educating everyone about diverse populations, including people with disabilities, Cuban citizens, at least on paper, are more aware of the needs of people with disabilities.

The process of signing up for the province's Persons with Disabilities designation was degrading, but I needed the money. My mom was my best advocate, filling out the paperwork, making doctor's appointments, and waiting in the phone cue several times for hours to get help. Part of the process involved going to the Ministry of Social Development office in person. The building was out of the way in a complex where every business looks the same from the outside. The inside of the office was drab with rows of chairs and a long desk of workers at the opposite end of the room. We took a number from the Take-a-Number dispenser like we were in the cue at a deli. As we waited, people who struggled with poverty, addiction, and mental illness, walked past. They were trying to pick up their monthly benefit cheques. Each time a person skipped the cue and went straight to an employee desk, the employee barked orders and demanded they take a number and wait. Sometimes we waited an hour, other times it took two. When we finally made it up to the counter, the workers were abrupt, demanding we present the right papers at the right times with the signatures in the right places. If we filled something out wrong or had questions, we were demeaned and treated like we should know better.

Spring, 2015

Gender Dynamics

I was curious about any gender dynamics that exist within the blind and visually impaired Cuban community. Lucia, as the gender equality representative at ANCI for her province, said that she did not notice any difference between men and women who are

blind and visually impaired. However, she followed this by saying that blind and visually impaired women must work harder and they struggle more to be able to complete house chores and to work. Lucia said this requires blind and visually impaired women to be “stronger.” Lucia spoke about motherhood and how it has been difficult to manage her fear about taking care of and raising her children.

While we ate breakfast in Luis’ kitchen before the interviews, Luis spoke about how the fathers in families decide what school to place their blind and visually impaired children. I was intrigued by this comment. If fathers have the power to decide what school their child attends, it may be that they have a bias towards choosing public schools or special schools. If Cubans see disability as a weakness, as is generally the case in Canada, I wonder if fathers may shy away from sending their blind and visually impaired children to special schools. Interestingly, none of the participants mentioned that they experienced stigmatization as blind and visually impaired people. This leads me to think that children learn to live with their visual impairment regardless of what type of school they attend.

I am also curious about what ANCI teaches students and whether both men and women are taught the same thing, or whether the skills taught are based on preference, interests, or gender. It may be that everyone is taught the same skills.

It was difficult for me to find English scholarly information about blind and visually impaired Cuban women specifically. The following information pertains to Cuban women and not necessarily Cuban women with disabilities. A major part of Fidel

Castro's mission after the Cuban Revolution was to improve the lives of minorities, including women (Lamrani, 2016; Gonzales, 2010).

In his first speech delivered on 1 January 1959 in Santiago de Cuba... Fidel Castro spoke of the situation of women and recalled that the mission of the revolutionary government was to put an end to the subordination of the most oppressed sectors of society... (Lamrani, 2016, p.110)

The Cuban Constitution makes it illegal to discriminate against a person based on their sex (Lamrani, 2016). Since the Cuban revolution, Cuban women have made gains in the areas of reproductive rights and employment rights. Despite these gains, women still struggle with the, "overburden of domestic and family responsibility and their limited access to senior management positions" (Gonzales, 2010, p.139). It makes sense to me, given Lucia's comments about domestic work, that blind and visually impaired women would face the same issues. Using an intersectional approach, blind and visually impaired women in Cuba would experience difficulties when completing work in the home and in gaining managerial levels of employment.

A new and progressive Cuban Family Code was ratified in September 2022. This piece of legislation deals with many areas of Cuban life and includes the rights of women, LGBTQ people, children, seniors, and people with disabilities. The legislation emphasizes the values of, "love, affection, solidarity and responsibility" (Peoples Dispatch, September 26, 2022). It outlines that people can marry individuals of the same

sex and LGBTQ couples can adopt and have access to fertility treatment. The Family Code acknowledges the role of women in the home. It regulates:

... the right of people to full equality between women and men, equal distribution of time spent on domestic work and care among all members of the family, without overloading any of them, and respect for the right of couples to decide whether they wish to have offspring and the number and time to do so, preserving, in any case, the right of women to decide on their bodies. Chathukulam & Joseph, 2022, p. 22

While this legislation is progressive and one-of-a kind, it is new. It is hard to know how well it will be enforced and how Cuban citizens will react to the latest rules. Nonetheless, the Family Code provides evidence that an effort is being made to promote greater equality between women and men in Cuba.

From my own experience as a woman in Canada, I know that I am treated differently compared with my blind and visually impaired male counterparts. The people who often harass me in public are predominantly male. When I have described these experiences to my blind and visually impaired male friends, they tell me that they have never had such things happen to them.

It was dark. I needed groceries and met up with a friend for the trip. I was working Grainger in harness. As we boarded the bus, I showed the driver my ID from the Canadian National Institute for the Blind and my bus pass. He demanded

that I prove my dog was working. I had just showed him that I am legally blind. What else would the dog be for, but to guide me? I had forgotten Grainger's identification. Not good enough. The driver told me to board and sit down. As we got off at our stop, the driver yelled towards the back of the bus to remember my dog's ID or I wouldn't be boarded next time. I felt belittled.

October, 2015

What I Learned and Where I Want to Go

I learned a lot about interviewing through this process. I wanted to ask open-ended questions that allowed participants to expand and elaborate in the direction they wanted the conversation to go. While I am happy with the questions I created, I think there is always room for improvement. I believe that the more input into the execution of a project like this, the better the results will be. If I have another opportunity to conduct interviews or a focus group, I plan to collect more feedback on my questions. This can be done by looking at what questions researchers have posed in the past and by asking current researchers for their advice. Interestingly, once the interviews I conducted were translated and transcribed, I learned that the way that one of the main questions was translated to participants was different than I intended. Jorge translated my first question: "Where have you found the greatest sense of community as a blind/visually impaired person?" as "Where have you felt more comfortable within a blind people community? What is the best blind people community?" This is likely why most participants brought up their association with ANCI as their greatest sense of community. If I have the

opportunity to interview people in the future, I will check that the questions translate accurately and convey the message I intend.

Since I interviewed the participants in Cuba, several of them have reached out to me. One participant emphasized that I should spend more time with blind and visually impaired Cuban activists. He said I would learn that blind and visually impaired activists are not afraid to be themselves, to go out at night, and to try new things. He said that he feels that most Cuban citizens are looking out for him. Given the chance, I would love to return to Cuba and learn more about the everyday lives of blind and visually impaired Cubans. It is one approach to interview people for 15 minutes, and a completely different approach to spend a few days getting to know how blind and visually impaired Cubans navigate their day-to-day lives.

Conclusion

I began my research because of a curiosity about other people's experiences of being visually impaired and my own experiences in a foreign country. I learned about the experiences and stories of blind and visually impaired Cuban activists through one-to-one interviewing. The information I gleaned showed that the blind and visually impaired Cubans I spoke with experienced a sense of belonging within their community. They also emphasized the importance of knowing their legal rights, had a strong desire to be independent, and told powerful stories. These stories were relatable to my own experiences, some of which I included in this paper in the form of personal vignettes. The

main areas I wanted to investigate revealed that the Cuban Revolution, and as a result, socialism, have prioritized the inclusion of people with disabilities in Cuban society. As a result of this effort, blind and visually impaired people are protected under the law and included in the education system. There are many directions this research can go in the future, including spending more time with blind and visually impaired Cubans to understand more fully how they live their daily lives. I am grateful for the opportunity to conduct this research and value the connections I have made both at York University and in Cuba.

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