How is Disability Seen? An Auto-Ethnographic Exploration of Disability in Urban Townships in Ethekwini, South Africa

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HOW IS DISABILITY SEEN?
AN AUTO-ETHNOGRAPHIC EXPLORATION OF
DISABILITY IN URBAN TOWNSHIPS IN ETHEKWINI, SOUTH AFRICA

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Fall 2019

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Acknowledgements

This Independent Study Project (ISP) gave me the space to reflect and grow both academically and personally, and I wouldn’t have been able to learn so much without the support of the people I met along the way. First, I would like to thank my participants for sharing their stories with me and for letting me into their lives. The topic of disability is not one that’s often talked about, and I am grateful for all of my participants’ openness and honesty in their discussions with me.

I would also like to thank the School for International Training (SIT) staff who provided support and guidance throughout my time in South Africa. Clive Bruzas introduced me to non-traditional approaches to research and gave me the knowledge and confidence to write an autoethnography. His lectures and perspective have expanded my understanding of community health and methods of inquiry. Thank you to Zed McGladdery who provided academic support throughout the program. I’d also like to thank Thando for helping me set up and translate my interviews and for fostering my growth during the program. Thank you to Thula and Hlobi for their assistance with program logistics and for creating a light-hearted and supportive environment during the semester. Special thank you to Robin Joubert for advising my ISP and for providing direction in my research.

Thank you to my classmates in this program for exploring new ideas and experiences with me. I have deeply enjoyed our conversations and shared experiences. I would also like to thank my homestay family for their kindness and for welcoming me into their home. I will always cherish the meals, conversations, and laughs that we had together.

Finally, I’d like to thank everyone back home who supported me during my time here in South Africa. Thank you to my advisor at Wellesley College Professor Smitha Radhakrishnan for encouraging me to study abroad and to see the world from various perspectives. Thank you to my friends at Wellesley College for encouraging me to pursue my research project and listening to my thoughts along the way. Thank you to my parents and brother for their love and support during my growth and journey while studying abroad and beyond.
Abstract

Disability is a topic that is often overlooked and not seen in day to day life. Disability may be visible or invisible to others, and individuals may have varying attitudes and opinions towards people with disabilities. Disability can also be conceptualized in different ways depending on if one takes on a bio-medical model or a social model of disability. In this study, I explored how disability is seen, both literally and metaphorically in urban townships in the eThekwini Municipality in South Africa. I conducted semi-structured interviews with individuals with disabilities and community members at large to understand people’s perspectives on disability. I synthesized my findings in my interviews through a reflexive autoethnographic approach that allowed my own perspectives and stories to live in relation to the perspectives and stories of my participants. The result of this study is a deeper understanding of myself and my own perspective on disability as a sibling of someone with a disability as it relates to the viewpoints and realities of other people.
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Introduction

The morning is muggy and grey. I step out of the car and walk towards the entrance of the field.

The Down Syndrome Association of KwaZulu Natal (DSA KZN) had gotten back to me a week into November about possibly speaking to parents of children with Down Syndrome. A person from DSA KZN invited me to their annual Buddy Walk where the organization raises awareness about Down Syndrome through a walk. This year it was held at the Curries Fountain Sports Development Centre\(^1\) on November 17th. She said that I could connect with parents at this event to learn more about their perspective as a family member of someone who has Down Syndrome.

I went up to the registration table to pick up my bright red t-shirt and there I met my contact from DSA KZN. She was running the event and in between tasks told me that there were many parents here at the event that I could speak to. She pointed out the families to me and quickly gave a few details before going back to managing the event.

I thanked her and walked over to the concrete steps where the crowd was queuing up for the walk to start. I slipped on the red t-shirt as the humidity swelled up around me. I watched as more people trickled into the field and more people put on their shirts. There were so many families at the walk and people of all races, genders, and abilities around me. I looked around and saw that everybody was sitting in groups with their friends and family. I had never been to any event that celebrated and advocated for people with Down Syndrome. I listened to the pop music that was blasting from the speakers and observed the flow of the event. After about an hour of waiting, the organizers announced that the walk was going to begin.

The walk went outside of the field and through the nearby Durban Botanical Gardens and looped back around to the field. During the walk, I felt tears swell to my eyes. I thought to myself, why have I never participated in any events like this? Why have I never stood in solidarity with my brother or taken the time to educate myself?

\(^1\) Curries Fountain Sports Development Centre is a sports complex in Berea, Durban where outdoor events and activities are held
My older brother Tovi was born with Down Syndrome. I don’t think I have ever critically thought about or reflected on my relationship with him and how our relationship has affected the way that I see and perceive disability. My time in South Africa initially pushed me into thinking about disability as it relates to health, but later on I realized I wanted to understand how disability is perceived and conceptualized. But to do this in three weeks? Three weeks didn’t seem like enough time to grapple with these issues. A whole lifetime probably wouldn’t be enough time. I am grateful that the journey of this process has given me the opportunity to understand more about myself and my understanding of disability through my conversations with other people. The relationship that I have with my brother keeps changing and growing as do my own perceptions of disability. I hope that you as the reader can follow along my meaning-making process and also take away something of your own from this project.
**Background and Significance**

The theme of our program is Community Health and Social Policy, so we were often presented with the definition of health. The World Health Organization defines Health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organization, n.d., n.p.). Looking up ‘infirmity’ on Merriam-Webster shows that the word is related to ‘disablement’ (Merriam-Webster, n.d., n.p.). This conceptualization of health pushed me to understand what disability is and how it relates to health.

Professor McIntyre gave a lecture on a broad overview of disability in South Africa, and she spoke about how there are inequities in healthcare access for individuals with disabilities. She noted that “The jury is still out internationally on the definition of disability” and brought up a thought-provoking series of questions of “who is disabled/who decides/how is it decided?” (McIntyre, 2019). I recall her pointing at students and asking them to categorize themselves based on if they have no, some, or a severe disability. I felt shocked that a professor would ask students to categorize themselves this way, especially since disability is not discussed or disclosed openly. When she pointed at me, she noted that I wore glasses.

“What would you categorize yourself as? You wear glasses so it appears that you have some form of a disability.”

I was taken aback by the question but also felt compelled to agree with her since my thoughts couldn’t catch up with my voice.

“*Today I was asked if I had a disability and the lecturer noted that since I have glasses, I must have some form of a disability. But I would never categorize myself as having a disability. My glasses help me see and they correct for my blurry vision. Maybe if I didn’t have glasses my sight could be considered a disability? But where do we draw that line? I guess the question really is who decides what a disability is.*” (Chao, C., Personal Journal, September 11, 2019)

Also, according to the 2011 Census in South Africa, “the national disability prevalence rate is 7.5%” and “Persons with disabilities increase with age. More than half (53.2%) of persons aged 85+ reported having a disability” (Lehohla, 2014). While these figures are out of date today in 2019, they represent the most current figures published by the South African government and
indicate that disability is prevalent within the country, especially in the elderly population. The percentage of individuals living with disabilities could easily be higher than 7.5% in South Africa.

While I was drawn to the topic of disability because of its relation to health, I felt most compelled to understand how people see disability. I had numerous conversations with my professor Clive Bruzas who listened to me recount my experience as the sibling of someone with a disability as I tried to conceptualize what I wanted my ISP topic to be. After approaching and leaving the topic of disability time and time again, I eventually decided to focus on the topic and my personal connection at hand. The driving question of the project is ‘How is disability seen?’ Seen is used literally to understand if people with disabilities are visible and represented in their communities but seen is also used metaphorically to understand people’s opinions and attitudes towards people with disabilities. I hoped that my interviews with participants would reveal how disability is seen, and I hoped that my own personal reflections would reveal how I see disability.

It’s important to me that I include my own personal reflections in my project because I have an older brother who has Down Syndrome. I cannot speak for my brother on how he sees disability, but it would be wrong for me to omit my own thoughts and opinions as I explored the perceptions of others. Thus, this project takes on an autoethnographic approach to explore my story as it relates to other people’s experiences.
Literature Review and Context

What is a disability

The World Health Organization (WHO) definition of disability is “an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations” (World Health Organization, n.d., n.p.).

But there are many different frameworks by which to view disability. The two models of disability that resonate most strongly with this project are the biomedical model and the social model. The biomedical model views disability as a disease where “Disability is regarded as objectively bad, as a pitiable condition… and tends to regard the person with disability as the one who needs to change or be fixed” (Retief & Letsosa, 2018, p. 3). The social model views disability as something that is caused by social conditions and is a “socially constructed disadvantage” (Retief & Letsosa, 2018, p. 3). The WHO definition of disability could be viewed through the biomedical or social model of disability and the interpretation would have a significant impact on how individuals conceptualize disability.

An Auto-Ethnographic Approach

An autoethnography “is an approach to research and writing that seeks to describe and systematically analyze personal experience in order to understand cultural experience” where the autoethnography is “both process and product” (Ellis, Adams, & Bochner, 2011, n.p.). I believe that exploring my own personal experience of having a brother with Down Syndrome adds a layer of depth to my research by doing an autoethnography. There is no way that I could have approached this topic without acknowledging and reflecting on my own experiences as a sibling of someone with a disability and an auto-ethnographic approach “acknowledges and accommodates subjectivity, emotionality, and the researcher's influence on research, rather than hiding from these matters or assuming they don't exist” (Ellis, Adams, & Bochner, 2011, n.p.).
Writing about Disability

As someone who doesn’t have a disability, I recognize that I don’t want to write about people with disabilities as the ‘other’, and I want to properly represent the perspectives of my participants. Richards ponders about “writing about the other self” (Richards, 2008, p. 1717) and the possibility of objectifying individuals with disabilities. She notes that “people living with disabilities or illnesses are seen as objects of study and not as agents of study. There seems to be an underlying assumption that such people need to be talked about, but should themselves remain silent as if they do not have anything useful to contribute” (Richards, 2008, p. 1719). I realize that I can never write about other people’s experiences or ever truly know what realities they’ve lived through. But I hope that this project gives a platform to all voices about their perception of disability. I also recognize that my project inherently talks about and potentially objectifies people with disabilities which is why I have weaved the stories of people with disabilities, community members, and my own in the hopes of mitigating the objectifying view of understanding people’s perceptions on disability and to see disability both literally and metaphorically.

Traditionally, individuals with disabilities “have thus not been as visible, accessible, or attractive to ethnographers as ethnically distinct and geographically distant populations” (Couser, 2005, p. 126). This lack of representation is also a reason to learn about disability through an autoethnography. Couser also examines how the memoir Riding the Bus with My Sister: A True Life Journey is an autoethnography because the author has to understand how her sister functions in her world and because the author has to “find her own sense of identity, her own emotions, and most of all, her own sense of family history at stake as she shares and recounts Beth’s [her sister’s] life” (Couser, 2005, p. 136). I want to examine the intersection of disability and ethnography while also attempting to understand my own brother’s life in relation to my own. I hope to represent the stories of my participants and myself through this project while being cognizant of objectifying the stories and realities of my participants.

The language that is used to represent people with disabilities is also incredibly important. Throughout this paper I have used the phrase ‘people with disabilities’ instead of ‘disabled people’. The phrase ‘people with disabilities’ is an example of Person-First Language and is used because “person isn’t a disability, condition or diagnosis; a person has a disability, condition or diagnosis” (Americans with Disabilities Act National Network, n.d., n.p.). Although
individuals may have their own preferences such as using Identity-First Language because “disability as an essential part of who they are and prefer to be identified with their disability first” (Americans with Disabilities Act National Network, n.d., n.p.). As a whole, I will continue to use the phrase ‘people with disabilities’ to write about individuals with disabilities to respect their personhood, and any deviation from this phrasing will be explained.

South African Policy on Disability

The South African Constitution outlines that discrimination based on identity is prohibited in its Bill of Rights. Specifically, the Bill of Rights outlines that discrimination based on disability is prohibited (The Constitution OF THE REPUBLIC OF SOUTH AFRICA, 1996, 1996).

South Africa also published a White Paper in 1997 on the Integrated National Disability Strategy that identifies key policy areas such as health care, education, rehabilitation, transportation, communication, social welfare and community development, and housing that affect individuals living with disabilities (Integrated National Disability Strategy, 1997, n.p.). The overarching strategy of the White Paper is to not only focus on the medical needs of people with disabilities but also to pay attention to their social needs (Integrated National Disability Strategy, 1997, n.p.).

The Convention on the Rights of Persons with Disabilities (CRPD) was passed in 2006 with the purpose 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 uses vague terms to describe how the rights of persons with disabilities should be protected and promoted, but nonetheless 162 countries have signed the convention with South Africa signing it in 2007.
Design and Methodology

I had struggled to get started on my project during the month of November. I had been out with a cold and fever for the two weeks and it was the first time I had gotten sick during my entire time in South Africa. I wasn’t able to go out and speak to participants during that time, so I had a lot of time to reflect and read the literature that I pulled. I spent the first two weeks of November reading over my research proposal and thinking about how I wanted to approach the topic of disability. The more that I read about disability and writing about disability the more that I was unsure of my topic.

*I can’t believe that I got sick just as ISP started. But maybe it’s for the best? I think I took on more than I can handle. How can I expect to ask others to talk to me about disability when I can barely speak about my own story?* (Personal Journal, November 8, 2019).

I had a grand plan of interviewing individuals with disabilities, family members of people with disabilities, and doing a focus group with community members about their perceptions on disability. But all of this screeched to a stop as I sat in my bed waiting to get over my sickness. It was in this time that I thought more about auto-ethnography and my own experiences with my brother.

Meaning Making

Historically, my experiences with academic writing typically involved writing analytically. I find that in my natural science, social science, and humanities courses I picked apart and analyzed the data and the stories without much consideration of the whole. It felt wrong to approach the stories that my participants told me with an analytic eye and to pull them apart to find answers. I wanted to keep the interviews as a whole and let participants share their stories and to speak for themselves.

I decided to write my project as a reflexive autoethnography which meant that I had to “describe and systematically analyze personal experience in order to understand cultural experience” (Ellis, Adams, & Bochner, 2011, n.p.). I want to portray my own understanding and perspective on disability as a result of my study and conversations with others. This is only possible by studying my own life in conjunctions with other’s lives to gain a deeper
understanding of our experiences. So rather than analyzing my participants’ individual stories and my own story, I am choosing to focus on each individual interview and have the participants share their own stories and words with you. I hope that through this method I am able to keep their perspectives and stories whole. At the end of the interviews I included snippets of my own stories, journal entries, and reflections that reveal my own perspective and how my participants’ stories have shifted and deepened my outlook. This structure is how I found my participants’ and my stories to naturally go together. This is not something that I would have done in traditional research, but I find it important to be honest and vulnerable as I share my perspective as the sibling of someone with Down Syndrome.

**Sampling**

My initial sampling plan was to interview two individuals with disabilities, three family members, and a focus group comprised of four to five community members at large to speak to me about how they see disability. I was open to interviewing anyone who was over the age of 18 and individuals of all genders and ethnicities. I excluded minors from my sampling plan because my study was not particularly focus on the experiences of minors. I hoped to interview people of diverse ages, genders, and backgrounds to get different perspectives on disability. I limited my scope of sampling to people living in urban townships in the eThekwini Municipality area because that’s where our program had personal connections and how we were able to find participants for our study. While this method of sampling may not represent all opinions in the eThekwini Municipality, I hope that the interviews will provide rich detail on how the participants that I spoke to perceive disability.

I wanted to first interview individuals with disabilities to get their perspective on how disability is seen and then move on to interviews with family members and community members. I hoped to share some of the experiences that I heard about from people with disabilities with the family member and community members sampling groups to see how family and community members reacted to these opinions. I worked with Thando to find participants who would be willing to speak with me for my study. Since I wanted to speak to people who have disabilities, I relied on Thando’s personal knowledge of knowing people with disabilities and possibly finding people who had more visible disabilities in the urban township areas.
Unfortunately, I couldn’t interview participants for the first two weeks of the month because of my illness and had lots of time to reflect. I finally got over my illness and I did my first two interviews with people with disabilities on November 19th, 2019. I attempted to schedule interviews with family members for the next few days with no luck. Family members either didn’t want to share their perspectives or didn’t have time to be interviewed since I had only a week left to do my interviews before I began my write up of my assignment. I was able to do a focus group with give community members comprised of young and middle-aged adults on November 24th, 2019. During the interview, it was revealed that two of the participants had a disability and the other three participants also had distant family members who had disabilities. Although it was in my sampling plan to interview community members that had little to no contact with disability, I realized that this was not a realistic expectation. Instead, their personal connections to disability added another dimension to conversation in the focus group that I did not initially expect.

The three interviews that I conducted were done either at Café Skyzers in Cato Manor2 or outside of Thando’s house. This was an attempt to meet participants in a neutral space that allowed comfort and some privacy during our discussions. The participants were thanked for their time with refreshments that I supplied.

I also attended the Buddy Walk that DSA KZN organized, and despite the invitation to speak to family members, I didn’t feel comfortable reaching out to people in a celebratory environment to poke and pry in their personal lives. The walk instead was a good opportunity for me to see how community members came together to celebrate and educate others about disability.

I also had my roommate ask me the interview question for family members, so that I could offer my own insights into the questions that I was asking my participants. This allowed me to get my own perspective and see how it lived in relationship with my participants’ perspectives.

The interviews were recorded on my personal phone with the consent of the participants and this allowed me to engage in conversations with my participants rather than attempting to quickly write down their responses.

2 Cato Manor is an urban township where the Community Health and Social Policy program does their 5 week homestays
Interview Structure

The interviews all began with obtaining informed consent from the participants and checking that participants knew that everything that was being said during the interview would only be used for this project. I had copies of the consent form in either English or isiZulu depending on which one the participant would like to read. Copies of the consent forms can be found in Appendices 4 and 5. I then obtained consent to record the interviews on my phone. All three of the subgroups that I was interviewing (people with disabilities, family members, and community members) were presented with the same interview questions but worded slightly differently to get their perspective based on whether they had a disability, were a family member, or were a community member. The three sets of interview questions can be found in Appendices 1, 2, and 3. The interviews were semi-structured with a list of questions but was open enough for fluid conversation between me and the participants. I also told all of my participants about my personal connection to the topic of disability and showed all of them a photo of me with my brother. I journaled and reflected on my conversations with the participants the evening of the interviews as their words were still fresh in my memory. These reflections also serve as primary data for this project.

Limitations and Biases

The limitations of this study were that I had a very small sample of people that I spoke to. I interviewed a total of seven people, eight if I count the interview that my roommate Amanda conducted with me. So there are no generalizations that I can make based on the interviews that I conducted, but that is what I had in mind when I started my research process – I hope that my participants’ stories can stand on their own and convey their own individual meaning to whoever is reading their stories.

My interviews with the participants who have disabilities were conducted in isiZulu with the help of a translator. Thus, there could have been some meaning lost when the questions that I asked were translated from English to isiZulu. My participants stories and words were probably also modified as some words or phrases don’t exactly translate from isiZulu to English. Language also presents a barrier in my interviews conducted in English because none of my participants’ first language is English. So the meaning of words and questions could have been interpreted differently than what I had intended them to mean.
I think my position as a researcher who is studying perceptions on disability who is also the sibling of someone with a disability introduces a bias into the study. But, the point of writing this study as an auto-ethnography is to acknowledge and incorporate my bias and personal opinion into my work and see how my perspective relates to other people’s.
Ethics

In conducting research there is always an ethical dimension to consider, and I think I’ve had the most difficulty when grappling with questions of ethics as I’ve written my ISP.

My first contact with considering the ethical dimension of the ISP was filling out the Human Subject Review Application. I checked the box that said my research may require a full review because “Children or vulnerable groups are involved (e.g. prisoners, educationally disadvantaged persons, cognitively impaired persons, trauma survivors, or populations considered vulnerable in local social situations or cultural contexts)”. I couldn’t definitively say that my sampling population didn’t include vulnerable populations, but why are people with certain disabilities considered ‘vulnerable’? Aren’t all research participants inherently vulnerable because their stories and perspectives are being studied by someone else? Why have we as a society determined that certain populations are vulnerable and how have we determined which populations are vulnerable?

Another concern was the 9th question on the Human Subject form: “How will you protect participants from feeling pressured to participate in the study due to any power differential?” My very role as an American student conducting research has so much power within itself. On top of that, I was planning to study how disability is seen which also has a power differential and echoed back to Richard’s concerns about writing about disability as the ‘other ’(Richards, 2008, n.p.). Ethically, I wasn’t and am still not completely sure about my role as someone without a disability writing about the perceptions of disability. It’s not my place to voice the concerns that stem from people’s own experiences, but I also felt that it was important that people’s stories and perspectives were heard. I shared my concerns with my friend Sophia, and she told me that “you’re not giving [your participants] a voice (because of course they’ve always had a voice), but you are giving them a microphone and a larger audience.” She noted that my work was done to acknowledge the experiences of other people and that my very act of listening was to attempt to understand my participants’ stories. I don’t want to speak on behalf of any of my participants, and I hope that their stories speak for themselves as you read them. But I will speak on my own behalf and how my own outlook has changed as a result of this project. I hope that my study shines a light on the topic of disability and elevates the voices of my participants, and I hope the accounts of my own understanding help you as the reader come to your own understanding as well.
Another aspect of the ethical dimension of this study is the privacy, anonymity, and confidentiality of the participants. These aspects were all discussed with my participants during the informed consent process. To provide privacy, the interviews were conducted in semi-private spaces where people could speak openly about their perspectives. There was also always someone on hand to translate from English to isiZulu in an attempt to help participants most honestly represent their thoughts. Participants were also told that they could decline to answer a question at any time and could end the interview whenever they wanted to. Anonymity was also a challenge as I wrote up this interview. I have used pseudonyms for all my participants in the following chapters, and I decided to also not disclose the specific ages of my participants. I grappled with how I would describe individuals’ disabilities in my project. A disability can make an individual identifiable, and I didn’t want to publish specific details about my participant’s disability in case it would make them identifiable. My participants were fine with me discussing their disability, but I have also decided to generalize the type of disability that my participants have to help them remain anonymous. My participants’ confidentiality was protected by storing all audio recordings and transcriptions on my password protected laptop and phone. My signed consent forms were stored in a locked office. After I finished writing up my ISP, I deleted all copies of the audio recordings and transcriptions, and I will shred the consent forms when I have access to a shredder. The raw transcriptions of my participants’ interviews will not be available anywhere online, but a digital copy of this ISP that recounts their stories will be available online and a physical copy will be in Cato Manor.

I also ran into an ethical dilemma as I was finding family members to interview. I went to the Buddy Walk that was organized by the Down Syndrome Association of KwaZulu-Natal where the person I was speaking to said that she gave me “full permission to talk to any and all parents.” I felt uncomfortable with asking probing questions for the purpose of research at a walk that was supposed to celebrate, educate, and empower people.

*Just because someone gives you ‘the permission ’to do something it doesn’t make it right. I had a gut feeling that it would be wrong to just approach someone with the goal of finding out their story. I don’t want to consume someone’s story for the purpose of my study. If I was in their shoes, I wouldn’t want some random person coming up to me to mine my story for their research* (Personal Journal, November 17th, 2019).
My final ethical consideration of doing this research was asking my participants to be vulnerable while I was reluctant to be vulnerable and honest about my own story. I have never been open or good at sharing my thoughts and feelings as a sibling of someone with a disability. I feel very emotional whenever I talk about the topic, but I have never put into words why I feel the way that I do. I recognized early on that I couldn’t expect my participants to be vulnerable and to share their stories and opinions if I didn’t do the same. The following three chapters serve to illustrate my participants’ stories while also illustrating my own reflections and personal stories as I have never really been willing to do before.
A Conversation with Sanele

(Sanele 2019, November 19th)³

I quickly walk up the hill to meet Sanele and Thando for my very first interview. I’m nervous because it’s late into the ISP period, and I haven’t started my interviewing process.

The wind howls around us as we walk into Café Skyzers. I sit down with my box of doughnuts and scramble to find my interview questions and consent forms. Sanele and Thando look at me patiently as I get flustered about starting my first interview. Sanele is a middle-aged adult man who is wearing a brightly pattern shirt this cloudy day. We go through the consenting process, and I ask if it’s alright to record the interview. Sanele tells me “yes, no problem”.

I click the record button on my phone and before I can even ask my first question, Sanele starts speaking in isiZulu very quickly. I’m taken aback as his rapid and unprompted response is unexpected, but I listen to see what he has to say. Thando translates and says “people with disabilities are being like disadvantaged in way and they are taken for granted… even with his mom like the people who gave birth to people who are disabled they also have a stigma around it. Also the money that is given to them by the government people misuse their money⁴. Just because they don’t think they can use their money wisely”⁵.

I nod in affirmation as I continue to listen to what he has to say. Sanele mentions that there are projects that he would like be a part of and Thando continues translating and says “Cause they don’t have a job like no one is gonna hire them. So, they should be involved in something, he wants to be involved in something and make a name out of himself”.

Sanele continues to speak in isiZulu very quickly and gestures his hands towards me. “He’s also saying he would very much appreciate assistance from people from the United States to create an NGO that assists them”

I think to myself: Can I do that? Are there any NGOs that support people with disabilities here?

³ Interviews will be cited at the beginning of the chapter to make clear who the participant is. Also, all names of the participants have been replaced with pseudonyms
⁴ A disability grant in South Africa is a monthly sum of money that is given to individuals with disabilities. The time period in which someone is eligible for a disability grant depends on their disability and individuals must apply to see if they are eligible for a disability grant [https://www.gov.za/services/social-benefits/disability-grant](https://www.gov.za/services/social-benefits/disability-grant
⁵ All the responses of the participant were given in isiZulu and translated by Thando. I will write out the translation that Thando gave, but the responses are from Sanele
I try to get in my first question, but Sanele continues to speak very quickly, and I’m grateful that he’s open to sharing his experiences, but I wondered if we would get back on track to the interview questions.

Thando sighs and says “hawu shame⁶ he’s saying that whenever there is a thing organized for people with disability – you know how functions and events have décor and they look all pretty – for them they’ll get the most nastiest hall and the trashiest food… there was an event organized in Pietermaritzburg and their accommodation was fine like the hotel was okay. But the hall was leaking…It was rubbish. The catering was paid so much, but I guess they gave them the cheapest catering. So that’s what bothers him the most. They don’t think that their minds work. But their minds work, they see things… they understand… he’s also saying that for people with disability their funerals don’t have dignity. They’re not dignified. They give them the cheapest coffins and the cheapest funeral arrangements”.

I nod in acknowledgement of the details and realities that Sanele is sharing with me, but I don’t really know what to say in response to his raw and honest experiences. I nervously glace down at my paper to ask the fourth question on my interview guide:

“Can you tell me what a disability means to you? Like how did you first learn about disability”

Sanele reveals that he was born with a vision impairment and a physical disability that affected his movement. Today he still has some residual impacts of his physical disability.

“He started realizing [that he had a disability] because family members were ill-treating him – like his uncle”

“And do you think your understanding of disability has changed as you’ve gotten older?”

“So he said that as he grew up he realized I need to accept it and it’s my life and I must make the most of it… so that’s what gives him the courage to pursue a project so that he can prove that a disabled person can do something. He’s a people’s person”.

I nod again, not really knowing what to say in response to what Sanele has just told me. I want the interview to be a fluid conversation, but I really don’t know what to say. Maybe it’s best to just not say anything?

“And how do people in your community react to your disability? How does it make you feel?”

⁶ A phrase in isiZulu that most directly translates to “oh no”
“He said that sometimes the kids are hidden in the family because the parents are scared of the reaction from the community… so he’s saying that it makes him really sensitive because people call him names. They’ll call him crazy and that’s when he put a stop and end to that. He wishes the government would take – you know when you assault someone you call them a curse word you can go report it – he feels like they should also have a right to report someone who calls them names. He’s like ‘no don’t call me that. I’m not crazy. you don’t know what I’m diagnosed with so don’t diagnose me’”.

I nod knowingly as I’ve heard derogatory terms such as ‘retarded’ being throw around a lot in my communities back in the United States. I wonder what the exact phrases are in isiZulu, but I don’t want to probe as it seems like a sensitive topic.

Sanele also recounts a time where he was trying to find a job.

“He’s saying that after he finished school, he was gonna apply for a job…So the counselor gave him a letter and said he must show it to them (to the offices that he wants a job [at]) and [show that] this [these skills] is what he has. They said ‘no you don’t have matric’7, and another guy assisted him”

“So you were able to get the job?”

“Yes, through a friend who had to call in. And ask for a favor.”

The interview is coming to an end and I ask Sanele if he has any questions for me or if there’s anything else he’d like to share.

“Also he’s asking since while you’re here… Can you bring other people and help him with his plan?”

I follow up with another question: “in what way?”

Thando translates: “He’s talking about taking his fruits and veggies and transporting them to the US” and then she laughs and starts talking to Sanele. I can’t understand what they’re saying but I can make out that Thando is explaining something to him. After a few back and forths, Sanele looks a bit dejected but says “okay okay”.

Thando laughs and turns to me: “I told him all you can do is follow up with him and keep up with his project and call him and stay in contact with him. I explained that you can’t take the fruits back to the US”.

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7 Matric is the final year of high school in South Africa and is the qualification that you get for passing your exams in the final year of school. Individuals often need matric for certain jobs or to apply to university
I flash a smile at both of them as I tell Sanele that I would love to stay in contact with him and ask Thando to send me his contact information but as the interview is coming to an end I feel like I have more questions than answers.

I feel like there is a stigma whenever I talk about my brother and his disability. I don’t often bring it up unless people ask, but I do feel a sense of stigma whenever I talk about it. Looking back, I also relate to what Sanele said about being given the cheapest option. I remember shopping for school supplies at the end of the summer when I was younger with my mom and brother. My mom would always let me pick out whatever supplies I wanted, but she always waited for the supplies to go on sale before purchasing supplies for my brother. But the things that were on our list were nearly identical. Why was it this way? ...I also wonder what phrases are used in Zulu to describe people with disabilities. I hate it when people use the word ‘retarded’ in any sense of the word really. It’s not a nice word to say. I remember a co-worker saying the word this summer and having so much difficulty discussing with her why it wasn’t an okay word to use. I couldn’t talk to her about it without crying. I’ve also heard people use it while I’ve been here [in South Africa], but I haven’t been able to say why we shouldn’t use that word to their face ...The interview also made me think more about the role of the United States and my own position and power. What can I do to listen to other people’s experiences and to learn more? But where do I draw the line between learning and actively getting involved? (Personal Journal, November 19th, 2019).

Amanda and I sit at the dining room table in our apartment in Windemere. It’s almost midnight, but we often have our best and most deep conversations later in the evening.

“Do you want to do the interview now?” she asks.

It’s been three days since I did my last two interviews, and I was waiting to hear if other people would be willing to participate in my study. Now seemed as good of a time as ever.

“Yeah. Let’s do the interview now. I’ll give you the interview guide so you can ask me the questions.”

“Can you tell me what a disability means to you?”
I ponder and pick my words carefully: “mmm I think a disability is a variation that one person has that may make doing typical activities more difficult or needing to do those activities in different ways. Broadly that’s how I would define a disability”.

“So, you mentioned that disability kinda has an effect on the person with a disability and their ability to participate in certain activities. So, do you think disability is both a biological variation (in some cases) or related to society in the way people interact with their social world?”

She was going off script. This definitely wasn’t on the interview guide. I think for a moment about what she’s asking.

“I think disability in the way disability has been constructed in my understanding of the world is that it can be biological, but it doesn’t have to be. Like it’s hard to say what is or isn’t a disability… I think it’s more about how we think about ability and what people are or aren’t able to do and whether or not society accepts that fact that people are able or not able to do certain things – and whether or not the circumstances or conditions allow people to live and celebrate their variation or not”.

“How did you first learn about disability?”

“I don’t know if there was one moment where I explicitly learned about disability. I think I was aware that my brother had a disability at a pretty young age?... but I think seeing the way that my parents would treat me differently and grandparents would treat me differently compared to my brother is when I first realized there was a difference.”
A Conversation with Velaphi

(Velaphi 2019, November 19th)\(^8\)

Thando and I head to the next location to speak to another participant. We had just finished speaking to Sanele, and now I was off to do another interview.

_I hope I do better job of talking to the participant. I feel like Sanele told me so much but I didn’t know what to say. I sat, absorbed, and tried to take it all in and attempted to understand._

We arrive at Thando’s house, and I wait outside on the deck as she invites the participant to come over to her house to speak with me.

After waiting for a few minutes, Velaphi comes around the corner, and I wonder how old he is. My sampling plan said that I was only going to interview adults who were over the age of 18 – I couldn’t include Velaphi’s story in my project if he was younger than 18. I smile at him and introduce myself, and I don’t know why but the tone that I take on is one that I often use when I talk to a child. I ask him how old he is. His answer shocks me, he is significantly older than 18 despite not looking like it.

On our way to Thando’s house, she noted that people treat Velaphi like a child, despite the fact that he is an adult. I wonder if this knowledge affected the way that I initially viewed and spoke to Velaphi. Or did I make an assumption when I first saw him and then proceeded to take on the tone of talking to a child. Either way, I was ashamed of my first interaction with Velaphi.

The three of us sit in plastic chairs as the wind howls around us – it doesn’t seem to be letting up anytime soon. Just as I begin talking about the consent form, we feel delicate drops of rain hitting our skin. We quickly pick up our chairs and head around to the back where there is a covering. I start to describe the consent form again. I ask for permission to record the interview, and Velaphi quietly said “yes, okay”.

I hit the record button, and Velaphi looks at me waiting for the first question.

I introduce myself and ask Velaphi a few demographic questions. Velaphi talks about his age, where he grew up, and the fact that he’s had his disability for “a long time”. His disability is muscular in nature and he also has a learning disability.

“Can you tell me what a disability means to you?”

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\(^8\) This interview was also conducted in isiZulu with Thando as the translator
As Velaphi is answering the question, he looks back and forth between me and Thando.

“He says he doesn’t understand it, and I don’t think they [Velaphi’s family] talks about it… He tried getting a [disability] grant, but he didn’t qualify”.

“Do you know why you didn’t qualify? Did they give you a reason?”

I get a single worded response back – “no”.

“Are people with different kinds of disability perceived or seen differently in your opinion? Like for example people with a vision impairment, or deaf, or have an intellectual disability or a physical disability? Do you think that people are seen differently?” I realize this question is lengthy and there are a lot of words that could be misinterpreted, but I really would like to see what Velaphi’s perspective is on the topic.

“He’s saying that people have a weird way of looking at them [people with disabilities] and they don’t like them and they also insult them… He’s saying they call them names”

_Ah, this seems similar to what Sanele was talking about earlier offensive terms that are used when speaking to people with disabilities. I wonder what the words that are used, but again I don’t feel right about probing the matter further._

“How do people in your community react to your disability?”

He looks at me as Thando translates his response. “They treat him well”.

“How do people in your community react to your disability?”

He looks at me as Thando translates his response. “They treat him well”.

“How do people in your community react to your disability?”

There is a long pause after Thando translates the question for Velaphi. He looks a little bit confused as he looks between me and Thando. I tell Velaphi that we can skip the question if he wants. After a few moments a small smile crosses his face and he talks to Thando.

“So, when he’s able to help around the house. Then he feels very supported and like he’s important”

“Do you think your community could do anything to better support you or include you?”

“So, he was saying that he wants a job. He applied at the Pavilion⁹, and they asked him questions, but they never replied.”

I nod and hope that in some way this nod can convey that fact that I hear what Velaphi is saying, but again I’m at a loss for words.

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⁹ The Pavilion is a shopping mall in Westville, KwaZulu-Natal
My final question for Velaphi is “what does education look like for people with disabilities?”

Velaphi speaks very quietly to Thando.

“He went [to school] until grade 5, I think that’s when he realized he has a disability”.

“So, were you not allowed to continue past grade 5?”

For the first time since we started the interview, Velaphi looks away from both me and Thando and looks down at the ground as he answers my question.

“His mom stopped him from going to school. He says that he wished he could have continued school… His mom just took him out”. I can tell by Thando’s voice and body language that she too is just learning about this now.

Velaphi doesn’t make eye contact with either me or Thando as she translates what he just said. I sense that this topic is sensitive in nature by his body language and don’t want to press any further on the topic.

I ask if he has any question for me or if he has anything else that he would like to share.

He gently says no, and he leaves just as quietly and quickly as he arrived.

Amanda asks me: “So during your journey of learning more about disability and what that means and what that looks like is there anything significant that you’ve learned outside your home? Whether it was at school or through friends that you kinda brought back to your home?”

She was going off script again! I hadn’t really thought about the question that she raised, and it took me a while to gather my thoughts.

“…just feel like in my home we don’t explicitly talk about disability at least not straight on. We’ll talk about things that are related to disability or about my brother’s disability and through that I’ll understand my parents’ perspective more, but I don’t think we’ve ever directly
had a conversation about it”. I never recognized how much my family doesn’t talk about disability until I verbalized it to Amanda.
Community Members’ Perspectives
(Isisa, Jabulile, Liyana, Lwandle, Siyanda, focus group interview 2019, November 24th)10

I arrive at Thando’s house carrying the refreshments for the focus group with my heavy backpack strapped behind me. I clumsily make my way down the steps as the people sitting under the covering watch me. I introduce myself to everyone as Thando gets chairs for everyone in the group.

Initially, there are four people who join the focus group. Isisa, Jabulile, and Liyana are all young adult women and Lwandle is a middle-aged man. Siyanda joins our focus group halfway through our discussion on the consenting process. He is a young adult man. Everyone consents to me recording the focus group on my phone.

“Can you tell me what a disability is?”
“A disability means domoroza” says Isisa. Everyone in the focus group laughs. Jabulile chimes in, “you just think the person is crazy… or slow”. A chuckle ripples through the group.

I ask: “Is that the word in Zulu?”
Jabulile answers “yes domoroza is what we say” and Isisa indicates that it’s a negative word.

Ahh, maybe that’s the word the Sanele and Velaphi were referring to.
“How did you all learn about disability?”
Jabulile notes that “you don’t actually learn about it [disability]” and Siyanda adds “our mothers don’t tell us these things”

“Has your understanding of disability changed as you’ve grown older?”
Lwandle jumps in – “yeah well now I’m one of the parts of the disability person because I got injured” as he points to his leg.

I didn’t realize that members of the focus group might have disabilities. I thought this focus group was just going to be community members who didn’t have a close or personal connection to disability.

Isisa contributes her perspective: “I’m more considerate and sensitive about it now than I was before. You know. Let’s take slow learners for instance before I was like ‘heí’ [laughing] and now I’m like ‘no actually they’re not stupid they’re just slow learners’ and I’ll kind of

10 Everyone in the focus group spoke English, so there was no need for a translator
defend them now rather than laugh and be like ‘no it’s not funny actually’ if someone makes fun of them”.

Lwandle ponders for a bit and then puts his thoughts out into the group: “In our culture and communities we don’t take it [disability] seriously in the homestead. When we see people outside doing something we laugh because we’re not taught about it… yeah we make fun about it. But besides that we’re only concerned if it’s directly about [connected] to you”.

Siyanda also reveals, “I’m disabled right. I hide my disability. People will never recognize. I have a secret. A big secret”.

I nod in acknowledge to all of the participants responses.

“What are some examples of disabilities that you know of or have come into contact with? (for example: disabilities in the media and/or in your community)”

A flurry of conversation breaks out amongst the group. The group is asking each other if stroke counts as a disability or if bipolar counts as a disability. The group doesn’t come to a conclusion on whether or not stroke or bipolar counts as a disability.

“Can you give me an example of a disability that you’ve seen?”

Isisa explains, “it’s the name that we wouldn’t know, like the term”.

“So are people with different kinds of disabilities perceived in different ways? (vision impairments vs. being deaf or hard of hearing vs. intellectual disability vs. physical disability etc)”

Jabulile tells me about a young family member who passed away: “she was normal but at the age of 5 she changed… I don’t know your mind just gets somewhere else you just want to cry and hold her. and then when I see someone else in that situation I’ll [be] like ‘ahh whatever’… and then you’ll see someone who is making a noise and jumping around – you don’t take it seriously you’re like ‘wei domoroza’”.

Isisa chips in and notes: “But for example if you see kids with Down Syndrome you feel sorry sometimes”.

*Isisa’s comment stings more than I thought it would. Is she saying this because my brother has Down Syndrome?*

Siyanda asks if I could elaborate on what is a disability.

I say that “my understanding of disability is that it’s a variation or difference that someone has that means that they have to communicate or do something in a different way”.
Siyanda follows up by clarifying “A disability is something that you’re born with right?”
“Not necessarily” I respond.

This discussion point sparks a debate about whether or not a disability is something that one is born with. The general consensus is that one can be born with a disability, but not necessarily.

Siyanda leaves the focus group at this time since he appears to be dissatisfied by the conclusion that the group has drawn. I thank him for his time and participation.

I direct another question at the group: “how do people in your community react to people with disabilities?”

Lwandle notes that “some will sympathize, and some will laugh… that’s what I’m saying… we’re not being taught well”. Jabulile continues by positing “yeah maybe after we get some education” … Isisa finishes her thought…“like know the different names like what this person identifies as”.

I want to bring in the stories that I heard from Sanele and Velaphi, “From past things that I’ve heard from people with disabilities in urban townships, they’ve mentioned that they don’t always feel included or supported in their community. Have you seen this happen in your community? Where people with disabilities aren’t included or supported by other people?”

Jabulile quickly responds by saying that “they’re actually being mis-used. They’ll make them clean the yard… Yeah they don’t do that to you [gestures to me] because everything is fine. But for her say she [gestures at Isisa] has a disability – they’ll make her walk from here to the mall… they expect you to buy things with 10 rand yet it’s your [disability grant] money. So, they don’t feel that you should be happy. They don’t see the need since you’ve got this illness with you… They say that you stay in the house even if there’s a ceremony. ‘Ooh stay at the house, people will laugh at me and having a son like you’. They’ll lock you in a room and you won’t even eat the whole day and then when everybody is away then they’ll give you food maybe or maybe not”.

Liyana jumps into the conversation for the first time and says “yeah they’ll say ‘you eat too much’”.

Everyone is nodding their head in agreement to what Jabulile and Liyana have just said. I ask a follow up question, “What could your community do better to support and include people with disabilities?”
Jabulile once again jumps to answer the question: “They should be informed about it. They should be told about the good terms and what you can do. They should be informed whether young or old then maybe they’ll have the sympathy to help each other”. Everyone in their group is nodding in agreement.

The focus group ends with a conversation on how community members don’t like to go to psychologists.

Jabulile asks once again, “Is bipolar considered a disability?”

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I have often pondered what my brother’s life and what my life might look like if he wasn’t born with a disability. It would probably be different. But every time I find myself getting caught up in the what ifs, I realize that I don’t see my brother’s reality in front of me. It’s not about changing the hypothetical or falling down the hole of “what if” or “if onlys”. It’s about embracing what’s in front of you and unlearning all of the negative stereotypes and preconceptions that I have about disability and untangling those in my relationship with my brother. It’s not about changing who my brother is or could be, but it’s about looking at myself and reframing my point of view as I live in relation with my brother. (Personal Journal, November 25th, 2019).

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It’s getting closer to 1am. We speak quietly as to not wake our sleeping roommates in the other room.

Amanda asks: “How have you reacted to your family member’s disability?”

I take a deep breath. This is the question that I was dreading to answer. Again, I pick my words carefully, “I think I reacted to my brother’s disability in terms of acknowledging it but not really digging deeper into the details or to understand his disability or even to understand how to be a good sibling who learns more. I think reacted mostly with avoidance and just not interacting with the realities that my brother faces but also the realities that I face as his sister”. I feel the tears well up in my eyes they begin rolling down my cheeks.

“Are you okay? Do you want to continue?” she asks.
I nod.

Amanda asks her own question: “This social distancing against marginalized people is really common. Do you think the distance that you had in getting to know your brother was something you learned from the outside world or something that was just a natural response to having a brother with a disability?”

I respond to Amanda through my tears, “If my brother can’t do things the same way that I can do things…. that shouldn’t change the way that he’s treated or is loved or be treated differently or loved differently. I feel like just different treatment at home affected the way that I viewed my brother and still view my brother… but I’ve realized that that’s something that I want to change and acknowledge and work on and unlearn which is hard. It’s something that’s very personal. But it’s something that I’m very aware of”.

Amanda followed up with, “How do other people’s reactions make you feel?”

I pondered, “My brother walks slower and then like people get caught up behind us I don’t know why I feel like I need to say I’m sorry on behalf of my brother to other people [but I do]. Like when I think about it I feel like I don’t need to say I’m sorry he’s just walking and takes more time but he’s just walking… but the thing that I hate the most is that when I tell people that I have a brother with Down Syndrome and the first thing that people say is that they’re sorry”. My voice cracks at this point, “you know it’s like I don’t know why you’re sorry that my brother has a genetic variation but he’s able to live his life differently but also beautifully. You don’t need to be sorry for that. I don’t need to be sorry for that. My brother doesn’t need to be sorry for that. My parents don’t have to be [sorry either]. Like I’m sorry our society has made it hard for people with disabilities to live their truth to be accepted by others but I’m not sorry that my brother is who he is. But at the same time I wonder why I have to apologize or justify when my brother lives his life differently and that’s something I have to work on and think about and acknowledge and it’s not something that’s done in a couple days or through a project or even years it’s
something that I’ll have to continue working on for my whole life and I think there’s just a lot of things to unlearn and relearn about understanding disability”.

Amanda nods along to what I’m saying.

“Do you think the process of unlearning and relearning… who do you expect to be a part of that process?”

“I think we all have to learn and relearn… for me it starts with what I have learned and how to acknowledge that things that I’ve learned may not be right and know that I’ll continue to make mistakes but learn from them and grow”.
Reflections

During the ISP period, there were many times in which Tovi messaged me “Facetime?” Sometimes I would call him back immediately to see him and catch up on his life back home. Some other times if I was on a roll with my writing, I would text him and say “Can’t talk now! I’ll call you later!”. Often times I would forget to call him later. Despite my forgetfulness my brother continued to text me “Facetime?” every few days and would also send me links to his new favorite song on YouTube, or send me screenshots of movies he was going to see in theaters, or send me pictures of the activities that he was doing. My most recent update from him is from November 23rd. It’s a picture of a vase of flowers that he arranged that’s sitting on our piano at home with the accompanying text of “Flower” and a red flower emoji. I see that I haven’t responded to his text.

“It’s about the self looking at the self in a relationship”

That’s what my professor Clive pondered as I asked him how I could make meaning of my interviews for my autoethnography.

My experience of writing this autoethnography has revealed that it is both a product and a process. Yes, I have this final product that I will submit as my final piece of academic work during my time studying abroad, but I’ve also gained deeper insights into how I see disability and how I have and haven’t seen my brother. I can always continue to reflect on my life as I live in relation to other people. One aspect of this study that I would like to expand on is the connection between disability and aging. I would like to explore my own understanding of aging and how that understanding intersects with disability.

Over this past month, I have been so caught up in creating the product for my work and thinking about the process that I have actively ignored my brother and my relationship with him. This fact in itself illustrates the process of the self that’s looking at the self in a relationship with others but also the world. It’s an ongoing process. The product of my autoethnography may be due but the process will never quite be done.
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Siyanda (2019, November 24). (C. Chao Interviewer)
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Appendix 1: Interview Guide for People with Disabilities

1. Introduce myself and the study to the participant

2. Go through consent form and make sure everyone understands what it is about and ask permission for interview to be audio recorded explaining about confidentiality and anonymity.

3. Create comfortable environment for discussion and sharing
   a. What is your name?
   b. What is your age?
   c. Where do you live in Durban?
   d. How long have you lived there?
   e. How long have you had your disability?

4. Can you tell me what a disability means to you?
   a. how did you first learn about disability?
   b. has your understanding of disability changed as you’ve grown older?

5. What are some examples of disabilities that you know of or have come into contact with? (for example: disabilities in the media and/or in your community)
   a. are people with different kinds of disabilities perceived in different ways?
      i. i.e. vision impairments vs. being deaf or hard of hearing vs. intellectual disability vs. physical disability etc.

6. how do people in your community react to people with disabilities (your disability?)
   a. how do other people’s reactions make you feel?
   b. do you feel supported and included in your community?
      i. if you said yes, can you give an example of a time you felt supported and included?
      ii. If you said “no” give some examples of how you were /are excluded
      iii. what could your community do better to support and include you?
   c. how do you think people in your culture perceive disability?
Appendix 2: Interview Guide for Family Members

1. Introduce myself and the study to the participant
2. Go through consent form and make sure everyone understands what it is about and ask permission for interview to be audio recorded explaining about confidentiality and anonymity.
3. Create comfortable environment for discussion and sharing
   a. What is your name?
   b. What is your age?
   c. Where do you live in Durban?
   d. How long have you lived there?
   e. How long has your family member had their disability?
4. Can you tell me what a disability means to you?
   a. how did you first learn about disability?
   b. has your understanding of disability changed as you’ve grown older?
5. What are some examples of disabilities that you know of or have come into contact with?
   (for example: disabilities in the media and/or in your community)
   a. are people with different kinds of disabilities perceived in different ways?
      i. i.e. vision impairments vs. being deaf or hard of hearing vs. intellectual disability vs. physical disability etc.
6. how have you reacted to your family member’s disability?
   a. in what ways has your family member’s disability had an impact on you?
7. how do people in your community react to your family member’s disability?
   a. how do other people’s reactions make you feel?
   b. do you think your family member who has a disability feels supported and included in your community?
      i. if you said yes, can you give an example of a time they felt supported and included?
      ii. If you said “no” give some examples of how they were/excluded
      iii. what could your community do better to support and include your family member?
   c. how do you think people in your culture perceive disability?
Appendix 3: Interview Guide for Community Members

1. Introduce myself and the study to the participant
2. Go through consent form and make sure everyone understands what it is about and ask permission for interview to be audio recorded explaining about confidentiality and anonymity.
3. Create comfortable environment for discussion and sharing
   a. What is your name?
   b. What is your age?
   c. Where do you live in Durban?
   d. How long have you lived there?
4. Can you tell me what a disability means to you?
   a. how did you first learn about disability?
   b. has your understanding of disability changed as you’ve grown older?
5. What are some examples of disabilities that you know of or have come into contact with? (for example: disabilities in the media and/or in your community)
   a. are people with different kinds of disabilities perceived in different ways?
      i. i.e. vision impairments vs. being deaf or hard of hearing vs. intellectual disability vs. physical disability etc.
6. how do people in your community react to people with disabilities?
   a. how do other people’s reactions make you feel?
   b. I’ve heard from people with disabilities in urban townships express how they don’t always feel included or supported by their community. Have you seen this happen in your community?
      i. if you said yes, can you give an example of a time someone with a disability was not supported and included?
      ii. If you said “no” give some examples of how people with disabilities were supported and included.
      iii. what could your community do better to support and include people with disabilities?
   c. how do you think people in your culture perceive disability?
Appendix 4: Consent Form in English

CONSENT FORM

1. **Brief description of the purpose of this project**
   The purpose of this project is to study the way that people understand, see, and react to disability in urban townships in Durban. The project will study people’s attitudes and opinions on disability through interviews with people with disabilities, family members of people with disabilities, and community members in urban townships in addition to my own personal reflection on my experiences as a family member of someone with a disability. The interviews and focus groups are informal in nature and are meant to be conversational, so please feel free to ask any questions about my own experiences. By signing this form, you are agreeing to participate in this study and have the information that you provide be published in an Independent Study Project that will be available on the internet. Your name and personal identifiers will not be published in the final report. The information from these interviews may be used in future research by the interviewer. You have the option to refuse to participate in the study or end your participation at any time.

2. **Rights Notice**
   In an endeavor to uphold the ethical standards of all SIT ISP proposals, this study has been reviewed and approved by a Local Review Board or SIT Institutional Review Board. If at any time, you feel that you are at risk or exposed to unreasonable harm, you may terminate and stop the interview. Please take some time to carefully read the statements provided below.
   a. **Privacy** - all information you present in this interview may be recorded and safeguarded. If you do not want the information recorded, you need to let the interviewer know.
   b. **Anonymity** - all names in this study will be kept anonymous unless you choose otherwise.
   c. **Confidentiality** - all names will remain completely confidential and fully protected by the interviewer. By signing below, you give the interviewer full responsibility to uphold this contract and its contents. The interviewer will also sign a copy of this contract and give it to you.

I understand that I will receive no gift or direct benefit for participating in the study.
I confirm that the learner has given me the address of the nearest School for International Training Study Abroad Office should I wish to go there for information. (406 Cowey Park, Problem Mkhize Road, Durban).
I know that if I have any questions or complaints about this study that I can contact anonymously, if I wish, the Director/s of the SIT South Africa Community Health Program (Zed McGladdery 0846834982)

_________________________                                 _____________________________
Participant’s name printed                                         Your signature and date

_________________________                                 _____________________________
Interviewer’s name printed                                        Interviewer’s signature and date

I can read English. If the participant cannot read, the onus is on the project author to ensure that the quality of consent is nonetheless without reproach.
Appendix 5: Consent Form in isiZulu

1. Ukuchazwa kafushane ngenhloso yalesifundo

Inhloso yalesifundo ukuthola nokwazi indlela abantu elokhishini abaqonda ngayo ngabantu abakhubazekile. Lesisifundo sizokhuluma ngemicabango nemibono mayelana nokukhubazeka ngokubuza imibuzo kubantu abakhubazekile, imindeni yalabo abakhubazekile, imiphakathi yaselokishini kanjalo nemibono yami njengomuntu onelungu lomndeni elikhubazekile. Imibuzo ebuzwa ndawonye nomu umuntu ngamunye kuzoba yingxoxo lapho nawe wamukelekile ukubuza imibuzo mayelana nelungu lomndeni wami. Ngokusayina leliform, uuyavuma ukuba ingxenye yalesisifundo futhi ulwazi olutholakale ku Independent Study Project ezotholakala ku-internet. Igama lakho nezinto ezingaveza ukuthi kukhulunywa ngawe ngokubalulekuкуnukhusheza kwezinto okungathini kwezinto ongathandi zazi

2. Amalungelo

Njengokomthetho wesikole iSIT lesisifundo sihloliwe sabhekwa abaphathi besikole. Uma uzwa sengathi usengozini yokuvezwa kwezinto ongathandi zazi

   d. Privacy - Zonke izimpendulo zizoqoshwa futhi zivikelwe ukuthi zingabonwa yiwo wonke umuntu

   e. Anonymity - Onke amagama abantu ayogcinwa eyimfihlo ngaphandle uma wena ungenankinga nokusetshenziswa kwegree umuntu


Ngiyaqonda ukuthi ngeke ngithole isipho noma umvuzo ngokusiza kulesisifundo. Ngiyaqiniseka ukuthi umfundi obuza imibuzo unginekezile ikheli lesikole esiseduze sakwaSIT uma ngifisa ukuyapha khona ukuthola imininingwane eminye uma ngiyidinga. (406 Cowey Park, Problem Mkhize Road, Durban).
Ngiyaqonda ukuthi uma ngingizimbele noma izikhala nginingathi umphathi wesikole uZed McGladdery kulenamba 0846834982 ngaphandle kokuzidalula igama lami.

_________________________                                 _____________________________
Igama lami                                            Ukusayina nosuku Iwanamuhla

_________________________                                 _____________________________
Igama lobuza imibuzo                                    Ukusayina nosuku Iwanamuhla

I can read English. If the participant cannot read, the onus is on the project author to ensure that the quality of consent is nonetheless without reproach.
Appendix 6: Ethical Clearance Form
(Adapted from the American Anthropological Association)
This document must be read, signed, and submitted to the AD prior to ethics review meeting.

In the course of field study, complex relationships, misunderstandings, conflicts, and the need to make choices among apparently incompatible values are constantly generated. The fundamental responsibility of students is to anticipate such difficulties to the best of their ability and to resolve them in ways that are compatible with the principles stated here. If a student feels such resolution is impossible, or is unsure how to proceed, s/he should consult as immediately as possible with the Project Advisor and/or AD and discontinue the field study until some resolution has been achieved. Failure to consult in cases which, in the opinion of the AD and Project Advisor, could clearly have been anticipated, can result in disciplinary action as delineated in the “failure to comply” section of this document. Students must respect, protect, and promote the rights and the welfare of all those affected by their work. The following general principles and guidelines are fundamental to ethical field study:

I. Responsibility to people whose lives and cultures are studied
Students' first responsibility is to those whose lives and cultures they study. Should conflicts of interest arise, the interests of these people take precedence over other considerations, including the success of the Independent Study Project (ISP) itself, for if the ISP has negative repercussions for any members of the target culture, the project can hardly be called a success. Students must do everything in their power to protect the dignity and privacy of the people with whom they conduct field study.

The rights, interests, safety, and sensitivities of those who entrust information to students must be safeguarded. The right of those providing information to students either to remain anonymous or to receive recognition is to be respected and defended. It is the responsibility of students to make every effort to determine the preferences of those providing information and to comply with their wishes. It should be made clear to anyone providing information that despite the students' best intentions and efforts anonymity may be compromised or recognition fail to materialize. Students should not reveal the identity of groups or persons whose anonymity is protected through the use of pseudonyms.

Students must be candid from the outset in the communities where they work that they are students. The aims of their Independent Study Projects should be clearly communicated to those among whom they work. Students must acknowledge the help and services they receive. They must recognize their obligation to reciprocate in appropriate ways.

To the best of their ability, students have an obligation to assess both the positive and negative consequences of their field study. They should inform individuals and groups likely to be affected of any possible consequences relevant to them that they anticipate. Students must take into account and, where relevant and to the best of their ability, make explicit the extent to which their own personal and cultural values affect their field study.

Students must not represent as their own work, either in speaking or writing, materials or ideas directly taken from other sources. They must give full credit in speaking or writing to all those who have contributed to their work.

II. Responsibilities to Hosts
Students should be honest and candid in all dealings with their own institutions and with host institutions. They should ascertain that they will not be required to compromise either their responsibilities or ethics as a condition of permission to engage in field study. They will return a copy of their study to the institution sponsoring them and to the community that hosted them at the discretion of the institution(s) and/or community involved.

III. Failure to comply
When the AD(s) feel that the student has violated this statement of ethics, the student will be placed on probation. In the case of egregious violations, students can be subject to immediate dismissal under the conditions of the SIT STUDY ABROAD dismissal guidelines.

I, ____Connie Chao____, have read the above Statement of Ethics and agree to make every effort to comply with its provisions.

Date: __10/21/2019__
Appendix 7: Local Review Board Approval

Human Subjects Review
LRB/IRB ACTION FORM

Name of Student: Connie Chao

ISP/Internship Title: How is Disability Seen? An Auto-Ethnographic Exploration of Disability in Urban Townships in Ethiopia, Saudi Arabia

Date Submitted: 28/10/2019

Program: SFH

Type of review:

Exempt ☐

Expedited ☒

Full ☐

Institution: World Learning Inc.
IRB organization number: IORG0004408
IRB registration number: IRB00005219
Expires: 5 January 2021

LRB members (print names):
Robin Joubert PhD
Clive Bruzas PhD
John McGladdery

LRB REVIEW BOARD ACTION:

☑ Approved as submitted

☑ Approved pending changes

☐ Requires full IRB review in Vermont

☐ Disapproved

LRB Chair Signature: [Signature]

Date: 28/10/2019

Form below for IRB Vermont use only:

Research requiring full IRB review. ACTION TAKEN:

☐ approved as submitted ☐ approved pending submission or revisions ☐ disapproved

IRB Chairperson’s Signature ___________________________ Date ___________________________
Appendix 8: Consent to Use of Independent Study Project (ISP)

Access, Use, and Publication of ISP/FSP

Student Name: Connie Chao

Email Address: cchao3@wellesley.edu

Title of ISP/FSP: How is Disability Seen? An Auto-Ethnographic Exploration of Disability in Urban Townships in eThekwini, South Africa

Program and Term/Year: Community Health and Social Policy, Fall 2019

Student research (Independent Study Project, Field Study Project) is a product of field work and as such students have an obligation to assess both the positive and negative consequences of their field study. Ethical field work, as stipulated in the SIT Policy on Ethics, results in products that are shared with local and academic communities; therefore copies of ISP/FSPs are returned to the sponsoring institutions and the host communities, at the discretion of the institution(s) and/or community involved.

By signing this form, I certify my understanding that:

1. I retain ALL ownership rights of my ISP/FSP project and that I retain the right to use all, or part, of my project in future works.
2. World Learning/SIT Study Abroad may publish the ISP/FSP in the SIT Digital Collections, housed on World Learning’s public website.
3. World Learning/SIT Study Abroad may archive, copy, or convert the ISP/FSP for non-commercial use, for preservation purposes, and to ensure future accessibility.
   - World Learning/SIT Study Abroad archives my ISP/FSP in the permanent collection at the SIT Study Abroad local country program office and/or at any World Learning office.
   - In some cases, partner institutions, organizations, or libraries in the host country house a copy of the ISP/FSP in their own national, regional, or local collections for enrichment and use of host country nationals.
4. World Learning/SIT Study Abroad has a non-exclusive, perpetual right to store and make available, including electronic online open access, to the ISP/FSP.
5. World Learning/SIT Study Abroad websites and SIT Digital Collections are publicly available via the Internet.
6. World Learning/SIT Study Abroad is not responsible for any unauthorized use of the ISP/FSP by any third party who might access it on the Internet or otherwise.
7. I have sought copyright permission for previously copyrighted content that is included in this ISP/FSP allowing distribution as specified above.

Connie Chao 26/11/2019
Withdrawal of Access, Use, and Publication of ISP/FSP

Given your agreement to abide by the SIT Policy on Ethics, withdrawing permission for publication may constitute an infringement; the Academic Director will review to ensure ethical compliance.

☐ I hereby withdraw permission for World Learning/SIT Study Abroad to include my ISP/FSP in the Program’s office permanent collection. Reason:

☐ I hereby withdraw permission for World Learning/SIT Study Abroad to release my ISP/FSP in any format to individuals, organizations, or libraries in the host country for educational purposes as determined by World Learning/SIT Study Abroad. Reason:

☐ I hereby withdraw permission for World Learning/SIT Study Abroad to publish my ISP/FSP on its websites and in any of its digital/electronic collections, or to reproduce and transmit my ISP/FSP electronically. Reason:

Connie Chao 26/11/2019

Student Signature Date

Academic Director has reviewed student reason(s) for withdrawing permission to use and agrees it does not violate the SIT Study Abroad Policy on Ethics.