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## Narratives of Disability and Displacement: Oral Histories of the Lived Experiences of Disabled Refugees

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## The University of San Francisco

#### NARRATIVES OF DISABILITY AND DISPLACEMENT: ORAL HISTORIES OF THE LIVED EXPERIENCES OF DISABLED REFUGEES

A Dissertation Presented to
The Faculty of the School of Education
International and Multicultural Department

In Partial Fulfillment
Of the Requirements for the Degree
Doctor of Education

By Jennifer Lynn Ward San Francisco May 2021

#### THE UNIVERSITY OF SAN FRANCISCO

#### Dissertation Abstract

#### Narratives of Disability and Displacement:

#### Oral Histories of the Lived Experiences of Disabled Refugees

Disabled refugees are considered as the most marginalized group of all displaced populations. Disabled displaced people are at particular risk of violence, exploitation, and abuse. Additional barriers to accessing humanitarian assistance, education, health care, and other services exist for disabled displaced people. The purpose of this study was to collaborate with disabled refugees who have resettled in the United States and to create a space for their stories to be told. This research project explores the narratives of the lived experiences of disabled displaced people through the lenses of three theoretical frameworks: human rights, disability justice, and Critical Refugee Studies. Together these frameworks work to shift the narrative around disability and refugeehood. Data were collected via one-on-one interviews with six disabled refugees who have resettled in various regions of the United States within the past 15 years. Six themes emerged from the data: 1) claiming education as a human right, 2) inequities in the resettlement camps, 3) lack of knowledge and training of resettlement workers, 4) human rights realized, 5) changing the narrative around disability and refugees, and 6) hope for the future. The findings of this study highlight the additional barriers that disabled refugees encounter both in the displacement camps and upon resettlement in the United States. Furthermore, the results support existing literature highlighting the need for training and cross-collaboration for both resettlement and disability organizations, along with increased awareness and understanding of the unique needs of disabled displaced people. Results from this study provide insight and implications for improving the resettlement experiences of disabled refugees in both policy and practice.

#### **SIGNATURE PAGE**

This dissertation, written under the direction of the candidate's dissertation committee and approved by the members of the committee, has been presented and accepted by the Faculty of the School of Education in partial fulfillment of the requirements for the degree of Doctor of Education. The content and research methodologies presented in this work represent the work of the candidate alone.

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#### **PROLOGUE**

During the dissertation defense on April 14, 2021, my dissertation committee members and I debated the appropriateness of the term "oral history" in this study, since not all the participants shared their stories in spoken, oral language. In fact, three of the six participants were Deaf and communicated with American Sign Language, which I then transcribed into text. Thus, it is arguable that the use of the word "oral" is exclusive and does not take into consideration those who use sign language, nonverbal communication, or other modes of communication. However, after further consideration, research, and consulting with some of the Deaf participants in this study as well as members of the Deaf community, I decided to continue to use the term "oral history." As one Deaf participant explained to me, oral history is something that is passed down from generation to generation as a form of storytelling. It is an expressive form of communication and storytelling in whatever form of language or communication the narrator uses and does not solely mean spoken language.

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#### LIST OF ACRONYMS

ADA Americans with Disabilities Act

CRC Convention on the Rights of the Child

CRPD Convention on the Rights of People with Disabilities

ICCPR International Covenant on Civil and Political Rights

ICESCR International Covenant on Economic, Social and Cultural Rights

IDEA Individuals with Disabilities Education Act

IOM International Organization for Migration

IRC International Rescue Committee

SDG Sustainable Development Goals

UDHR Universal Declaration of Human Rights

UN United Nations

UNHCR United Nations High Commissioner for Refugees

#### **DEFINITION OF TERMS**

The following definitions clarify the terms used in this research.

Ableism: Stereotyping, prejudice, discrimination, and social oppression toward disabled people. (Bogart & Dunn, 2019); The belief that nondisabled people are superior, have a better quality of life, or have more valuable lives (Brown, n.d.).

Asylum-Seeker: A person who flees their own country and seeks sanctuary in another country by applying for asylum. An asylum seeker must demonstrate that his or her fear of persecution in her or her home country is well-founded (UNHCR, 2019).

*Disabled:* Having physical or mental differences or impairments wherein society does not view their bodies, ways of thinking, communication, sensing, or moving as "normal" (Brown, n.d.). The CRPD defines disabled people as those having long-term physical, cognitive, intellectual, or sensory impairments which, when interacting with various barriers, may hinder full, effective, and equal participation in society (CRPD, 2006).

Disability: The social disadvantages and exclusions that people with impairments face in all areas of life (Thomas, 2014). Disability arises out of the interaction between one's impairment and barriers, such as attitudinal and environmental barriers, may hinder full, effective, and equal participation in society and access to opportunities (Save the Children, n.d.).

Displaced Person: People or groups of people who have been forced to flee their homes or places of habitual residence as a result of armed conflict, internal strife, or habitual violations of human rights. They may cross international borders, becoming refugees or asylum seekers, or seek safety within the borders of their own country, becoming internally displaced people (UNHCR, 2019).

*Impairment:* Physical, sensory, emotional, and cognitive differences diverging from culturally valued norms of embodiment (Cameron, 2014). An impairment can be long or short term and can be caused by medical or genetic reasons or as a result of accidents or violence (Save the Children, n.d.).

Please note: It is important to understand the difference between *impairment* and *disability*. A person with an impairment is no longer disabled with the removal of barriers through the use of assistive devices, rehabilitation, and habilitation specific to the impairment. Most disabled people do not consider the impairment to be the main problem; rather, the attitudes of others are what cause additional barriers (CBM, n.d.).

Figure 1

Impairment vs. disability

$$Impairment + barrier = disability \\ Or \\ Impairment + accessible environment = inclusion$$

*Note*. Disability inclusive development toolkit. Christian Blind Mission, n.d. Retrieved from https://www.cbm.org/fileadmin/user\_upload/Publications/CBM-DID-TOOLKIT-accessible.pdf

*Invisible Disability:* A disability that is not immediately apparent. Some examples are chronic pain or illness, chronic fatigue, mental illness, brain injuries, and chronic migraines. It is estimated that 10% of people living in the United States have a medical condition which could be considered an invisible disability (Disabled World, 2020).

Marginalization: The erasure and silencing of the viewpoints of a group of oppressed people. (Brown, n.d.).

*Migrant:* Any person who is moving or has moved away from his or her place of usual residence, whether across an international border or within a State, temporarily or permanently, regardless of legal status, whether the move is voluntary or involuntary, and for a variety of reasons. A universally accepted definition for migrant does not yet exist (IOM, 2019).

*Refugee:* The United Nations defines a *refugee* as someone who has been forced to flee his or her country because of persecution, war or violence for reasons of race, religion, nationality, political opinion or membership in a particular social group (UNHCR, 2019).

A disability justice framework utilizes identity-first language. For the purpose of keeping in line with this framework, I will use identity-first language throughout this paper.

*Identity-first language:*(disabled person/disabled people) affirms that disability is an integral part of disabled people's identities and experiences. It recognizes the importance of disability in how it defines and shapes individual and collective experiences (Brown, n.d.).

*People-first language:* (person with a disability; people with disabilities) affirms that people with disabilities more than labels or diagnoses but are human beings who should be thought of as people first (Brown, n.d.).

While both terminologies aim to emphasize a person's value and worth, people-first language suggests the person can be separated from the disability. It is important to note that neither identity-first nor people-first language should be used exclusively in any situation. Some individuals and groups prefer people-first language, and it is important to respect how different communities and individuals choose to identify themselves. When in doubt, ask the person their preference. The participants in this study use identity-first language when referring to themselves.

#### **CHAPTER I: THE RESEARCH PROBLEM**

#### **Statement of the Problem**

Article 14 of the Universal Declaration of Human Rights (UN, 1948) proclaims, "Everyone has the right to seek and to enjoy in other countries asylum from prosecution," which includes disabled people. The United Nations High Commissioner for Refugees (UNHCR) currently reports that at the end of 2019, 79.5 million people were forcibly displaced worldwide; of this total number, 41.3 million are internally displaced, 25.9 million refugees, and 3.5 million asylum-seekers (2019). Importantly, as many as 14 million displaced people are disabled. (Women's Refugee Commission, 2018). According to the UNHCR annual Global Trends Report, worldwide displacement numbers are the highest ever recorded (UNHCR, 2019).

Historically, disabled people have been marginalized and oppressed, facing multiple instances of discrimination. Disabled refugees and asylum seekers are at particular risk of violence, exploitation, and abuse. In many cultures, a high level of stigma is associated with disability. Additional barriers to accessing humanitarian assistance, education, health care, and other services exist for disabled displaced people. Those with disabilities may be left behind or may not survive the journey. In addition, many refugees acquire impairments during displacement, due to persecution, trauma, or abuse (Elder, 2015). Resettlement options for disabled refugees are often based on charity and view disability from a medical perspective, versus looking at providing equity and equal opportunities (Mirza, 2011a).

Crock, Smith-Khan, McCallum, and Saul (2017) suggest that the true number of disabled people worldwide is underestimated, and the current number of disabled displaced people is actually much higher than reported. The reason for this underestimation is the tendency to

overlook disabled refugees during the conflict, as well as the aftermath. Those crossing borders as refugees and asylum seekers are even more likely to be ignored or overlooked.

Refugees, asylum-seekers, and other displaced people face multiple oppressions and systems of disadvantage that influence their experiences (Elder, 2015; Besic, Paleczek, & Gasteiger-Klicpera, 2018). In addition to their already existing multiple identities, displaced people acquire the additional identity of refugee or displaced person (Elder, 2015). The intersectionality of these multiple identities – disability, gender, refugee status – all influence the attitudes and biases of the general public and create additional systems of disadvantage (Besic et al., 2018). Mirza (2011a) reports discriminatory practices that view refugees as less desirable immigrants, thereby restricting their mobility in pursuit of safer, more sustainable living conditions.

For many disabled displaced people, additional challenges often start during flight. Due to the ensuing chaos, some may be left behind because they are unable to move without assistance. No one may stop to help, or the people may be unable to call out for help. Visual, hearing, and cognitive impairments may make it harder to detect and understand warning systems and can also lead to confusion and disorientation. Families often have to make decisions about what to take with them, and adaptive or assistive equipment may be left behind. This can make the flight even more difficult for the disabled person as well as the caregivers (Shivji, 2010).

Moreover, oftentimes staff working in humanitarian agencies and situations hold common misperceptions about disabled people, such as: they require specialist care or their needs will be met through general aid distributions; they are unable to help others; or they are unable or unwilling to participate in programs, activities, or education (Kett & van Ommeren,

2009). Additionally, funding and resources are often allocated to those injured or disabled as a result of conflict, and those disabled prior to the conflict are overlooked (Kett & van Ommeren, 2009).

A common theme across scholars is the need for more research and information regarding the programming and placement of refugees and other disabled displaced people (Crock, et al., 2013; Mirza, 2011a; Mirza, 2011; Shivji, 2010; Smith-Khan, Crock, Saul & McCallum, 2014;). Policy makers, humanitarian workers, and government workers working with refugees and other displaced people do not have the training and expertise in working with disabled people. While some policy changes have taken place in recent years, evidence suggests these changes happened on paper and not necessarily in practice (Mirza, 2011b). One example is the majority of humanitarian workers reporting they were unaware of existing guidelines for field officers issued by UNHCR in 1992. These guidelines outline the provision of assistance to disabled refugees (Mirza, 2011b). Furthermore, humanitarian agencies have historically viewed disabled people as "different" and needing specialized expertise, therefore outside of their realm of responsibility (Mirza, 2011b).

Across differing contexts and countries some common protection concerns were noted both by disabled people as well as their caregivers. These include the following: a lack of participation in community activities and decision making; stigma and discrimination; emotional, physical and sexual violence; lack of access to health care specific to one's disability; and unmet basic needs among families of people with multiple disabilities (Pearce, 2015). Disabled refugees often face feelings of isolation, depression, and inadequacy (Mirza, 2012; Roberts & Harris, 2002).

More training and cross-collaboration are needed for both humanitarian staff and disability organizations, as well as increased awareness and understanding of disability and the needs of disabled displaced people. Current policies and practices often overlook the unique needs of disabled displaced people, and lack of resources or inadequate distribution of resources contribute to continued marginalization and oppression of this group. In order to effect change in policy and practice we need to hear the narratives and lived experiences of those people directly impacted by them. A lived experience is an immediate awareness of life and at its core is "a certain way of being in the world" (Van Manen, as cited in Chao, 2019, p. 810). These narratives "challenge stereotypes of dependence and the perceived lack of independence in the person with disabilities" (Dawson, 2019, Acts of Resistance section, para. 7). "We need to find ways to facilitate the hearing of these experiences of the oppressed" (Pease, 2010, p.179).

#### **Background and Need for the Study**

More research and information are needed regarding the programming and placement of refugees and other disabled displaced people (Crock, et al., 2013; Shivji, 2010.; Mirza, 2012; Smith-Khan et al., 2014; Mirza, 2011a). Crock, Smith-Khan, McCallum, and Saul (2017) claim there is insufficient research to show what kinds of accommodations are in place in both refugee camps and the host countries. More research needs to be done on how disability is identified. Due to differing notions of what constitutes a disability and a tendency to adopt a medical model of disability versus a social or rights-based model, the true number of disabled displaced people is thought to be underestimated (Smith-Khan et al., 2014).

Additionally, more research and scholarship in the area of disability and displacement is needed in order to address the marginalization and stigmatization of this population, as well as the pressing human rights issues at hand. Failure to provide equal access to assistance, resources

and services for disabled people is discriminatory and a violation of the 2006 UN Convention on the Rights of People with Disabilities (Human Rights Watch, 2017). Research has been done on resettlement experiences (Duell-Piening, 2018; Elder, 2015; Mirza, 2011a; Mirza, 2012), the process of applying for asylum, refugee status, and accessing services (Cummings & Hardin, 2017), and the general obstacles and barriers disabled displaced people encounter (Roberts & Harris, 2002; Smith-Kahn et al., 2014). However, insufficient research conveys a full understanding of the lived experiences and situations disabled displaced people have faced and continue to face.

This project addresses this gap in the research by using oral history to collaborate with disabled refugees and creating a space for their stories to be told. As a powerful method of storytelling, oral history seeks to uncover processes and link individual experiences with the larger context in which those experiences occur (Leavy, 2011). Since this research project is based upon *collaboration with*, not *research on*, the participants, oral history is an appropriate methodological approach. In my role as the researcher, I will provide a platform that allows them to tell their own stories in their own words and to amplify voices that have thus far gone unheard.

Two *Voice of Witness* anthologies are vivid examples of how oral history can serve to honor refugee voices. The first is *Out of Exile: Narratives from the Abducted and Displaced People of Sudan* (Walzer, 2009), which uses oral history to humanize the human-rights crisis in Sudan. Sudanese men, women, and children tell their stories of exile, displacement, slavery, and exploitation and in doing so shed light on a situation largely hidden from the rest of the world.

The second volume, *Solito, Solita: Crossing Borders with Youth Refugees from Central America* (Mayers & Freedman, 2019), is a collection of oral histories that tell the stories of refugee youth fleeing their home countries in South America to seek safety, protection, and a

better life in the United States. These stories bring to light the circumstances that cause them to embark on these dangerous journeys and the struggles they encounter along the way, as well as the challenges they face in their attempts to resettle in the United States.

Furthermore, oral history closely aligns with a disability justice framework in that it centers the voices and leadership of those most impacted – disabled refugees. This research project aims to give space for the participants to tell their own full stories and in their own words. It is my hope that by sharing their stories and experiences, we will open up room for dialogue on disability, refugees, and human rights as well as confront stigma related to disability.

#### **Purpose Statement**

The purpose of this study is to explore the narratives of the lived experiences of disabled displaced people, including refugees, asylum-seekers, and forcibly displaced people. Particularly, I examine their experiences navigating the resettlement process as disabled people both in the displacement camps and in the United States. To contextualize their experiences, this study assesses their experiences with resettlement agencies and caseworkers in terms of being able to meet the unique needs related to their impairment.

#### **Research Questions**

This study investigates the following research questions:

- 1. How do disabled people describe their experiences living in displacement camps in regard to accessing programs, resources, health care, education, and other services?
- 2. How do the participants describe their resettlement experiences upon arriving in the United States and the ease and/or difficulty of accessing programs, resources, health care, education, and other services?

3. How do the participants assess their experiences with resettlement agencies and caseworkers in terms of being able to meet the unique needs related to their impairment?

#### **Theoretical Frameworks**

This research utilizes the frameworks of human rights, disability justice, and Critical Refugee Studies (CRS) to examine the narratives based on the lived experiences of disabled displaced people. To better understand the lived experiences of refugees and disabled displaced people it is important to include a human rights framework that includes both refugee rights and disability rights. A human rights framework states all people are born free and equal, and,

Everyone is entitled to all the rights and freedoms set forth in this Declaration, without Distinction of any kind, such as Race, colour, sex, language, religion, political or other opinion, National or social origin, property, birth or other status (UDHR, 1948, Articles 1 and 2).

A human rights framework centers human dignity through viewing each person as valued because of their inherent self-worth. Through this lens, individuals with a disability are included in all decisions affecting them; more importantly any "problem" is located within society as opposed to within the individual. A disability justice framework has at its core giving leadership to those most impacted by the systems they are fighting against. Critical Refugee Studies considers refugees to be producers of knowledge versus a problem to be solved, and as such views them as human beings deserving of all fundamental rights and privileges.

#### **Human Rights Framework**

The Universal Declaration of Human Rights (UDHR) is the foundation for international human rights law, which applies to all people at all times. The basic principles of the human

rights framework are universality, indivisibility, participation, accountability, transparency, and non-discrimination (NESRI, n.d.).

A primary purpose for the establishment of the United Nations High Commissioner for Refugees (UNHCR) in 1951 was to aid, protect, and monitor refugees. It considers the protection of refugees to be human rights work.

Human rights violations are a major factor in causing the flight of refugees as well as an obstacle to their safe and voluntary return home. Safeguarding human rights in countries of origin is therefore critical for the prevention and for the solution of refugee problems. Respect for human rights is also essential for the protection of refugees in countries of asylum (UNHCR, 1995, p. 2).

Many of the provisions delineated in existing international human rights treaties coincide with those of the UNHCR's Executive Committee Conclusion 22, which serves as a basic reference point for the protection of refugees and other displaced people. While the Excom Conclusion is not considered to be a legally binding document, the international human rights treaties do create legal obligations for those states which are party to them. Some examples of these coinciding rights are:

- "not be subjected to restrictions on their movements": Covenant on Civil and Political Rights, Art. 9 and 12; Convention on Elimination of Racial Discrimination, Art. 5.d(i)
- "not be subjected to cruel, inhuman or degrading treatment": Universal Declaration of Human Rights, Art. 5; Convention Against Torture, Art. 2 and 16; Covenant on Civil and Political Rights, Art. 7

 "no discrimination on the grounds of race and religion...": Universal Declaration of Human Rights, Art. 2 and 7; Covenant on Civil and Political Rights, Art. 2.1 (UNHCR, 1995).

#### **Disability Justice**

Disability justice is a developing framework that considers ableism to be at the root of disability oppression and, as such, works to create alternative practices that are rooted in justice. Disabled queers and activists of color developed this framework to address their belief that the Disability Rights Movement has excluded many disabled groups, such as disabled people of color, disabled immigrants, those who are disabled and houseless, disabled incarcerated people, and many others (Sins Invalid, 2019).

At the core of a disability justice framework is the understanding that all bodies are unique and essential; all bodies have strengths and needs that must be met; all bodies are powerful because of the complexities of them; and all bodies are confined by multiple identities and groups which cannot be separated (Sins Invalid, 2019). Disability justice holds ten principles:

- Intersectionality
- Leadership of the most impacted
- Anti-capitalist politic
- Cross-movement solidarity
- Recognizing wholeness
- Sustainability
- Commitment to cross-disability solidarity
- Interdependence

- Collective access
- Collective liberation (Sins Invalid, 2019).

The second principle - leadership of the most impacted - highlights the perspectives of those most affected by oppressive systems. This core principle of the disability justice framework will serve as a foundation for this study.

A disability justice framework argues that ableism helps make possible other oppressive systems, such as racism, sexism, Christian supremacy, and queer- and transphobia, and that these systems are tightly intertwined (Piepzna-Samarasinha, 2018). Within this framework, disability is not defined in terms of white, male, or straight terms. Instead, it centers all those who are marginalized within mainstream disability organizing – such as refugees and immigrants (Piepzna-Samarasinha, 2018).

#### **Critical Refugee Studies**

Critical Refugee Studies (CRS) is an emerging area of study that centers refugees as knowledge producers versus refugees as problems, objects of rescue, and crises (Espiritu, 2014). A CRS lens facilitates a way to access refugee knowledge and consider the new forms of knowledge to be produced. At its core, CRS considers the root causes of displacement to be imperialism, (US) militarization, and colonialism (Espiritu, 2014). In an effort to shift the dominant narrative of refugees as victims in needs of rescue, as passive recipients of aid, and as a problem needing to be solved, CRS reconceptualizes refugees as knowledge producers (Espiritu, 2014). CRS calls for a world where all refugees are seen as human beings deserving of all fundamental rights and privileges (Critical Refugee Studies Collective, n.d.).

Together these three frameworks center the stories of disabled displaced people at the forefront of the discourse and seek to understand disability from the perspective of disabled

people and refugees. Additionally, they allow us to view the experiences of both disabled people and refugees through a human rights lens in an attempt to shift the narrative around both disability and refugeehood.

Figure 1

Theoretical Frameworks



#### Limitations

The participants in this study were selected since they came to the United States as refugees, asylum-seekers, or forcibly displaced people within the past 15 years. Initially I had anticipated that one limitation might arise from a potential difference between my cultural beliefs and those of the participants, particularly, in regard to disability. Therefore, I was mindful not to impart my opinions and biases onto the participants while conducting the oral histories,

analyzing the data, and writing up the findings. I addressed this issue by familiarizing myself with the participants' cultures and their respective views regarding disability.

Another limitation resulted from linguistic differences between the participants and me. Some of the participants had just begun to learn English and chose to do their interviews in English. Also, all three Deaf<sup>1</sup> participants communicated via American Sign Language (ASL). In these cases, I conducted the interviews using American Sign Language, a language which I am comfortable using but of which I am not a native user.

My positionality as a non-disabled person could be viewed as a limitation since it does not allow me to truly understand the lived experiences of the disabled participants and the systems they have had to navigate. However, while I do not have first-hand experience as a person with a disability, I have worked as a teacher of students with disabilities for most of my career. Therefore, I do have some understanding of the unique support needs of disabled people. Additionally, I need to acknowledge my positionality and privilege in terms of race, education, and status as a United States citizen by communicating in an open, respectful way. Being upfront and straightforward about the project and its purpose was an effective way to address this power dynamic. It was important for me to always keep in mind that I was not there to study the participants, but rather to learn from them.

Lastly, I had to consider my position as an outsider to the communities in which I entered for this project – the disabled community, the refugee community, and the various ethnic and

<sup>&</sup>lt;sup>1</sup> Deaf with a "D" refers to members who culturally and linguistically identify as being Deaf and belong to the Deaf community. Deaf with a "d" refers to the audiological condition of not hearing. Both terms will be used throughout the paper, depending on the context. Not everyone in the Deaf community identifies as belonging to the greater disability community. However, Deaf participants were included because in their home countries they are considered disabled and for the purposes of immigration paperwork they are required to register as a disabled person.

cultural communities. Being an outsider might have created barriers to trust and willingness to participate. This lack of trust could have caused some participants to not share some personal and private experiences. In order to build as much trust as possible, I reinforced the participants' right to confidentiality, included them in the entire oral history process from beginning to end, and took steps to ensure they understood the purpose of oral history as well as their role in this project. By amplifying their voices and experiences, I aimed to make this their project as much as mine. I succeeded in doing this by using their own words as much as possible, and by conducting semi-structured interviews in which the participants took the lead and shared what they wanted to talk about and include in their stories.

#### **Educational Significance**

This study focuses on the narratives based upon the experiences of disabled displaced people and aims to provide recommendations and strategies for policy makers, humanitarian workers and organizations, and non-governmental organizations on how to better meet the unique needs of disabled displaced people. As previously stated, the narratives of disabled displaced people are missing in the current literature and research. These lived experiences need to be heard in order to effect change in policy and practice, as well as in the resettlement process. "Because oppression and privilege are more visible to those who are oppressed, they must always be the leaders in social movements for change" (Pease, 2010, p. 182). For this reason, it is critical that the research and literature includes the voices of the refugees.

This study aims to use the frameworks of human rights, disability justice, and Critical Refugee Studies to center disabled people in the discourse, understand disability from the perspective of the disabled people, view their experiences through a lens of human rights and human rights violations, and challenge the existing narratives around disability and

displacement. Additionally, it strives to examine the ways in which societal barriers limit or prevent access to resources, education, community programs, and health care for disabled displaced people, versus the disability itself.

#### CHAPTER II: REVIEW OF THE LITERATURE

#### Restatement of the Purpose of the Study

A common theme across scholars is the need for more research and information regarding the programming and placement of refugees and other disabled displaced people (Crock, et al., 2013; Mirza, 2011a; Mirza, 2011; Shivji, 2010; Smith-Khan, Crock, Saul & McCallum, 2014). More research and scholarship in the area of disability and displacement is needed in order to address the marginalization and stigmatization of this population, as well as the pressing human rights issues at hand. Failure to provide equal access to assistance, resources and services for disabled people is discriminatory and violates the 2006 UN Convention on the Rights of People with Disabilities (Human Rights Watch, 2017). Duell-Piening (2018), Elder (2015), and Mirza (2011a, 2012) have done research on resettlement experiences, with Elder focusing on life histories to explore the personal experiences. Cummings and Hardin (2017) focused on the specific aspects of refugee experiences, such as the process of applying for asylum, refugee status, and accessing services, while Roberts and Harris (2002) and Smith-Khan, Crock, Saul, & McCallum (2014) have conducted studies on the general obstacles and barriers disabled displaced people encounter.

However, insufficient research exists to fully understand the lived experiences and situations disabled displaced people have faced and continue to face. Many scholars have conducted oral history research with refugees (Thomson, 1999; Nur, 2008; Mayers & Freedman, 2019), as well as with people with disability (Hirsch, 1995; Pelka, 2012; Manning, 2010; Walmsley & Atkinson, 2005). However, an oral history perspective of disabled refugees is missing in the current literature.

More training and cross-collaboration are needed for both humanitarian staff and disabled person's organizations, as well as increased awareness and understanding of disability and the needs of disabled displaced people. Current policies and practices often overlook the unique needs of disabled displaced people, and lack of resources or inadequate distribution of resources contribute to continued marginalization and oppression of this group. In order to effect change in policy and practice we need to hear the narratives and lived experiences of those people directly impacted by them. "We need to find ways to facilitate the hearing of these experiences of the oppressed" (Pease, 2010, p.179). These narratives "challenge stereotypes of dependence and the perceived lack of independence in the person with disabilities" (Dawson, 2019, Acts of Resistance section, para. 7).

A preliminary review of the literature identifies the following four themes that will be explored in this literature review: 1) A Human Rights Framework for Refugees and Disability 2) Intersectionality and Identity of Disabled Displaced People, 3) Immigration Policy, Past and Present, and 4) Resettlement Experiences.

#### A Human Rights Framework for Refugees and Disability

At the center of human rights is respect for human dignity. Since human rights are fundamental rights, they cannot be earned or taken away from an individual or group. A human rights framework reaffirms that all human beings are rights-bearers with inherent self-worth.

#### **International Refugee Law**

The UN adopted the Convention Relating to the Status of Refugees in 1951, which was entered into force on April 22, 1954 and has since had one amendment in 1967. This Convention outlines the most comprehensive rights of refugees at an international level. The Refugee Convention defines the term *refugee* and delineates States' obligations as well as addresses rights

such as religion (Article 4), non-discrimination (Article 3), wage-earning employment (Article 17) and more (United Nations, 1951). Due to geographic and temporal limitations the 1951 Convention imposed, the *1967 Protocol* was implemented as a supplement to the Refugee Convention, without limitations of time or place. Together, the 1951 Convention and 1967 Protocol were designed to assure refugees the enjoyment of their rights to the greatest extent. States around the world have developed complementary laws and standards in response to regional specificities.

International refugee law is founded on the 1951 Refugee Convention and its 1967 Protocol. However, these do not operate in isolation. International bodies of law, such as human rights law, humanitarian law, and criminal law, complement and work alongside refugee law to ensure the safety and protection of refugees, asylum seekers, and other displaced people. The Refugee Convention was drafted in response to the refugees displaced by World War II. The intention was to provide legal protection for the large number of displaced people in Europe (McAdam, 2017). The Refugee Convention is considered a guiding framework which outlines minimum standards and conditions by which states must function.

Critics of the Refugee Convention claim that it is too restricted and outdated and is no longer adequate to respond to the current displacement crisis (McAdam, 2017; Quinn, 2011). Quinn (2011) outlined two major criticisms: The Convention's definition of who is a refugee is narrow and does not reflect the evolving nature of conflict and patterns of migration; and it does not address mass movements, such as those happening in camp environments. Many countries receiving refugees and asylum seekers are poor and lack adequate infrastructure to support the large-scale influxes. The Refugee Convention does not take into account the burden of sharing provisions and the fact that some countries may bear especially heavy burdens when accepting

displaced people. Quinn (2011) pointed out that while the Convention continues to have relevance in the protection of refugees and other displaced people, it still needs to be subject to regular review to ensure it recognizes and includes the changes and gaps. Furthermore, Parekh (2009) argued the Refugee Convention has failed to recognize and include the protection of newly emerged social groups, such as disability and women who have experienced gender-based violence. The UNHCR, however, claims the Refugee Convention continues to remain relevant (Parekh, 2009).

Crock, Ernst, and McCallum (2013) examined the extent to which the CRPD applies to refugees. During the drafting of the CRPD, some of the participating state parties asserted that states' obligations under the Convention apply only to nationals, arguing that human rights protections are not guaranteed. Furthermore, these same state parties claimed that challenging economic and social conditions of some countries may make it difficult to support disabled nationals, let alone disabled displaced people arriving in their countries. Critics of this position assert that human rights, by definition, are universal and apply to everyone simply on the basis of being human. International human rights treaties, such as the International Covenant on Economic, Social and Cultural Rights (ICESCR) and the International Covenant on Civil and Political Rights (ICCPR), along with the UDHR, recognize the inherent rights of all people, not only those belonging within a state's jurisdiction (Crock, et al., 2013). Thus, Crock, Ernst, and McCallum (2013) contend that the CRPD does indeed apply to refugees and other displaced people, citing Article 11 which obligates states to take measures to protect disabled people in situations of risk.

#### Disability as a Human Rights Issue

Degener (2016) outlined the shift from a medical model of disability to the social model of disability and its impact on policy and practice. The medical model of disability came about in 1980 as a result of the World Health Organization's definition of disability, 'the effects of the impairment on everyday activities' (Llewellyn & Hogan, 2000, p. 158). A medical model of disability views disability as a problem, illness, or condition needing to be cured. Emphasis is placed on treatment and medical care. During the 1970's, disability rights activists, along with the disabled community, worked to change the perception of disability from one of impairment to one of social exclusion. Mike Oliver, a disability activist, coined the term "social model of disability" in 1983 (Shakespeare, 2006). In contrast to the medical model, a "social model of disability" looks at the societal barriers that prevent disabled people from fully participating in society, such as physical barriers, language and communication barriers, and societal attitudes and beliefs. Disability is not viewed as an attribute an individual possesses, but rather as a collection of conditions, many of which are created by the social environment.

This change from the medical to the social model of disability brought about a paradigm shift in disability policy and practice by understanding that disabled people are rights holders and human rights subjects versus impaired beings. As a result, the United Nations adopted the Convention on the Rights of People with Disabilities (CRPD) and entered it into force in May 2008. The CRPD was considered a major step forward for the disability community and how the world thinks and acts about disability (Meekosha & Soldatic, 2011). A primary aim was to acknowledge and outline the human rights of disabled people. The CRPD was a pivotal instrument in the shift from a medical model of disability to that of a social model, which initiated many law and policy reforms.

Degener (2014) claimed the CRPD introduced an alternative model of disability – the human rights model – as an improvement on the social model as well as a tool with which to implement the CRPD. Degener (2014) outlined six key tenets of the human rights model: 1) claims that impairment does not hinder human rights capacity; 2) encompasses both sets of human rights (civil and political, as well as economic, social, and cultural; 3) values impairment as part of human diversity; 4) acknowledges issues of identity; 5) offers a basis for the assessment of prevention policy; and 6) strives for social justice.

A rights-based model of disability is based on the social model and shares the same premise that it is society that needs to change. This model focuses on equity and rights and aims to include all people equally within society. At the core of this model is the idea that human rights for everyone is an inalienable right and that all rights are applicable and indivisible. A rights-based approach considers disabled people as decision makers, citizens, and rights holders. Like the social model, the rights-based model aims to transform unjust systems and practice (CBM, n.d.). Scholars such as Conte (2016), Peterson (2014), and Parekh (2009) have considered the intersection of refugee law and disability law. Conte (2016) examined the CRPD and to what extent it can be applied to refugees. Peterson (2014) analyzed refugee and asylum law with a human rights framework, referring to the UN Convention on the Rights of People with Disabilities to do so. Lastly, Parekh (2009) explored the Refugee Convention's application to disabled people by examining the wording of the original document.

Under refugee law, there are five grounds (race, religion, nationality, political opinion or membership in a particular group) for claiming refugee status. Conte (2016) argued that of the five grounds that warrant refugee status, only one is intended to include disabled people—membership of a particular social group. However, membership in a social group alone is not in

itself sufficient to seek refugee status; rather, it is necessary to demonstrate the connection between group membership persecution (Conte, 2016).

In order to be granted asylum or refugee status, one must prove persecution. However, the Refugee Convention does not clearly define the term, leaving it open to much interpretation by national courts. Peterson (2014) outlined the difficulty disabled applicants face proving they meet the criteria for refugee or asylum status. These difficulties include using both subjective and objective criteria to prove their fear is well-founded, connecting their membership in a specific social group to their fear of persecution, and demonstrating that the issues in question have risen to the level of 'persecution.' Conte (2016) supported this stance, particularly for people with mental or intellectual disabilities, arguing that this population may have greater difficulty recognizing and assessing dangerous situations which would lay claim for asylum or refugee status. Additionally, Parekh (2009) noted the ambiguous language within the Refugee Convention through the use of terms such as *persecution*, *well-founded fear*, and *social group* which are not clearly defined. This ambiguity leads to increased difficulty for disabled people to argue their claim.

Since its development in 1951, the Refugee Convention has largely remained unchanged. In spite of this, the UNHCR continues to consider the contents of the Convention to be relevant in the current world climate. Parekh (2009) noted that new social groups have emerged over the past few decades, such as disabled people and women experiencing gender-based violence; however, the Refugee Convention fails to take into consideration the protection of these newly identified social groups. Parekh's (2009) argument was that, if disability is not viewed as a social group, the Refugee Convention does not apply to those people seeking asylum under the grounds of disability-related persecution.

The social model of disability is not reflected in the Refugee Convention of 1951; in fact, the word 'disability' is not explicitly mentioned in the Refugee Convention. However, the CRPD supports both the social and human rights models of disability, therefore proving persecution on grounds of membership in a particular social group. This changing definition of disability allows applicants to claim asylum based on deprivation of basic human rights. This is a shift from historically acceptable bases, such as torture and threat to life (Peterson, 2014). Similarly, Conte (2016) claimed the CRPD, in the context of refugees, can reinforce the legal gaps of the Refugee Convention by applying the concept of reasonable accommodation when applying for asylum.

Furthermore, this burden of proof in proving prosecution can be alleviated through the application of the CRPD. This can be done in two ways: 1) by providing a human rights framework in which refugee law should be situated; or 2) used in conjunction with the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT) in the "defensive" asylum programs of states (Peterson, 2014).

Meekosha and Soldatic (2011) looked at how disability began to be viewed as a human rights issue with the adoption of the CRPD in 2006, and how this shift became central to the disability movement's fight for recognition. They also explained how the CRPD helped unify disability-rights movements across the global North and global South. Degener (2016) outlined the human rights model of disability and argued it is an improvement on the social model. When initially drafted, the CRPD was intended to replace the medical model of disability with the social model of disability. However, Degener (2016) claimed the drafters of the CRPD went beyond that and created a treaty based on the human rights model of disability, which considers human dignity as the foundation of human rights. Quinn and Degener (2002) claimed that the

human rights model "focuses on the inherent dignity of the human being and, subsequently, but only if necessary, on the person's medical characteristics" (as cited in Degener, 2016, p. 34).

The CRPD advocates for disabled people to be treated with respect and dignity and the fulfillment and enjoyment of their human rights, rather than looking at them as objects of pity or needing charity. Additionally, it calls for the protection of disabled people in situations of risk or humanitarian emergency (Pearce, 2015). Article 11 recognizes that disabled people are especially disadvantaged in situations of emergency, conflict, displacement, or a combination of these (Smith-Khan et al., 2014). The Convention is based on a human rights approach in supporting disabled people, including refugees, asylum-seekers and other displaced people. Some of the guiding principles outlined in the CRPD that directly apply to disabled displaced people are:

- Respect for inherent dignity, individual autonomy, including the freedom to make one's own choices, and independence of people
- Non-discrimination
- Full and effective participation and inclusion in society
- Respect for difference and acceptance of disabled people as part of human diversity and humanity
- Equality of opportunity
- Accessibility
- Equality between men and women
- Respect for the evolving capacities of disabled children and respect for the right of disabled children to preserve their identities (UNHCR, 2019).

The following section considers these inherent human rights and examines how they have been implemented and protected in humanitarian situations.

## **Humanitarian Response to Disabled Refugees**

In its 2010 Executive Committee Conclusion (ExCom Conclusion) on refugees with disabilities, the UNHCR recognized the CRPD by acknowledging the inherent dignity and equality of disabled people, and that disability is an evolving concept. In doing so, they considered how it should be applied in displacement (Crock et al., 2017). Smith-Khan, Crock, Saul, and McCallum (2014) outlined how the CRPD and the ExCom Conclusion align in recognizing not only the impairments experienced by disabled people but also the environmental factors at play. This is further outlined in the *Internal Classification of Functioning, Disability and Heath* (ICF) developed by the World Health Organization (WHO), which looks at disability through the lens of three inter-connected areas: impairments, difficulties in executing activities, and participation (Smith-Khan et al., 2014).

Additionally, Kett and van Ommeren (2009) discussed how disability is addressed in humanitarian programs. They claimed the CRPD has garnered greater attention to disability within the United Nations, leading to the implementation of several UN non-governmental organization initiatives that focus disability within the humanitarian arena. One example is the inclusion of disability as a specific crosscutting issue in the *Sphere Handbook* as of 2004. The *Sphere Handbook* is a key text for humanitarian staff and practitioners working with refugees, asylum-seekers and other displaced people (Kett & van Ommeren, 2009).

Duell-Piening (2018) examined the ways in which the CRPD has been effective in improving access to resettlement in Australia for disabled refugees. Additionally, she looked at areas in which Australia's compliance with the CRPD has failed to address the multiple areas of

discrimination faced by disabled refugees. Duell-Piening (2018) found that, while the CRPD has proven to be effective in the resettlement process for disabled people in Australia, policies and services do not adequately meet the needs of and uphold the rights of the disabled people being resettled in Australia. She, therefore, proposed a global approach to improve CRPD compliance in resettlement programs which includes the establishment of a Resettlement Submission Category for disability to protect and promote the rights of disabled people.

Momin (2017) described the shift towards application of human rights law to refugees, expanding the responsibility for protection and aid from one's own state onto the international community. This shift came about because of moral, legal, economic, and security reasons.

According to Momin (2017), states may be motivated to resettle refugees due to both an intrinsic rationale and instrumental rationale. An intrinsic rationale is based upon a human rights approach to aiding and resettling refugees as the right thing to do, either morally or legally. An instrumental rationale takes a human-rights approach primarily to lead to more sustainable outcomes (Momin, 2017). Furthermore, state actors have a moral obligation to fix the "structural injustice" (Momin, 2017, p. 59) caused by their actions or inactions.

While very little literature exists addressing the human rights of disabled displaced people, scholars have written about the human rights violations of refugees, as well as those of disabled people. For example, Pittaway and Bartolomei (2001) examined the intersectionality of race and gender in refugee situations, focusing on discrimination faced by refugee women from their intersecting identities. They argued that resettlement policies discriminate against women through the use of gender blindness, specifically in relation to sexual and gender-based violence refugee women experience during armed conflict, in refugee camps, as strategies of war, and in countries of resettlement (Pittaway & Bartolomei, 2001).

Several scholars have conducted studies on violence, including sexual violence, among disabled people. McGilloway, Smith, and Galvin (2018) reported that intellectually disabled people are at a significantly greater risk of experiencing sexual violence than the general population. This is corroborated by Dammeyer and Chapman's (2018) national survey on violence among disabled people. Results from this study showed a higher prevalence of violence among disabled people, with the highest risk group being the mentally disabled. Significant findings from this study revealed that gender plays an important role in rates of violence. Rates of intimate partner violence were higher among women with chronic mental illness than men with chronic mental illness (Dammeyer & Chapman, 2018). Similarly, Basile, Breiding, and Smith (2016) conducted a study on the risk of sexual violence among disabled people in the United States and found this population is to be especially vulnerable to sexual violence. Some reasons for this heightened risk are economic dependence, dependence on caregivers for daily living needs, and negatives attitudes and beliefs towards disabled people and disability (Basile, et al, 2016).

Marshall and Barrett's (2018) study examining the situation of refugee-survivors of sexual and gender-based violence with communication disabilities included 54 participants, composed of 50 humanitarian and partner organizations staff, as well as four caregivers of refugees with communication disabilities in both camp-based and urban settings. Findings from their study showed the reality of refugee-survivors with communication disabilities to be at greater risk of sexual and gender-based violence, as well as denial of or compromised human rights (Marshall & Barrett, 2018).

In her examination of the human rights and social models of disability, Peterson (2014) claimed that the CRPD, by supporting both models, allows disabled refugees and asylum seekers

to claim persecution on grounds of membership in a particular social group. This shift in how disability is viewed enables applicants to claim refugee or asylum status based on deprivation and violation of basic human rights, versus the traditionally acceptable grounds like torture and physical threat.

Mirza (2011b) suggested that the humanitarian response to disability issues has been slow to develop and applied inconsistently. However, displacement camps themselves have been innovative sites in disability rights praxis due to grassroots efforts as well as disability advocacy and organizing. International humanitarian groups and non-governmental organizations (NGOs) have facilitated some of these efforts, while disabled residents living in the camps have initiated others. Mirza (2011b) cited the example of a U.S. agency that organized disability conferences and workshops in camps in Dadaab, Kenya. These workshops aimed to allow the disabled refugees living in the camps to voice both their concerns and needs. These workshops resulted in a heightened sense of unity and purpose among Somali refugees living in the camp. Due to the positive response to this initiative, UNHCR invited Handicap International, a humanitarian organization, to be the operating partner. The aim was to improve conditions in the camps as well as to streamline services and programming and to make them more accessible to disabled people living in the camps (Mirza, 2011b).

Mirza (2011b) presented examples of disabled refugee-led efforts to fill gaps overlooked by humanitarian organizations. One such initiative is Care Villa, founded by a landmine survivor in Mae La camp in Thailand, after realizing landmine survivors did not have access to the services they needed. The purpose of the Care Villa facility is to provide emotional support, rehabilitation services, and vocational training for those survivors without family support. Mirza (2011b) cited additional instances of disabled refugees who themselves took responsibility to

provide for the needs of the camps' disabled residents. Additionally, some disabled refugees in northern Uganda organized to fight for more equitable access to food distribution programs (Mirza, 2011b). Mirza (2011b) also noted examples of advocacy groups working together across gender, ethnic, and national divides in the Dzaleka camp in Malawi.

### **Intersectionality and Identity of Disabled Displaced People**

Psychologists consider group membership and affiliation to be one of the defining aspects of identity. Through identity, we are able to make sense of different and distinct parts of our self-concepts (Dunn & Burcaw, 2013). Forber-Pratt, Merrin, Mueller, Price, and Kettrey (2020) claimed identity is socially and historically constructed. Understanding identity development is an important component for those belonging to marginalized minority groups. Forber-Pratt et al., (2020) defined social identity as knowledge of one's belonging to a social group as well as the significance associated with group membership. Chao (2019) used the term *hybridity* to illustrate that identity is hybrid and consists of cultural practices spanning time and communities in which individuals move between. Using the concept of hybridity, Chao (2019) argued the formation of identity is a fluid – rather than fixed- process.

# **Refugee Identity**

Heilbrunn, Gorodzeisky, and Glikman (2016) explained that identity transformation is often a part of immigration. These deep changes in identity are a part of the acculturation process, in which a new identity is created. This new identity is a combination of the new and old. Powell (2012) supported this theory, stating identities move as the displaced bodies move, constructing new identities. Furthermore, Chao (2019) looked at the cultural model of acculturation and adaption as a way to explain identity (re)construction. Chao (2019) drew on poststructuralist theory to examine refugee youth experience before and after resettlement, and

what influences those experiences had on their identity development. Poststructuralist theory views identity as one's understanding of his or her relationship to the world, the way that relationship is constructed across time and space, and how the person considers possibilities for the future (Chao, 2019). Chao (2019) highlighted refugee identity as a multi-layered, multi-faceted construct. As immigrants and refugees adapt to their new society, they often face identity crisis. The newly acquired refugee identity is accompanied by more instances of racism and discrimination (Chao, 2019).

This process of two cultures coming together, referred to as 'acculturation', inevitably leads to one of the two cultures changing. One becomes more dominant and, as a result, the subordinate culture takes on elements of the other (Berry, 1989). Acculturation is an inevitable part of refugee identity formation, which can lead to identity loss, stress, and feelings of alienation (Berry, 1989). In addition to the grief caused by fleeing their homes, refugee groups often must deal with acculturation and its ensuing conflicts (Berry, 1989). Conversely, 'assimilation' is the process of adapting or adjusting to the culture of a group or nation, often giving up one's own culture and language in order to blend in with the dominant culture (The World Staff, 2017). These stressors of having to resettle in a country with a vastly different language and culture can impact the adjustment and well-being of refugees as well as other displaced people (El Khoury, 2019).

In examining acculturation and assimilation, Eng and Han (2000) coined the term "racial melancholia" to describe the mourning of the loss of one's country, culture, language, and so on in a refugee context. When a person chooses or is forced to leave their home country, the process of mourning begins. According to Lobban (2006) this mourning is a continuous process that never really ends. Assimilation into a new country and culture reinforces these losses through

feelings of pressure to belong and to take on the language, customs, and beliefs of the new country (Lobban, 2006). This phenomenon is especially real for refugees and displaced people, as they must deal with conflicting feelings of loss, grief, and nostalgia along with positive feelings they may hold towards their new country. Eng and Han (2000) claimed that mourning and melancholia coexist during the process of assimilation, which is a significant factor for refugees and other displaced people in suggesting that melancholia is integrated into everyday life.

## Refugitude

In writing about the Cambodian diaspora, Um (2015) advanced the term "refugitude" to describe the state, conditions, and consciousness of being a refugee. The term "refugee" conjures up the idea of needs, whereas refugitude shifts from any negative connotations and gives equal attention to hope and the future. Refugitude centers refugee experiences and meaning-making while also taking into account the role of external forces and conditions in creating refugee situations, such as militarization, colonialism and other geopolitical forces. Therefore, refugitude creates a shift in how we think about and understand the category of refugee and examines it through a different lens (Nguyen, 2019). Nguyen (2019) argues that a gap exists between the legal definition and global concept of refugee, which States refer to when developing policy, and the lived experience of refuge. Refugitude considers the ongoing experience of refuge, as opposed to being an endpoint achieved once one arrives in their final destination of refuge.

## **Disability Identity**

Disability is one of the few identity groups one is either born into or could become part of at any time, due to illness or accident (Bogart & Dunn, 2019). Forming group identity can be challenging because Dunn and Burcaw (2013) explained two important elements of disability

identity: a positive sense of self, and a feeling of connection to and solidarity with other members of the disability community. When examining disability identity through disability narratives, Dunn and Burcaw (2013) suggested that, by developing a disability identity, disabled people can more easily navigate the social stresses associated with being a member of a minority group that is often ignored. Forber-Pratt and Zape (2017) supported this argument by stating a healthy identity is crucial not only in creating a stronger sense of self, but also for facing ableism through the reaffirmation of goals and personal worth. Additionally, Hahn and Belt (2004) suggested community belonging and disability affirmation may develop as a way to cope with social discrimination, outsider status, and being viewed as different.

### **Intersecting Identities**

Crenshaw (1995) coined the term "intersectionality" to describe how multiple aspects of one's identity contribute simultaneously to form a unified system of oppression. Disability identity intersects with all other social identities (e.g., gender, race, class), creating multifaceted social identities for disabled people (Bogart & Dunn, 2019). In addition to already existing identities of gender, race, class and disability, displaced people with disabilities take on the additional identity of displacement.

In their analysis of intersectionality, Erevelles and Minear (2010) outlined the problem of focusing on a singular notion of identity (e.g., sex or race), stating that this single identity is often used to explain the experiences of an individual or group. Through the lens of Critical Race Theory, they drew on two narratives to demonstrate how individuals located at the intersections of race, class, gender, and disability are viewed as non-citizens by social institutions (legal, educational, and rehabilitational) designed to support and protect them. Erevelles and Minear

(2010) argued disability is often omitted in discussions of intersectionality, which can have disastrous consequences for disabled people of color.

Refugees, asylum-seekers and other displaced people face multiple oppressions and systems of disadvantage that influence their experiences (Elder, 2015; Besic, Paleczek, & Gasteiger-Klicpera, 2018). In Elder's (2015) study of the resettlement of disabled refugees, he found that, in addition to their already existing multiple identities, displaced people acquire the additional identity of refugee or displaced person. The intersectionality of these multiple identities – disability, gender, refugee status – all influence the attitudes and biases of the general public and create additional systems of disadvantage. Mirza's (2011a) study comparing the resettlement experiences of disabled Cambodian and Somali refugees revealed discriminatory practices that view refugees as less desirable immigrants, therefore restricting their mobility in pursuit of safer, more sustainable living conditions.

Elder (2015) discussed the fluidity of identity post-resettlement. At times, refugees are drawn to a *cultural diasporic identity*, which includes their national identity. At other times, they relate more strongly to a *diasporic disability identity*. Upon resettlement, disabled refugees often create new identities around culture, disability, displacement, or new community activities. These identities are fluid and largely influenced by past experiences, as well as their resettlement experiences. At times one identity may be more salient than the others. Through shaping and developing each of these identities, refugees come to new ways of being, understanding, and interacting in the world.

Through the examination of literary representations of disabled refugees, Dawson (2019) proposed a social model of refugeeness in an attempt to challenge the popular conceptions of refugees as hopeless, dependent beings. He does so by looking at how refugee status and

disability identity intersect when viewed through the lens of the social model of disability.

Dawson (2019) argued both refugees and disabled people are minoritized and stigmatized based on societal actions and beliefs; therefore, they are made to endure non-accommodating environments. Much like the social model of disability worked to shift the focus of disability away from the medical perspective, Dawson (2019) proposed the social model of refugeehood as a shift from the defective and dependent notions of refugees.

## **Immigration Policy: Past and Present**

# A History of U.S. Immigration Policy and Disability

Historically, U.S. immigration laws and policies have discriminated against and denied entry to those sharing characteristics with marginalized groups in the United States, such as racial and political minorities, disabled, poor, and LGBTQ, and others deemed "undesirable" (Johnson, 2017). The Immigration Act of 1882 was the first comprehensive immigration law enacted by the federal government. This Act greatly influenced future immigration legislation by setting a precedence of exclusion based on undesirable characteristics and group membership.

Specifically, the passage of the Chinese Exclusion Act of 1882 is considered another pivotal moment in American immigration history, setting a precedent of racial and ethnic exclusion (Lew-Williams, 2014). Congress passed this Act in response to large numbers of immigrants, especially Chinese laborers. The passage of the Chinese Exclusion Act suspended the immigration of Chinese laborers and relegated Chinese immigrants already living in the United States an inferior status compared to European immigrants (Chinn, 2017).

Baynton (2005) outlined historic immigration policy regarding disability. The Immigration Act of 1882 excluded people with physical and mental disabilities on the grounds that they would become public charges. At that time, disability was a primary deciding factor on

whether an immigrant would be allowed to resettle in the United States (Baynton, 2005). Immigration laws became increasingly more restrictive towards potential "defective" immigrants, with the Immigration Act of 1891 changing the criteria from being unable to care for oneself to "likely to become a public charge" (Nielsen, 2012, p. 103). While disabled immigrants were still granted admission into the United States, they were subject to more intense scrutiny (Baynton, 2005). The assumption behind it was that bodies considered defective would be unable to perform wage-performing labor, therefore unable to support oneself and become dependent on public assistance (Nielsen, 2012). This LPC clause (likely to become a public charge) continues to be present in immigration policy today.

In 1996, the UNHCR developed a Resettlement Handbook to address the needs of refugees and to aid in the resettlement process. The original edition of the Handbook addressed the resettlement of disabled refugees, stating that resettlement should only be considered for those disabled refugees whose needs could not be treated locally, or whose quality of life or safety were seriously threatened (Crock et al., 2013). That which could be addressed locally, such as prosthetics and hearing aids, should be. This policy implied that disabled refugees who met this criterion were not eligible for resettlement. The UNHCR eliminated this policy in the revised edition of the Handbook put out in 2011. Crock, Ernst, and McCallum (2013) outlined the Handbook's updated stance on disability, which states decision makers must take into consideration each individual's history, profile, and vulnerability when considering their case, as the same act or circumstance may affect people differently.

Mirza's (2011a) study on disability and cross-border mobility found that, historically, resettlement of disabled refugees was not considered to be the best option, and was, at one point, considered to be the last option for disabled refugees. She cited the UNHCR's 1996 service

guidelines stating, 'resettlement should be the last option for disabled refugees' (Mirza, 2011a, p.16). Alternate solutions, such as medical evacuation, were recommended by the UNHCR, which encouraged medical interventions to fix or minimize disabilities. Additionally, countries were encouraged to help disabled citizens integrate in their communities, versus turning to resettlement. Mirza (2011a) went on to explain how this stance has evolved in recent years to one of considering disability as an indicator of heightened risk. This was reflected in the UNHCR's Heightened Risk Identification Tool developed in 2007. Despite attempts by the UNHCR to encourage more acceptance of disabled refugees, some resettlement countries, such as Australia, restricted resettlement for disabled refugees, citing the additional cost and burden on resources (Mirza, 2010). Other countries, such as the United States, Ireland, Finland, and Chile, were more open to accepting disabled refugees, but have established strict guidelines for resettlement, based on the need for medical intervention (Mirza, 2010).

Mirza (2011a) outlined shifts in U.S. immigration and resettlement policy. In 1996, the U.S. Department of State established three priority categories for refugee resettlement, one of these being people deemed most vulnerable, which included refugees with mental and physical disabilities. This change in policy was put into practice during a joint resettlement initiative led by the United States and UNHCR, in which approximately 2000 disabled refugees and their families from the Dadaab camps in Kenya were resettled in the United States (Mirza, 2011a).

Significantly, the United States has signed but not ratified the CRPD. Signing the treaty demonstrated the intent to fulfill its own national legislative requirements and served as a preliminary endorsement of the instrument. However, creating a binding legal obligation to uphold the treaty requires the further step of ratification (UN, n.d.). While President Obama signed the CRPD in 2009, the US Senate has since failed to ratify it on two occasions (Kanter,

2019). Currently, 177 countries have ratified the CRPD. Both the UDHR and the CRPD address immigration and mobility as human rights, including the right to seek asylum from persecution, liberty of movement, and the right to freely leave and enter one's country.

## **Immigration Policy in the Trump Era**

To look at similarities between the Chinese Exclusion Act of 1882 and President Trump's immigration policies post-2016 election, Chinn (2017) offered the Chinese Exclusion Act as an important context for understanding nativism and nativist exclusion in the United States. The Chinese Exclusion Act refused to grant entry to Chinese immigrants on the basis of undesirable traits, culture, and race. During his first three weeks in office in January 2017, President Trump issued three executive orders which called for drastic changes to previous immigration enforcement protocol (Johnson, 2017). Unlike previous presidents, Trump's policy changes targeted immigrants of color and specific religions. His immigration policies, such Muslim bans, zero tolerance policies, and Public Charge, aim to reduce the number of immigrants of color and members of racial, ethnic, and religious groups (Villazor & Johnson, 2019).

Disabled refugees are considered the most marginalized group of all displaced populations. Mirza (2012) reported that at one point in time, the United States was one of the leading countries in terms of resettlement and provided for priority resettlement for disabled refugees. According to Akamatsu and Cole (2000), immigration officials in some countries may be concerned that disabled refugees could place added strain on social and medical services, possibly leading them to deny formal entry into a country. However, since 1996 U.S. immigration policy had taken into consideration the totality of one's circumstances when considering the public charge rule (Disability Rights, 2018). This policy has changed under the direction of President Trump.

In August 2019, the Department of Homeland Security announced a new "public charge" policy which allows the United States to deny entrance to those people deemed likely to become a public charge (LPC) (Kim, 2019). While this policy is not new, it is more restrictive than previous LPC rules in that it expands on the programs and benefits that will count against being granted a visa or permanent resident status (The Arc, 2018). This policy affects not only disabled immigrants applying for entrance into the US, but also those on the path to become permanent residents or citizens (Kim, 2019). In January 2020, the U.S. Supreme Court ruled in favor of this policy. This public charge rule will possibly deny access to medical care, food and housing benefits, and other basic human rights guaranteed under the Americans with Disabilities Act (ADA).

In addition to restricting the entrance of disabled refugees and asylum seekers, the Trump administration eliminated the medical deferred action program, which allowed immigrants with serious health conditions to seek life-saving medical treatment in the United States – including children and disabled people (Schulte, 2019). Many disabled people seek entrance in the United States to access disability-related services, such as health care and rehabilitation services, that are not available in their respective countries (Kim, 2019). With the elimination of this program, many disabled immigrants, along with their caretakers, are not only being denied access into the United States, but also facing deportation.

The situation for disabled children born in the United States to undocumented parents is another concern. Fries (2019) shared the story of an eight-year-old girl with cerebral palsy who was born in this country. Her parents have lived in California, undocumented, for more than a decade. If deported, her parents would face the decision of relocating her back to Mexico, where

her chances of survival would be minimal due to lack of necessary equipment and medication, or leaving her in the care of friends or relatives in the United States.

Around the world, disabled immigrants find themselves in similar situations. A visiting scholar in Toronto was forced to turn down an appointment because his disabled partner was denied entrance (Fries, 2019). A professor at York University was denied permanent residency because his son has Down syndrome. Parallel scenarios are occurring in Australia and many European nations. For example, barriers to citizenship exist in Spain and Italy for disabled people. Citizenship in France may be denied due to disability. Germany requires both citizenship and language tests, which are often difficult or inaccessible for those with disabilities (Fries, 2019).

### **Resettlement Experiences**

Although scant research exists on disabled refugees, a handful of studies have focused on their resettlement experiences. Elder (2015) reported on the resettlement experiences of disabled refugees in the United States, focusing on their stories of education and employment as well as their post-resettlement goals. While the participants in Elder's (2015) study were able to access higher education and employment upon their resettlement in the United States, they also shared many experiences of inadequate accommodations that limited their ability to live self-determined lives. Similarly, Roberts and Harris (2002) conducted surveys and interviews with disabled refugees/asylum seekers in Britain. Results of this study support Elder's (2015) findings, with participants reporting lack of information on available services, linguistic difficulties, and lack of access to education or job training, all of which hindered their independence and self-sufficiency.

Mirza's (2012) global ethnography analyzed how policies and practices within the U.S. resettlement program have influenced disabled refugees' access to occupational participation.

The study's findings suggest a strong emphasis on self-sufficiency and work among U.S. refugee programs. In contrast, service providers and resettlement agencies examined in the study tended to determine disabled refugees as "non-employable," thereby channeling them towards the welfare system, often without considering the refugees' aspirations (Mirza, 2012). The lack of supports and accommodations put disabled refugees at continued risk of occupational deprivation, further compounded by inaccessible environments, societal prejudices, and their dual status as disabled refugees (Mirza, 2012).

Furthermore, Mirza (2012) reported U.S. refugee resettlement programs strongly emphasize the binary options of work or welfare, ignoring the occupational needs of disabled refugees. Mirza's findings suggest that lacking appropriate supports and services in place to develop occupational skills or explore options can result in negative outcomes for refugees. Many ultimately struggle to find employment avenues that allow them to be self-sufficient and to integrate in U.S. society, leading to further feelings of inadequacy and isolation (Mirza, 2012).

### **Inclusion, Participation, and Access to Programming**

Disabled people have unique support needs and accommodations, which are not often available in refugee camps or other emergency placements. Displacement and refugee camps are often difficult to navigate for individuals with physical disabilities, such as dirt roads that may be rocky or full of holes; inaccessible bathrooms; long distances between buildings and facilities; and other barriers and obstacles. Areas are difficult to navigate for people with low vision and visual impairment due to insufficient lighting and uneven roads and walkways. Sivunen's (2019) study of Deaf refugees seeking asylum in Finland often found a scarcity of interpreters or anyone knowledgeable in the signed language used.

Shivji (2010) reported that for many displaced disabled people, additional challenges often start during flight. Due to the ensuing chaos, some may be left behind because they are unable to move without assistance. They may not encounter someone who stops to help, or the disabled people may be unable to call out for help. Visual, hearing, and cognitive impairment may make it harder to detect and understand warning systems and can also lead to confusion and disorientation. Families often have to make decisions about what to take with them and be forced to leave behind any adaptive or assistive equipment. This can make the flight even more difficult for the disabled person as well as the caregivers (Shivji, 2010).

Kett and van Ommeren (2009) reported that oftentimes staff working in humanitarian agencies and situations hold common misperceptions about disabled people, such as thinking they require specialist care or their needs will be met through general aid distributions; they are unable to help others; or they are unable or unwilling to participate in programs, activities, or education. Additionally, humanitarian agencies and workers allocate funding and resources to those injured or disabled as a result of conflict, and those disabled prior to the conflict are overlooked.

In Shivji's (2010) report on disability in displacement, he stated that a multitude of larger systems, structures, and environmental factors exist to influence the experiences of disabled displaced people, both in the refugee camps and as they try to navigate their way in a new country. Life in refugee camps is an incredibly challenging experience for everyone. For disabled refugees, life in refugee camps is even more difficult, as the necessary supports are often nonexistent. Due to the often-temporary nature and rapid installation of infrastructure such as housing and other services, the support needs of all inhabitants may not be taken into account. Uneven surfaces, long distances, narrow doors, inaccessible bathroom facilities, and many more

barriers to accessibility often exist (Shivji, 2010). Displacement often causes a disruption of access to necessary health services, such as medication, therapy, or specialized equipment. This disruption can at times lead to permanent disabilities as a result of injury, illness, or birth-related causes.

The physical layout and infrastructure of displacement camps are often not accessible for those with physical disabilities, therefore impeding access to facilities and services such as schools, clinics, water and food distribution points, and bathroom facilities. This leads to increased isolation of disabled people. Reilly (2010) did report positive examples for improved physical access in the Dadaab refugee camp, through the provision of specially designed wheelchairs that were able to be used in the sandy terrain.

In Elder's (2015) study of the resettlement experiences of disabled refugees, one refugee with a visual impairment shared that no supports were available in his refugee camp to accommodate his disability, even though systems and routines were in place for processing refugees in the country. This participant discussed the difficult lifestyle, stating, "They simply threw us there...No support...So there was not cooking, there was not anything for us to do.

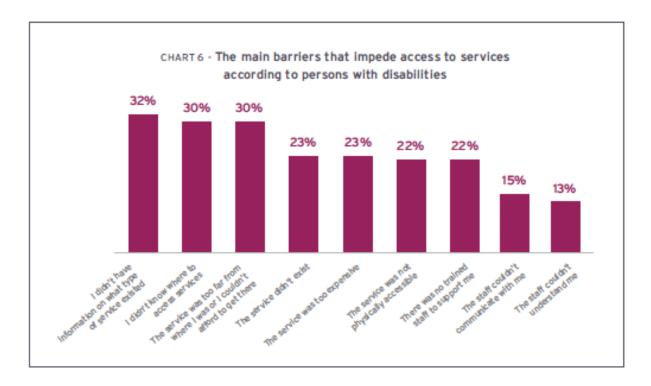
There were no bathrooms, not anything...There [were] no smooth roads in the camp, we can't move [around] easily" (Elder, 2015, p. 11). When this participant requested an immediate pass as an urban refugee to pursue a better situation, he was told by the authorities of the country where the camp was located that he was required to stay a minimum of three months. This mandate caused the participant to later leave the camp illegally in order to have his basic living needs met, with the appropriate supports, while awaiting relocation. This policy could have disastrous implications for disabled people as they are forced to leave the safety of the camp in order to

survive. Leaving illegally could also greatly impact future chances of being granted refugee or asylum status.

In the "Disability in Humanitarian Contexts Advocacy Study" conducted by Handicap International (2015), disabled people identified nine types of barriers to explain gaps in their access to services during a humanitarian crisis (See Figure 3).

Figure 2.

The main barriers that impede access to services according to people with disabilities.



*Note.* Disability in humanitarian contexts: Views from affected people and field organizations. Handicap International. 2015. Retrieved from <a href="https://www.hi-us.org/disability\_in\_the\_humanitarian\_context#:~:text=Global%20Report%20%7C%20Disabilityw%20in%20Humanitarian%20Context%20(2015)&text=Results%20found%20that%2085%25%20f,into%20account%20in%20humanitarian%20response

Types of barriers identified by disabled people:

Attitudinal: A negative attitude towards diversity and resistance to adapt; sometimes coming from unconscious bias; impacts accessibility on all levels because most of the other barriers are rooted in attitudes as well.

*Environmental:* Natural or man-made (e.g., staircases, narrow doors, inaccessible public transportation, lack of accessible public toilets, poor lighting, etc.); can be caused by natural disasters (destruction of roads and buildings, restricting access to services).

*Informational:* Information is not made available or accessible for everyone; often invisible but can exclude a large number of people; includes early warning systems and evacuation, relief operations, and access to aid.

*Institutional:* Institutional policies and procedures that discriminate against disabled people, such as organizational practices that are not flexible or adapted to disabled people, leading to exclusion (Handicap International, 2015).

### **Healthcare Needs**

The Convention on the Rights of People with Disabilities (CRPD, 2006) calls for appropriate health and rehabilitation services. Mirza (2011c) noted a lack of research on the access to appropriate healthcare in displacement settings for disabled refugees and asylumseekers. Mirza (2011c) pointed out that while disabled people have some of the same healthcare needs as the rest of the population, specific needs related to disability, such as aids and devices, surgeries, medications, and therapy, often go unmet in these settings. Lack of aids and equipment, such as wheelchairs, impedes access not only to health services, but also to other services available in the camps as well, such as food distribution, employment, and other resources. This in turn affects one's independence and quality of life. Therefore, Mirza (2011c)

argued that providing the services and assistance needed by disabled displaced people allows them to be independent rather than being passive, dependent residents of the camps.

For internally displaced people (IDP), the situation is often worse, as IDP camps tend to be more isolated and do not have access to resources supplied by the UN agencies and international non-governmental agencies (NGOs) (Mirza, 2011c). IDP camps are not managed by international organizations but are the responsibility of the national government. Additionally, Mirza (2011c) found the health services and hospitals in the camps focused on life threatening conditions, making them a priority over chronic and long-term conditions related to disability.

In a study examining the healthcare provision of IDPs in Nigeria, Ekezie, Timons, Myles, Siebert, Bains, and Pritchard (2018) audited nine camps. They reported poor living conditions as well as uneven distribution of resources, including limited access to health-related resources. This led to increased risk of the spread of disease and infection to those living and working in the camps (Ekezie, et al., 2018). Results of this study showed substandard living conditions according to minimum standards set forth in the *Sphere Handbook*. Similar conditions were found in Abuya and Ikobe's (2010) study on IDP camps in Kenya. Findings from the study demonstrated that the state failed to protect the rights of its citizens, which led to serious threats to the lives and livelihoods of those citizens living in the IDP camps (Abuya & Ikobe, 2010). For disabled IDPs, these substandard living conditions and inadequate access to healthcare services is even more detrimental, as their unique disability-related needs may not be met. Additionally, they may be at greater risk of illness or injury due to substandard living conditions.

### **Accessibility of Resources**

According to Shivji (2010), refugees, asylum seekers and other displaced people are often seen as passive recipients of aid and assistance, versus active participants who may be able to

contribute ideas, skills and expertise. This point is supported by Kett and von Ommeren's (2009) findings that most programs and assistance view disabled people as a vulnerable group needing protection rather than focusing on the issues of inclusion and environmental barriers.

Deaf displaced people face additional challenges to accessing resources and support in their host countries, due to barriers in language and communication, limited knowledge of the unique support needs of Deaf refugees, and scarcity of volunteers and service providers trained in any kind of signed language. For example, through the use of linguistic ethnography, interviews, and ethnographic observation, Sivunen (2019) documented the experiences of 10 Deaf asylum seekers in Finland. A major finding was recognizing linguistic barriers from the first day of the participants' arrival in Finland. Sivunen (2019) found that Deaf refugees did not always participate in reports and studies due to not comprehending opportunities when they arose because of linguistic barriers and lack of interpreters.

In Sivunen's (2019) study, Deaf refugees and asylum seekers were housed in Finnish reception centers while awaiting decisions regarding their cases. Participants reported not receiving instruction in Finnish Sign Language (FinSL) until after being at the reception center for about one year. Participants often reported feelings of loneliness, isolation and depression due to not being able to take part in activities. Additionally, they reported feeling confused and showed signs of post-traumatic stress. While these reception centers generally provided services such as labor and study activities, social and health services, Finnish language instruction and interpreting, Deaf members were often not able to participate, or not able to understand what was happening when they did participate.

Roberts and Harris (2002) found disabled refugees and asylum seekers in the United Kingdom commonly reported having their personal needs unmet. In addition, inadequate

housing, difficulty with communication, feelings of extreme isolation, and the need for support for those participants with children were recurrent themes. Service providers often do not have the training and knowledge of the needs of disabled displaced people, thereby struggling to provide services to meet their needs appropriately (Roberts & Harris, 2002).

Pearce (2015) reported on the findings from a six-month research project conducted by the Women's Refugee Commission in 2008. Results indicated disabled people were often overlooked during needs assessments, not consulted in program design, and hidden in shelters. In this same report, disabled people expressed difficulty accessing assistance programs, largely due to societal, environmental, and communication barriers. This difficulty led to increased risk of violence, abuse and exploitation.

While examining disability and humanitarianism in refugee camps, Mirza (2011b) found camps often face shortages of essential supplies, such as soap and cooking fuel, needed by the entire population. Displacement and refugee camps frequently deal with limited resources and a vast variety of needs, which can cause dilemmas over distributional ethics. Those in charge of budgeting and allocating resources often must make difficult decisions about how to spend the budget to best meet the needs of the entire camp population. Allocating funding for the specific needs of the disabled could mean not having sufficient funds to meet the basic needs of the rest of the population. On the other hand, purchasing supplies for the entire camp population could mean disability specific needs are unmet.

Kett and van Ommeren (2009) reported the likelihood of rights-based approaches and aid leading to more inclusive programming immediately after an emergency or conflict situation when agencies, donors, and mass media are in the field. This focus on human rights, equity, and justice often dissipates without the support of strong national and international partners. Kett and

van Ommeren (2009) considered these challenges as opportunities to increase awareness of disability organizations and strengthen their ability to become more active.

Roberts and Harris (2002) conducted a study to learn about the situation of disabled people resettled in Britain. They found high levels of unmet needs, commonly associated with the intersecting identities both as refugees or asylum seekers and as disabled people. Many of the barriers to accessing resources and aid were due to communication and linguistic difficulties. Additionally, refugees often were not aware as to which services and resources were available, thereby preventing the study participants to receive services and aid which would have greatly benefitted them (Roberts & Harris, 2002).

#### **Access to Education**

Rodriguez and Dieker (2018) examined inclusive education for Palestine refugees. In their report, they state approximately 10% of disabled children living in developing countries have access to some kind of formal education. Refugee children are at a much higher risk of not attending schools than non-refugee children, and for disabled children living in displacement areas the numbers of children accessing education are much lower (Rodriguez & Dieker, 2018). Akamatsu and Cole (2000) argued that schools are the most significant agents of change at both the societal and individual levels. They not only are important for academic purposes, but also may provide access to mental health services which in turn aid in acculturation and adaptation.

Displaced children often face disruption to formal schooling and lack access to quality education (Rodriguez & Dieker, 2018). Many barriers exist to receiving an education, including attitudinal bias. Besic, Paleczek, and Gasteiger-Klicpera (2018) studied the intersectionality of disability, refugee status, and gender. Results of their study show attitudinal bias can impede the full inclusion of both disabled students and refugee students in school as well as in society.

Article 24 of the Convention on the Rights of People with Disabilities specifically addresses education and calls for equal access to free, quality, and compulsory inclusive education. Schools that are put into place rapidly or temporarily may not be accessible. Teachers may not have the necessary training, materials or equipment needed to teach disabled students.

Akamatsu and Cole (2000) discussed the importance of meeting the psychoeducational needs of Deaf immigrant and refugee children. They found refugee and immigrant parents may not feel empowered to work as educational partners with the school due to linguistic barriers, cultural differences and other adjustment difficulties. They may be reluctant or unable to navigate the school system to seek help and may end up feeling misinformed or ill-informed about their child's education.

Besic, Paleczek, and Gasteiger-Klicpera (2018) surveyed the general public in Austria in order to gauge their attitudes towards refugee children with and without disabilities. They did so by using Crenshaw's (1989) theory of intersectionality - the interconnectedness of overlapping social and identity categories which can create a system of disadvantage. Besic, Paleczek, and Gasteiger-Klicpera (2018) further investigated the impact societal and attitudinal barriers may have on the education of disabled refugee children, as well as the role the intersection of multiple identities plays. They looked at whether disability type (physical disability vs. behavioral disorders), refugee status (Austrian vs. refugee child) and gender impacted the attitude of the general public. Results showed that the students' attributes do indeed impact the public's attitudes. The intersection of disability type and refugee status affect attitudes towards the inclusion of refugee boys and girls differently. More positive attitudes were shown towards the inclusion of Austrian students, students with a physical disability, and girls into mainstream primary schools (Besic et al., 2018).

Refugee and displacement camps are often difficult to navigate independently for people with physical disabilities. One refugee with a physical disability in Elder's (2015) study shared his experience trying to access education in the camp where he resided. Unable to move around independently and without access to a wheelchair, he was unable to get to and from school on his own and had to rely on the help of his brother. After his brother left the camp, the participant was unable to attend school, as he had no means of getting there and no one to help him (Elder, 2015).

A Deaf participant in Elder's (2015) study shared her experience attending school in a refugee camp. While she was able to attend school, the school did not have any teachers who knew sign language, nor any interpreters; therefore, the Deaf students were unable to follow along. The participant shared a story of the Deaf students all talking to each other about how they didn't like school because they didn't understand what was going on and were unable to keep up with the lessons. The Deaf students were expected to know what was happening in the school and to answer questions correctly, and they were beaten if they did not do so. The participant shared how she and the other Deaf students were afraid to attend school because of the physical abuse; together they discussed their options if they decided to leave school.

## Summary

This literature review synthesized important findings from existing research on the international framework of human rights including refugee rights, the rights of disabled people, and the international humanitarian response to disabled refugees. Additionally, it discussed disability identity and refugee identity and how these intersecting identities create additional systems of oppression and disadvantage. This literature review also compared past and current immigration policy and noted how it has excluded- and continues to exclude- immigrants and refugees on the basis of culture, race, and disability. Lastly, it focused on the resettlement

experiences of disabled refugees, including the challenges they face to access resources, life in the resettlement camps as disabled people, and their resettlement experiences in their new countries.

These works contextualize this present study and illustrate the gap in research regarding the lived experiences of disabled refugees. This gap lays the framework for the present study through using oral history to collaborate with disabled refugees and creating a space for their stories to be told in their own words. This research aims to amplify unheard voices by giving primary agency to the narrators themselves. To date, no other study has utilized oral history in looking at the experiences of disabled refugees, their stories.

#### **CHAPTER III: METHODOLOGY**

## **Restatement of the Purpose of the Study**

The purpose of this study was to explore the narratives of the lived experiences of disabled displaced people, including refugees, asylum-seekers, and forcibly displaced people. It examined their experiences navigating the resettlement process as disabled people both in the resettlement camps and in the United States. It also assessed their experiences with resettlement agencies and caseworkers in terms of being able to meet the unique needs related to their impairment.

### **Research Design**

Oral history was the methodology utilized in this study. According to the Oral History Association (2018), the field of oral history studies past events through gathering, preserving, and interpreting the voices and memories of people, communities and participants. This study focuses on the narratives and perspectives of disabled displaced people and aims to amplify unheard voices by giving primary agency to the narrator. By utilizing an oral history approach, the stories of disabled displaced people are amplified. Questioning, listening, recording, and preserving diverse historical perspectives are all integral parts of oral history (Oral History Association, 2018).

Chimamanda Adichie (2009) explains the dangers of a single story and warns about the risks of critical misunderstanding when we only hear a single story about a person or country. Single stories create stereotypes that are not only untrue, but incomplete as well. That single story becomes the only story. The single story around disability is one of pity, brokenness, and incapability. The single story around refugees is that of fear, difference, and less desirable beings. These single stories rob people of dignity, emphasize our differences while ignoring our

similarities, and cloud our recognition of humanity and equity (Adichie, 2009). The ideology of ability considers disability a burden and something to be feared. This is echoed in the perceptions of refugees as the Other to be feared and denied a place in the community (Dawson, 2019).

Oral history is a unique qualitative method of interviewing that emphasizes participants' perspectives (Leavy, 2011). It is imperative that the researcher be fully present with the person narrating his or her story (Leavy, 2011). Qualitative research methods allow the researcher more opportunities for engagement in in-depth research with marginalized populations than quantitative research methods. Additionally, by using a qualitative approach, participants are able to tell their life stories and experiences in their own voices and on their terms. This creates spaces in which marginalized voices can be heard (Woodley & Lockard, 2016).

Our stories matter. Stories can be used to empower and humanize, and to repair broken dignity caused by a single story (Adichie, 2009). Through oral history we are able to understand the world, human experience, and history in a personal, emotional way (Mayote & Kiefer, 2018). Additionally, first person accounts provide clarity and insight to important events that would be considered incomplete without them. Voice of Witness, a non-profit organization that uses oral history to promote social justice and human rights, uses the term "forcing space" to describe the process of giving primary agency to the narrator whose story is being told (Mayote & Kiefer, 2018, p. 13).

Two key concepts are centered in oral history: 1) the interview process is viewed as an opportunity for learning and growth, where the narrator becomes the teacher and the interviewer the student; 2) through active listening, power, privilege, and difference are openly acknowledged throughout the process as a crucial part of oral history (Mayotte & Kiefer, 2018).

#### **Research Site**

Originally, this research was to take place in San Diego, California, in a site chosen by the participants, whether in their homes or in another selected location. I chose San Diego for two reasons. Since 2009, San Diego County has led the State of California in refugee resettlement, taking in more refugees than any other county, the largest groups originating from Iran and Iraq (Amin, 2016). Also, I live in San Diego and have many community connections, so I anticipated having more ability to recruit participants for the study.

Due to the personal nature of the information participants would be asked to share, I had hoped for face-to-face communication since this is an important part of building trust and rapport. However, due to the COVID-19 global pandemic in 2020, San Diego County was under strict stay-at-home orders, and the county implemented social distancing protocols of maintaining six feet distance between people not belonging to the same household. For these reasons, all but one of the oral history interviews were conducted virtually. Only one interview was conducted in person outdoors at a park following social distancing guidelines. Conducting virtual interviews allowed the research site to extend throughout the United States and so participants were recruited from other regions of the country beyond San Diego.

## **Participants**

Six disabled refugees who have resettled in the United States participated in this study.

All participants were over the age of 18. In order to focus on recent and current policies, procedure and practices, participants have resettled in the United States during the past 11 years. Participants are from a variety of racial, ethnic, and cultural backgrounds, as well as differing disability labels. I recruited participants through contacts and connections I have to members in the refugee community. Only participants who were willing and eager to participate and share

their stories were included. Those who were hesitant or uncertain about sharing their stories were not asked to participate, out of respect for their wishes. Only participants whose cases have been finalized and who have been granted permanent resident or citizenship status were included, so as not to jeopardize any pending cases or risk deportation. When recruiting participants, I reached out to some individuals who work and volunteer with asylum seekers entering the United States at the Mexico-US border. Due to the precarious nature of their cases and that fact that many of the cases were still pending, no asylum seekers ultimately participated in this study.

#### **Data Collection**

Several steps were involved in the data collection process. Potential participants underwent an initial screening and those who fit inclusion criteria for this study were selected. The purpose of the study, as well as the purpose and goal of oral histories, was explained prior to beginning the narrating process. Participants were asked to sign a release form granting permission to record the conversation, transcribe, and possibly publish the content of the interview. They were informed that nothing would be shared without their consent. Each participant was given the option to choose a pseudonym; however, all chose to use their given names. Some felt very strongly that they wanted to use their name because they sensed the importance of sharing their stories. The participants felt a strong connection to their narratives and were proud of what they had been through, the challenges they have overcome, and what they have accomplished.

Oral histories were conducted individually. Prior to the interview sessions participants were given the choice to conduct the interviews in English or in their preferred language and have a translator present. However, none of the participants requested to have an interpreter present. All interviews were conducted in either English or American Sign Language. Initially, I

had planned for all interviews to be conducted in person, due to the sensitive and personal nature of the stories being shared. However, due to the COVID-19 pandemic, it was not safe to meet in person. Thus, I conducted the interviews virtually, via Zoom or Videophone and, in one case outdoors in a park, following socially distancing protocol of six feet between the participant and myself.

As mentioned previously, I conducted the interviews with the Deaf participants myself, using ASL. I conducted the interviews through Zoom and recorded each interview so I could transcribe them later. I am proficient in ASL, having studied the language for many years and using it both professionally and socially for more than 20 years. Conducting the interviews myself allowed for direct communication with the participants versus receiving the information through an interpreter. After each interview, I watched the video recordings and transcribed from ASL into written English.

Interview sessions lasted from one-two hours each, with two-three interview sessions per participant. I asked participants to share personal emotional stories and experiences with me - a stranger. When asking participants to share such personal, intimate stories, I knew how important it was to create brave spaces. Brave spaces allow for a fuller range of human experience, by making space for nuance, complexity, ambiguity, joy, discomfort, humor and contradiction (Mayotte & Kiefer, 2018). Since I needed to build trust and rapport as a crucial first step, I intentionally took time to do so during the initial meeting. I structured the beginning of the initial interview session with each participant to establish rapport and trust through finding common ground, such as shared interests and experiences, mutual friends and community connections, and family life. I found participants through my contacts in the refugee community as well as friends and colleagues who work with refugees. These common contacts facilitated initial

communication and "vouched" for me as a person who could be trusted. These introductions helped in the process of building trust and rapport with participants as they were open and willing to answer any questions and shared their stories without hesitation.

# **Data Analysis**

I interpreted the data using the processes of coding and determining themes. Each interview was recorded. I transcribed interviews and edited them for clarity and cohesion as needed, while ensuring the integrity and ownership of the story as well as honoring the voice of the narrator as much as possible. A critical part of the oral history process is sharing the transcripts with the participants to allow them to check for accuracy. As a result, I provided transcriptions to all participants in English, since none of the participants requested translations. I granted participants the final say in what was to be included. After reviewing the final transcript, they had the option to add, change, or delete any information.

I then hand coded the data for themes and subthemes guided by the research questions. Data were organized using a combination of predetermined and emerging themes. I created a spreadsheet with a separate tab for each participant to organize the data according to each theme and subtheme. These themes helped to answer each research question and form the basis for the findings in Chapter 5.

#### **Ethical Considerations**

Participants were asked to share very personal and intimate, perhaps traumatic experiences and stories. Since recounting these experiences may be triggering, the questions I asked had potential to bring up trauma. It is important I understood the ways in which trauma can manifest itself in the participants' lives and take steps to be supportive, collaborative, and responsive to the narrators and their stories. In *Say It Forward*, Mayotte and Kiefer (2018)

outline some important guidelines to consider when planning interviews: 1) allowing enough time for the interviews; 2) respecting narrators' self-determination; 3) emphasizing narrator's anonymity; 4) soliciting input from the narrators and give them choices; and 5) listening with empathy and compassion without judgement.

Even if these steps are followed and care taken to ensure participants are given the respect, autonomy, and consideration they deserve, retraumatization may occur. Therefore, to prepare for any possible retraumatization, participants were given the option to invite a friend or family member to the interview sessions to offer emotional support; however, none of the participants chose to do so. Additionally, I was mindful to be open with the participant about the purpose of the project, express gratitude, and be prepared to stop the interview at any time if necessary. Establishing rapport and trust, being honest and transparent, and allowing the participants to have a sense of control may help alleviate potential harm or risk of retraumatization.

My hope is that sharing these stories and first-hand experiences will lead to greater awareness of the situation of disabled refugees and potentially enact change. However, the reality is that I do not know what the impact will be. I was mindful to be transparent about this from the beginning and not make promises implying that participation in this project will change or impact anyone's life. However, my aim was that the participants felt empowered and heard; together we can build empathy and a deeper understanding of the human rights issues at hand.

### Secondary Trauma

The National Child Traumatic Stress Network defines secondary trauma as "the emotional duress that results when an individual hears about the firsthand traumatic experiences of another" (n.d.). Listening to traumatic stories and experiences of others can take an emotional

toll. Van der Merwe and Hunt (2019 conducted a study on vicarious and secondary trauma in trauma researchers and fieldworkers, such as those working in South Africa and doing Holocaust research. Findings from their study confirmed the presence of distressing symptoms researchers experienced in the data collection process (van der Merwe & Hunt, 2019). These symptoms, associated with secondary trauma, include feelings of grief, depression, anxiety, rage, and shame (van der Merwe & Hunt, 2019). Recommendations from this study call for trauma researchers to take extra care, including regular supervision, trauma counseling for debriefing, and emotional check-ins (van der Merwe & Hunt, 2019).

While I did not experience symptoms of secondary trauma to this degree during the course of data collection, I did find myself at times becoming somewhat emotional while listening to the participants' stories of violence, trauma, and abuse. I felt it was important that the narrators not sense this so as not cause further triggering. As a result, after learning about the effects of secondary trauma in researchers, I started to take time after each interview for reflection and to decompress from these negative emotions.

### **Background of the Researcher**

My interest in the experiences of disabled refugees stems from my work as a teacher in East County San Diego. As a teacher, I attend many meetings for students recently arrived in the United States from other countries, mainly the Middle East. These students have already been identified with a disability and are enrolling in school, often for the first time. As part of the educational team, I attend the intake and evaluation meetings, the purpose of which is to gather background information from the parents and determine a course of action for the student's education.

While these students and families came from different countries, the majority were Syrian who spent varying amounts of time in refugee camps in Jordan before relocating to the United States. As I listened to the stories the parents told about their child's background and medical history, I came to realize how dire the situation was, both in the refugee camps and upon resettling in the US. These families have had to navigate life in refugee camps as well as the resettlement process under several marginalized identities. Linguistic and cultural barriers make these already difficult situations even more challenging.

My interest was piqued and as I started doing research on disabled displaced people, I soon came to realize the lack of research on this topic, especially using oral history as a method to capture their stories. As a White, non-disabled American woman I do not have the same lived experiences that the participants in this study do; therefore, I cannot possibly truly understand what it is like. The decision to use an oral history approach came from listening to refugee parents of disabled children and their struggles navigating the systems in different worlds – their home countries, the displacement camps, and finally in their new home, the United States.

#### **CHAPTER IV: CAUSES OF MIGRATION**

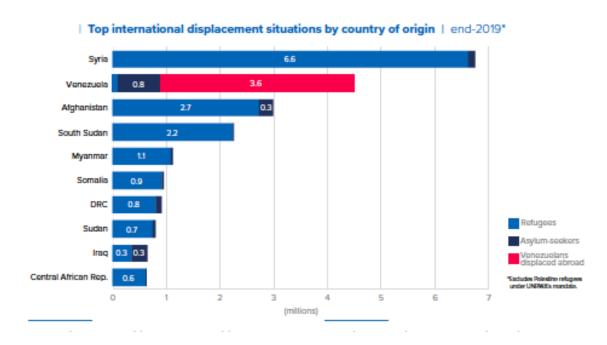
Leaving their own homes, countries, and sometimes families in search of a safer, better life is one of the hardest decisions displaced people have to make. Often, they have little or no choice, as their lives or the lives of their loved ones are in danger. They may be forced to flee persecution or human rights violations such as torture or child marriage. Some may have been targeted because of ethnicity, religion, sexuality, or political opinions. Still others attempt to escape armed conflicts and violence (Amnesty International, 2020). This chapter outlines some of these domestic forces (push factors) that can lead to migration, as well as the pull factors (conditions in the foreign countries which influence migration). It then provides an overview of the risks and challenges associated with migration, particularly for disabled people. Lastly, it describes the sociopolitical situation in the participants' home countries which ultimately led to their migration and resettlement in the United States.

### **Push/Pull Factors**

According to the UNHCR *Global Trends: Forced Displacement* report (2019), 79.5 million people were forcibly displaced worldwide at the end of 2019. This number is the highest on record to date and has increased annually in the past decade (UNHCR, 2019). Some reasons for this increased displacement are continued persecution, conflict, violence, human rights violations, or other events causing serious disruption to public order.

Figure 3

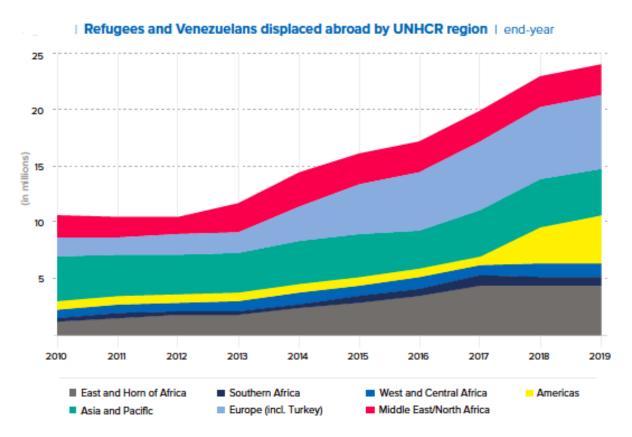
Top international displacement situations by country of origin.



*Note*. From UNHCR Global trends: Forced displacement in 2019. Retrieved from https://www.trtworld.com/africa/why-somali-migrants-are-fleeing-the-horn-of-africa-24950

Until around 2010 the number of displaced people was relatively stable. Although new displacement continued as wars and conflicts dragged on, many displaced people were able to return to their homes or resettle permanently in their host countries or in a third country. This has shifted in the past decade (2010-2020) and displaced people have fewer options for rebuilding their lives. This shift is due to ongoing wars and conflicts, countries accepting fewer numbers of refugees, and host countries struggling to integrate displaced populations (UNHCR, 2019).

**Figure 4**Refugees and Venezuelans displaced abroad by UNHCR region.



*Note.* From UNHCR Global trends: Forced displacement in 2019. Retrieved from https://www.trtworld.com/africa/why-somali-migrants-are-fleeing-the-horn-of-africa-24950

Over two-thirds of the world's refugee population is living in protracted refugee situations<sup>2</sup> (Hanafi, 2014). Protracted refugees are often confined to camps and mostly dependent on humanitarian aid. These situations are caused by inaction or non-sustained international action both in the country of origin and the country of asylum. Protracted refugees often have to survive without socio-economic or civil rights such as the right to work, run businesses, or own

<sup>&</sup>lt;sup>2</sup> The UNCHR (2020) defines a *protracted refugee situation* as more than 25,000 refugees from the same country living in exile for five or more consecutive years in a given host country.

property (Hanafi, 2014). In protracted refugee situations, refugees are often waiting out their time in the same circumstances of war and violence that caused them to flee in the first place. During this waiting period, often spanning years and even decades, refugees find themselves unwelcome, barred from opportunity, and raising children without a nation to call home (Wilson, 2011). Additionally, levels of sexual violence, arms and drug smuggling, trafficking of women and children, and the recruitment of child soldiers are high in refugee camps, further increasing the dangers for residents of the camps. (Wilson, 2011).

Until the root causes of displacement are addressed in these and other countries, people will continue to seek safety and protection, escape poverty, and seek better work and educational opportunities (UNHCR, 2018).

# **Risks and Challenges of Migration**

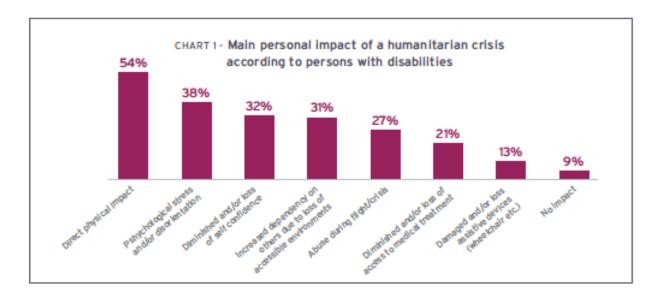
Migrants encounter enormous risks and dangers on their journeys, including death, detention and arrest, kidnapping, sexual and physical abuse, and human trafficking. Once settled and starting to build a new life, many face racism, xenophobia, and discrimination in their new countries. People fleeing their homes find themselves in precarious situations which make them targets for those who prey on the powerless and defenseless. Protected in the past by family and community, these structures are disrupted, adding to their risk. Families are often separated during conflict or flight or in the refugee camps. Because many displaced people find themselves in a "stateless" situation, no longer belonging to a country, legal and governmental protection often no longer exist for them (Women at Risk International, n.d.). Refugee camps are sustained by the UNHCR. Funding for the camps is dependent on donor response for food, shelter, sanitation, medical care, and other basic necessities (Wilson, 2011). Donor fatigue or lack of donor response can greatly impact care and services the camps are able to provide.

During flight, refugees face a new set of hazards in addition to those they are fleeing. They are often forced to take drastic measures such as seeking aid from smugglers to help them cross international borders. These smugglers may victimize those under their care, or may work in conjunction with drug, sex, and labor traffickers. In spite of the enormous risks and dangers migrants face, many believe it is their only hope for a better future. However, for the majority, their high expectations are not realized upon arrival in their destination countries and they face a difficult life once there (Gulleid, 2019). While refugees gain may freedom from oppression and persecution in their home countries, this does not guarantee they will receive freedom, equity, or justice upon resettling in the United States (Nguyen, 2019). Once resettled, refugees often face a lifetime of low-wage labor with little opportunity for upward mobility (Nguyen, 2019).

As mentioned previously, disabled people are in situations of increased vulnerability during migration and flight. In a study by Handicap International (2015), disabled displaced people outlined personal, social, and economic impacts experienced during humanitarian crisis. These personal impacts are identified in Figure 6, and Figure 7 highlights the social and economic impacts as identified by disabled refugees.

Figure 5

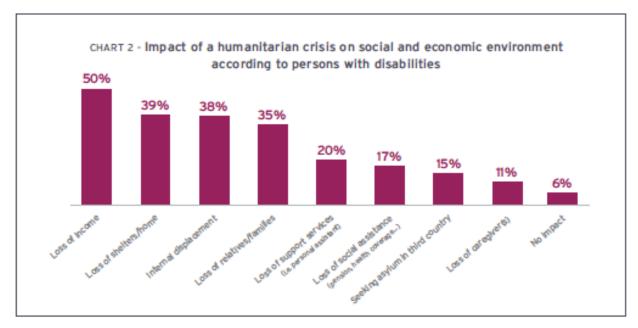
Main personal impact of a humanitarian crisis according to people with disabilities.



*Note*. From Disability in humanitarian contexts: Views from affected people and field organizations. Retrieved from https://www.un.org/disabilities/documents/WHS/Disability-in-humanitarian-contexts-HI.pdf.

Figure 6

Impact of a humanitarian crisis on social and economic environment according to people with disabilities.



*Note.* From Disability in humanitarian contexts: Views from affected people and field organizations. Retrieved from <a href="https://www.un.org/disabilities/documents/WHS/Disability-in-humanitarian-contexts-HI.pdf">https://www.un.org/disabilities/documents/WHS/Disability-in-humanitarian-contexts-HI.pdf</a>.

Handicap International published a report in 2015 that includes survey results of disabled displaced people and field organizations. In this report, 27% of disabled respondents reported being subject to physical, psychological, sexual, or other types of abuse. Thirty-three percent of female respondents reported abuse (Handicap International, 2015). Marshall and Barrett's 2018 study found people with communication difficulties to be especially targeted for abuse and violence. Handicap International's (2015) survey reports the same findings, stating that those with communication difficulties, hearing and visual impairments, and difficulty with memory or concentration are particularly subject to abuse during times of crisis.

## Participants' Homelands

The following section describes the sociopolitical situation in the participants' homelands at the time of their migration and includes the push/pull factors that ultimately led them to make the decision to leave their country, culture, and, in some cases, their families. Their homelands include Afghanistan, Bhutan, Democratic Republic of Congo, Ethiopia, Iraq, and Somalia.

Participants

Table 1

Name	Age	Home Country	Country of Camp/Refuge	Time Spent in Resettlement Camps	Arrival in US	Disability Identity
Diutay	36	Ethiopia	Kenya	14 years	2019	Deaf
Gopal*	35	Bhutan/Nepal	Nepal	20 years	2011	Deaf
Hala	23	Iraq	Syria	1 year	2009	Deaf
Jacques	33	Democratic Republic of Congo	Rwanda	17 years	2013	Physical
Masuod	34	Afghanistan	NA	NA	2019	Physical
Rihana	25	Somalia	Ethiopia	5 years	2014	Physical

<sup>\*</sup>Pseudonym

## Ethiopia

Ethiopia has a history of conflict, violence, and human rights abuses. From 1974 to 1991 Ethiopia was ruled by a communist military dictatorship known as the *Derg*. During the time, referred to as the "Red Terror" campaign, more than 150,000 students, academics, and political opponents were murdered; countless more were arrested, tortured, and disappeared (Human Rights Watch, 2017). In 1991 the Tigrayan Peoples' Liberation Front (TPLF) overthrew the dictatorship, but the human rights abuses continued (Human Rights Watch, 2017). In 2004, Human Rights Watch published a report documenting the denial of basic human rights to Ethiopian citizens and incidences of human rights violations committed by the government and military. This report outlined police brutality, torture, and illegal detention, as well as attacks on civilians by the Ethiopian military in the state of Gambella (Human Rights Watch, 2004). Diu shared that his parents and brother were not killed as a direct result of conflict, but because his brother had fled the military. Military officers went to Diu's family home in search of his brother and shot and killed him and their parents.

#### **Bhutan**

As early as the 1600s ethnic Nepalese migrated to southern Bhutan since they were commissioned by the Bhutanese government to work (Mørch, 2016). This migration continued for many decades, unsupervised by the Bhutanese government, and many were granted Bhutanese citizenship under the 1958 Nationality law (Human Rights Watch, 2003). In the 1980s the Bhutanese government adopted a "One Nation, One People" policy in response to the growing ethnic Nepali minority (Schultz, 2016). This policy made it illegal to teach Nepali languages in schools and required people to dress in the traditional clothing of the Drukpa, the majority cultural group of Bhutan (Schultz, 2016). Ethnic Nepalis without formal land titles or

records of having paid land taxes were denied citizenship. Additionally, this policy led to progressive discrimination aimed at the political, economic, and cultural exclusion of Nepalispeakers, Lhotshampas (Human Rights Watch, 2003).

In response, ethnic Nepalese led peaceful demonstrations which caused the Bhutanese police and army to respond with violence, destruction of houses, forcing people off their land, and other abuses. Thousands of Nepalese fled these abuses or were forcibly deported; many forced to sign "voluntary migration certificates" denouncing their Bhutanese citizenship and rights. The majority, including Gopal and his family, fled to refugee camps in Nepal, while a smaller number relocated to India (Human Rights Watch, 2003). Amnesty International considered this one of the most protracted and neglected refugee situations in the world (Schultz, 2016). Some families, such as Gopal's, lived in the camps for more than two decades (Schultz, 2016). Due to this expulsion of the Lhotshampas, Bhutan became the world's biggest creator of refugees per capita (Mørch, 2016), which contrasts greatly with the image Bhutan has created for itself as one of the happiest countries in the world (Mørch, 2016).

### Iraq

Iraq has been in a state of conflict on and off since the 1980s, including the Iran-Iraq war (September 1980-August 1988) and the Gulf War (August 1990-February 1991), which involved western military forces (Asylum Insight, 2018). As a result, Iraqis sought asylum in many countries, with the majority going to Iran. The U.S. military has played a large role in the conflict in Iraq, notably the 2003 invasion and removal of Iraqi president Saddam Hussein.

In 2014 the extremist group Islamic State of Iraq and Syria (ISIS) took control of northern regions of Iraq, causing more internal displacement as well as large numbers of asylum seekers fleeing the country, fearing racial, religious, gender, and political persecution. Human

Rights Watch has reported ISIS forces sexually assaulting and enslaving Iraqi women and executing journalists (Asylum Insight, 2018). Hala shared her family's experience with threats of harm made by ISIS towards her father, her sisters, and herself. These threats caused Hala's family to feel unsafe and ultimately to make the decision to flee to Syria and then the United States.

## **Democratic Republic of the Congo**

Known as Zaire until 1997, the Democratic Republic of the Congo (DRC) has experienced two wars since 1996, resulting in violence, collapse of infrastructure, and displacement (USHMM, 2013). According to Humanity House (2016), the DRC has experienced the deadliest conflict since World War II, with between four and five million lives lost.

The first war began in 1996 as a direct result of the genocide in Rwanda. Rebel groups from Rwanda, Burundi, and Uganda targeted Congolese Tutsi groups and launched an invasion of the DRC in October 1996, causing many people to flee to neighboring countries, including Jacques's family. This conflict resulted in rebels ousting President Mobutu and replacing him with a rebel leader, Laurent Kabila. In what is known as "Africa's first world war," the Kivu Conflict began in 2004 as an armed conflict between the DRC military and the Hutu group, Democratic Forces for the Liberation of Rwanda. Peacekeeping efforts during this conflict have focused on the prevention of force in the conflict and minimizing human rights abuses such as sexual assault, torture, unlawful killings, and the recruitment and use of child soldiers (Amnesty International, 2008).

# **Afghanistan**

Afghans began fleeing the violence in their country more than 40 years ago, seeking refuge in nearby countries and creating the world's largest protracted refugee situation (Asylum

Insight, 2018). Afghanistan is the second largest country of origin in terms of numbers of refugees, second only to Syria (Asylum Insight, 2018). In 1996 the Taliban, an Islamic militant group operating in Afghanistan and western Pakistan, took control of the capital city of Kabul and by 1998 was in control of most of the country. The Taliban enforced severe restrictions on women and education, causing a new wave of Afghans to flee.

In October 2001, the United States waged an invasion of Afghanistan, leading to another surge of refugees leaving the country. Although a new constitution was adopted and elections took place following the 2001 overthrow of the Taliban, conflict between the government and the Taliban continues. More recently, the Taliban has regained strength and is controlling most of the country once again. In 2015 the United States Department of State compiled a report citing widespread human rights violations along class, race, gender, and religious lines (Asylum Insight, 2018).

In 2009, Congress passed the Afghan Allies Protection Act of 2009, which provided Special Immigrant Visas (SIV) to Afghan citizens who had worked for a minimum of one year for or on behalf of the U.S. government in Afghanistan (Human Rights First, 2018). This program allowed those whose lives were threatened due to their work in support of the U.S. military mission in Afghanistan to resettle in the United States. Masuod and his family received Special Immigrant Visas through this program because of his work in Afghanistan with the United States military.

## Somalia

According to the United Nations High Commissioner for Refugees (2020) refugees from Somalia have been living in camps for almost 30 years, which is considered a protracted refugee situation. Many factors have been at play during this time period, mainly violence and famine,

which have led to Somalians fleeing their homes. In early 2020, flash flooding in the Southern regions of Somalia displaced over 650,000 people into makeshift shelters constructed from clothes, plastic bags, cardboard, and sticks. Food insecurity has been an ongoing problem due to dry conditions in some areas and flooding in others.

Al-Shabab (the Youth) is an insurgent group formed in the early 2000s, seeking to establish an Islamic state in Somalia. This group is responsible for deadly attacks across East Africa (Council on Foreign Affairs, 2020). When Rihana was a young child, her parents were killed as a result of this violence. Somalia has endured years of conflict and attacks by Al-Shabab, forcing thousands to flee their homes. In Somalia and other countries in the Horn of Africa, youth are migrating in large numbers due to lack of employment opportunities. Other factors include political prosecution, poor economic conditions, low quality or lack of access to education, and the idea of a better quality of life in Western and European countries (Gulleid, 2019).

All the participants in this study shared the same experience of fleeing their homes and countries due to human rights violations, including violence, conflict, child marriage, and gender violence. As disabled people, their situations were even more dire, as many of them could not access education or employment, and they lacked basic necessities and human rights in both their home countries and the resettlement camps. They resettled in the United States with hopes and dreams of education, freedom, and better opportunities for themselves and their families.

#### **CHAPTER V: REFUGEE STORIES**

### **Participants' Profiles**

This chapter serves to contextualize the migration journey of the participants. The first section includes a brief introduction with background information on each participant in this study in order to make sense of their stories. The following sections present the findings that emerged from the research questions and oral history interviews.

# **Diutay from Ethiopia**

Diutay (Diu) is 36 and married with four children. He was born hearing and became deaf at the age of eight after becoming ill. He and his brother fled Ethiopia after his parents were killed by rebels in 2005. They fled to Kenya after being arrested and tortured by Ethiopian police officers. In the Kenyan refugee camp Diu learned both Kenyan Sign Language (KSL) and American Sign Language (ASL). Because he had already learned to speak when he was younger it was easier for him to attend school.

Diu finished high school and attended college to become a teacher. After graduating from college, he returned to the refugee camp and taught Deaf children. Diu returned to college once again to study Information Technology Communication. In 2019 he resettled in the United States. Currently, he is studying for his BA in Early Childhood Education. Diu hopes to return to Ethiopia someday to help establish education for Deaf children there.

## **Gopal from Bhutan**

Gopal is 35 years old. He was born in Bhutan, and his family fled to Nepal when he was six after being forced out of Bhutan by the Bhutanese government. In Nepal they lived in a refugee camp for 20 years before coming to the United States in 2011. Gopal was born hearing but started to lose his hearing when he was around six years old and was completely deaf by the

time he was eight. The doctor in the refugee camp examined him but could not identify the cause. He attended school in the refugee camp in Nepal with hearing students and teachers. Unable to understand what his teachers were saying, Gopal taught his friends some sign language and they were able to tutor him after school, so he could pass his classes. After high school, he worked and saved money to attend college for two years. He then returned to the camp to work as the Disability Center in the camp, teaching sign language to other deaf residents, organizing activities and events, and assisting other members of the center.

Currently, Gopal is married with two children and works two jobs. Through his work at a local non-profit organization, Gopal assists Deaf newcomers adjust to life in the United States by teaching classes in American culture, providing resources for learning ASL, and teaching them the things he wishes someone had taught him when he first arrived.

## Hala from Iraq

Hala was born in Iraq as the youngest of twelve siblings. Hala and her four siblings are Deaf, and the remaining seven are hearing. Currently, she is an American Sign Language instructor. Hala's family fled Iraq and went to Syria after the Islamic State of Iraq and Syria (ISIS) issued threats of harm to her father, her sisters, and her. As a child, Hala saw her older hearing siblings go to school, while her deaf siblings stayed home and worked in the family business. She dreamed of going to school one day.

In 2009, Hala came to the United States with some of her family members, after being denied visas for Australia because the family had too many deaf children. When Hala arrived in the United States at the age of 13 she attended school for the first time.

## **Jacques from the Democratic Republic of Congo**

Jacques is from the Democratic Republic of Congo (DRC). Currently, he is 33 years old and has been in the United States for almost seven years. His family fled DRC for a refugee camp in Rwanda, walking for two weeks on a dangerous journey. Education in the camp was limited to middle school, but Jacques wanted to attend high school. In 2008 he returned to DRC for high school and while there he was shot in the hip by rebels during the civil war. After he became paralyzed, he was taken back to the refugee camp in Rwanda where he experienced severe depression. Eventually, Jacques completed high school through a special program, with the help of his friends.

Jacques now drives for rideshare companies, is married, and has two children. He is a leader in his community and volunteers his time to help other newcomers. Jacques has future hopes to mentor and counsel other disabled refugees as well as those who have experienced trauma since he can relate so closely to their experiences.

## **Masuod from Afghanistan**

Masuod grew up in Afghanistan, where he studied Information Technology there and worked with the United States military. As a result, he was considered a spy by the Afghani government, which put his own life and the lives of his wife and children in danger from the Taliban. Masuod and his family applied for and were accepted for Special Immigrant Visas (SIV) for his work with the United States. He became disabled as a teenager as a result of rheumatoid arthritis. As a disabled man, he has experienced discrimination from colleagues, neighbors, and even his own family members. Married with four children, Masuod and his family resettled in the United States in 2019.

#### Rihana from Somalia

Rihana is 25 years old and from Somalia. After contracting polio has a baby, Rihana has walked with crutches or used a wheelchair ever since. Because she was disabled, Rihana could not attend school in Somalia or in the refugee camp in Ethiopia.

Rihana's mother was killed in an explosion at the marketplace when Rihana was only five years old. Then her father was killed by Al Shabab militants when she was six. After their deaths Rihana was separated from her three siblings when she went to live with her mother's friend. Since the time when her siblings went to live with other relatives and neighbors, she has not seen them and does not even know where they are now. When Rihana was only 13 years old, the son of her caretaker who had passed away told Rihana she had to marry him in order to stay in their house. Afterwards, Rihana fled Somalia with neighbors to avoid child marriage and seek safety. Using wooden crutches and poor shoes, Rihana walked for six months from Somalia to Ethiopia.

After living in a refugee camp in Ethiopia for five years, Rihana came to the United States in 2014. She became a U.S. citizen in 2019. Currently, she is studying for her GED in hopes to become a social worker or counselor someday in order to help women in Somalia. She also hopes to return to Somalia to search for her siblings and be reunited with them. An interesting note is that Rihana plays wheelchair basketball for the local and state teams.

### **Findings**

The purpose of this oral history study was to examine the lived experiences of disabled displaced people. In doing so, this study sought to understand what their experiences reveal about the conditions for disabled people living in resettlement camps as well as their resettlement experiences after arriving in the United States. The presentation of this study's findings is

organized into six central themes: 1) Claiming education as a human right, 2) Inequities in the resettlement camps, 3) Knowledge of resettlement workers, 4) Human rights realized, 5) Changing the narrative, and 6) Hope for the future. Education as a human right was further broken down into three subthemes: Lack of educational opportunities in the participants' home countries, inaccessible education in the resettlement camps, and educational dreams come true in the United States. These themes and subthemes emerged during the processes of transcription and coding the interviews as key components of data analysis.

# Theme 1: Claiming Education as a Human Right

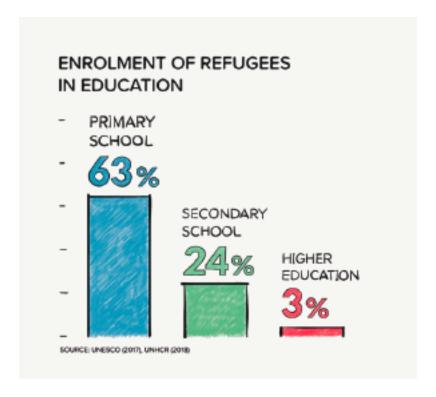
I wanted to learn. I wanted an education. (Interview with Hala, August 6, 2020)

Article 26 of the Universal Declaration of Human Rights calls for the right to education for everyone. Furthermore, it calls for *free* education at the elementary and fundamental stages (UN, 1948). The Convention on the Rights of People with Disabilities (UN, 2006) recognizes the right to education in Article 24, stating that States Parties should ensure an inclusive education for all disabled people. These calls for the right to education are further outlined in Article 28 of the Convention on the Rights of the Child (UN, 1989) and Article 22 of the Refugee Convention (UN, 1951). I make note of these international conventions that include the right to a free, inclusive education for all because, as I discuss in this section, this is not the reality in many countries for neither disabled nor displaced people.

According to a 2019 UNHCR report titled *Stepping up: Refugee Education in Crisis*, 7.1 million refugee children worldwide are school age. However, 3.7 million of those children are not attending school.

Figure 7

Enrolment of Refugees in Education



Note. From Stepping up: Refugee education in crisis. Retrieved from https://www.unhcr.org/steppingup/.

Each participant was asked to share their educational experiences in their home countries, in the resettlement camps when applicable, and in the United States if relevant. Participants' experiences varied greatly, ranging from not having any access to education whatsoever, to graduating from college and returning to the camp to teach. Factors that contributed to these differing experiences were: type of disability, age at which the participant became disabled, whether or not the participant lived in a resettlement camp, and age of resettlement in the United States.

## Lack of Educational Opportunities in the Participants' Home Countries

While education for disabled people is not the main focus of this study, it is important to briefly share the participants' educational experiences in their home countries prior to migrating in order to contextualize their later experiences.

Of the three Deaf participants only one, Hala, was born deaf. Gopal and Diu were both born hearing and became deaf as young children; therefore, they had already developed a strong language foundation in their native spoken language. These skills generally transfer to learning other languages, including signed and written languages. When discussing their education both in their countries and in the resettlement camps, both Gopal and Diu mentioned this important piece of information, stating that because they were born hearing and had some knowledge of a spoken language, they were more successful in school with hearing teachers and peers than the other Deaf students. However, they also both shared how difficult school was without interpreters or teachers and peers who knew sign language.

Hala and her four deaf siblings did not attend school in Iraq, as there was no Deaf education program in their village, nor any teachers trained in Deaf Education. Hala shared how she dreamed about going to school as a young child; seeing her hearing siblings attend school in Iraq while she and her Deaf siblings had to stay home both saddened and frustrated her. "My hearing brothers and sisters went to school, but my Deaf siblings and I didn't. My village didn't have education for Deaf children. I wanted to learn. I wanted an education" (Interview with Hala, August 6, 2020)

Because Gopal moved to the refugee camp in Nepal when he was only six years old, he attended school in Bhutan for only a few months. I share his educational experience as a Deaf person in the refugee camp in Nepal in the following section. Diu attended elementary and

middle school with hearing teachers and peers in Ethiopia and completed his education in the camp in Kenya. It was not until he attended college that Diu had sign language interpreters as part of his education.

Participants with physical impairments also had vastly different experiences. Masuod attended school regularly up until he became sick as a teenager and was physically unable to go. After taking a break for two years he returned to school, graduating both high school and college in Afghanistan. Masuod studied Computer Sciences and after graduation he worked on a project for the United States military in Kabul.

Rihana expressed that because of her disability she did not have access to education in Somalia.

I never went to school. If I didn't have a disability I could go to school. There it is not the same for people like me and people without disabilities, because they have more options. I think it depends on your family. Your family decides. And my family died when I was young, so I didn't have a lot of opportunity. (Interview with Rihana, November 1, 2020)

Rihana explained that women in her culture get married young and have to depend on their husband to survive. The situation is more difficult for women with disabilities because they do not have the opportunity for an education and have less rights than women without disabilities.

Worldwide, children with disabilities have been excluded from educational opportunities. Participants' experiences show us that this continues to be a reality in the 21<sup>st</sup> Century. Even for those participants who were able to attend school, their education was not inclusive because of the barriers that existed, and students did not receive appropriate support services they needed.

Despite these obstacles, their determination and perseverance demonstrate that education is a universal dream shared by children around the globe.

### Inaccessible Education in the Resettlement Camps

Four of the six participants lived in resettlement camps after fleeing their countries. Time spent in the camps ranged from five to twenty years. Participants' experiences regarding education in the camp varied depending on their disability. Deaf participants attended school in their respective camps, completing both high school and going on to attend college. However, they attended school with hearing teachers and peers; only one had access to interpreters at the college level.

#### As Diu described:

They have inclusive education in Kenya - all the kids went to school. The UN paid the teachers. They couldn't deny kids. They required the refugee kids in the camp to go to school. For the Deaf students it was their first time to go to school. We started at Class 1 or 2 until middle school. For high school, the UN picked some students and sent them to the city. College is hard. The interview is hard. Deaf people can pass? Not really. Only me because before I was hearing and went to a hearing school.

All the school buildings were together. The Deaf kids had five or six classes. But they socialized with the hearing kids sometimes. For example, for music class they all came together. But for class they were separate. But if a Deaf student wanted to join the hearing class they could. And if a hearing student wanted to join the Deaf class it was ok. So, there was a lot of socialization. (Interview with Diu, December 4, 2020)

Diu's experience in the resettlement camp in Kenya was unique in having some elements of inclusivity. Despite these attempts at providing an inclusive education, he still struggled with

language and communication barriers due to not having interpreters or teachers who signed. Diu explained the extra effort he had to put into his studies in order to succeed, and how he adapted and changed his approach because the system was not set up to take into account the communication needs of the Deaf students.

In 2008 I finished middle school. I was an adult but in school with kids. I finished middle school in Ethiopia when I was 21 years old. When I arrived in Kenya, I found that the education in Ethiopia is lower. In Ethiopia I finished class 7. When I went to Kenya, I started in class 5 again. The kids start school young. I was in school with kids who were 13 and 14 years old. In middle school I was with hearing students. Communication was hard. Why? They spoke English, a different language. Writing was okay, why? Because I copied the teacher, and I went home and studied. At the hearing school I tried to lipread, but it was hard, so I wrote. (Interview with Diu, December 4, 2020)

Although Diu stated that all students were required to attend school in the Kenyan camps, he also shared that it was not always possible for students with physical disabilities. He explained the roads in the camp were bad and students who used wheelchairs could not travel independently. If those students lived near the schools, the teachers and students would push them so they could attend school. But they were unable to help those students who lived too far away, and therefore those students could not attend school.

Gopal also shared his frustration with school and how he almost gave up because he couldn't pass the class. He did not have interpreters or teachers who knew Nepalese Sign Language and so he really struggled. With the encouragement of his family and support from his friends he passed his classes and graduated high school, and then went to college.

I tried to go to the hearing school, but the teacher spoke, and I couldn't understand any of it. I failed and failed 3rd grade so many times. I was ready to give up, go find a job or something. I couldn't understand and I didn't learn anything. But my family, my brother, said no, you're still young, 11, 12, 13 years old. An education is important. They really encouraged me to continue. But in 1996 I went to the sign class and started learning Nepalese sign language. Sometimes at school (hearing school) the teacher didn't come, or it was break time or whatever, I tried to teach my friends who lived near me sign language. They picked it up fast, I could read lips a little bit, so we could communicate. I understood them better than the teacher who just talked and talked, told stories, I didn't understand any of that. During breaktime or after school I asked my friends to help me. I asked them what the teacher said at school, what they talked about, about the homework. My friends were willing to help me, so they explained it and I understood, and I passed the classes. (Interview with Gopal, December 12, 2020)

Gopal had friends who were willing to help him, family members who encouraged and supported him, and the motivation to work hard to get an education. He explained how after he taught his friends some sign language, they acted as his tutors and interpreters.

It's not the same as America where if you fail you can still move to the next grade. In Nepal if you fail you stay in the same grade, so I stayed in 3<sup>rd</sup> grade two times and I really felt bad and was depressed. I wanted to quit. But I taught my friends sign and they helped me, and I really improved a lot. I was able to pass the classes. My friends were like my interpreters, they helped me to communicate and understand. After I graduated from high school, I went to college for two years. I went out of the camp for two years to go to college. (Interview with Gopal, December 12, 2020)

After graduating high school in the resettlement camp, both Diu and Gopal left the camp to attend college in the city, returning to the camps when they completed their studies.

As Diu stated,

My friend in America who is Deaf (his name is James N.), he came to America in 1998. In 2011 he helped me go to school. He paid \$1300 for one year of college for me. Then when I finished college, I went back to the camp to be a teacher. When I went to college it was mixed, KSL (Kenyan Sign Language) and ASL. But for middle school and high school it was only KSL. I started to learn KSL in 2011. There was a teacher but not a good one. They didn't have a license. They told me to go to the city and the government will teach me better. So, I went but it was mixed, KSL and ASL. At college I had interpreters. There were three interpreters. They were good! They knew both ASL and KSL. I went to college three times. The first time for six months then for one year. The last time for two years. Two times to be a teacher and one time to study ICT. Around 2017 I went to college again and studied ICT, Information Communication Technology. (Interview with Diu, December 4, 2020)

Gopal's college experience differed from Diu's in that he did not have interpreters.

He described how he understood the course materials and passed the classes by using both

Nepalese and English textbooks.

Food was free, school was free, the hospital was free. They were run by organizations which were under UNHCR. The schools were run by Caritas, the hospital by AMDA – Association of Medical Doctors of Asia. I didn't have interpreters at college. I learned more of the Nepalese language and in college I studied English. I had the same book in English and Nepalese, so I read the book in Nepalese then in English and I

quickly understood. It's the same now in America, for example, if I search for something in Google it shows up in English. If I don't understand I translate it to Nepalese.

(Interview with Gopal, December 17, 2020)

Many participants shared the pressures and difficulty of life in the resettlement camps.

Lacking sufficient food, adequate shelter, and financial resources in addition to dealing with the day-to-day stress all added to the mental pressures of attending college. Both Diu and Gopal left the camp for extended periods of time in order to attend college, but the mental toll of what was happening in the camps where their families were still living added to the pressure.

After I graduated from high school, I went to college for two years. I went out of the camp for two years to go to college. After I finished, I came back to the camp and worked at the disability center as a professional worker, not a volunteer. School was free until high school. I went to college when I was 22, 23 years old. In college I studied Humanities. I went to college for 3 months then had 2 months off. At that time, I worked in the fields, digging, etc., to save money to pay for college. When I went to college a fire destroyed our house and we lost everything. That created more pressure, more mental pressure, trying to figure out what to do. (Interview with Gopal, December 17, 2020)

Diu and Gopal described the struggles they encountered as Deaf students in hearing schools. Both men used their experiences to return to the camp and provide improved, more inclusive experiences for other Deaf students, Diu as a teacher for Deaf students and Gopal working at the camp disability center.

Participants with physical disabilities were not able to attend school due to the cost and distance, both factors making it inaccessible. Rihana shared that not only was the school about two hours away, but also, she could not afford the cost because her parents had died.

Jacques moved to the resettlement camp in Rwanda as a child. He did not have a disability at that time, so he was able to attend school without the same barriers he would have encountered if he were disabled. Jacques explained that the education was free until middle school but the UNHCR stopped paying for high school; therefore after 9<sup>th</sup> grade he had little opportunity to continue their education.

I will say until 9<sup>th</sup> grade we could go to school. There was not a chance to finish the high school diploma. So many students were going to Congo to find their dreams and a better living and to get a high school diploma. So, people were going back and forth, especially young people. I would say students. Because in Rwanda before 2005 students had a chance. When they finished the 9<sup>th</sup> grade they continued with progression. UNHCR paid for their school fees outside the camp in Rwanda. They paid for their school fees, those who passed high school with good grades, they paid for their university. But the time came when they said no more school fees so when they finish the 9<sup>th</sup> grade they would stay home or go to learn, other stuff, I don't know how to call it, those things like making materials, carpenter, learn how to build a house, how to sew things, everything. (Interview with Jacques, November 10, 2020)

Jacques and his peers had hopes of continuing on to high school but were not able to do so in Rwanda. For that reason, Jacques returned to the DRC to attend high school, returning to Rwanda during holidays. It was during that time in the DRC, pursuing an education, that Jacques was shot and paralyzed by rebels. This hope for an education and a better life is one of the most common pull factors that lead people to migrate. In Jacques' case, his desire to complete high school led him to return to the country which he had already fled, knowing it was

dangerous and the living conditions were not good. His dream of finishing his education outweighed the risks of returning to DRC for school.

After he became paralyzed Jacques wanted to continue his education but couldn't attend school because of his depression and inaccessibility to the school. His friends helped him finish school through a special program and he graduated high school.

But in the refugee camp, after like three years, I started a program with my friends. They were teaching me some necessary courses and I went to do the private candidate exam and then I got my high school diploma in Rwanda. I got a high school diploma in Rwanda three years after I was shot. (Interview with Jacques, November 10, 2020)

These stories reinforce the existing research regarding barriers disabled refugees encounter accessing education in the camps, but they also reflect on their strength and determination. A common thread in their success is the support of friends. This support by friends, whether it was paying for college, tutoring, or providing emotional support, was critical in almost all of the participants' stories of success.

An inclusive education does not simply mean all students can attend school. Diu mentioned that the camps in Kenya practiced inclusive education by requiring all students to attend school; however, as we learned from Diu's personal experience, students did not always have the accommodations and supports they needed in order to be successful. This is also reflected in Gopal's case. Deaf students were allowed to attend school, but they had to work extremely hard, studying after school and engaging peer support, to pass their classes and get an education. Inclusive education is much more than just physical presence. Inclusive systems value

the unique needs, abilities, and contributions of all students, provide opportunities for all students to learn and grow.

#### Educational Dreams Come True in the United States

One of the major pull factors that cause people, especially youth, to migrate to the United States is the hope of obtaining an education. The pursuit of education was a common theme throughout the oral history interviews. All of the participants, with the exception of Hala, resettled in the United States as adults.

At the age of 13, Hala's dream of attending school was finally realized. Hala explained that the United States was her family's third choice for resettlement but after discovering that their deaf children would have the opportunity for an education here, they made the decision to come to this country. Hala's hearing siblings were able to enroll in school immediately. She remembers begging her parents to find a way for her to start school, too.

There was a school very close to our home. My older siblings went to adult school and my other hearing siblings went to the high school that was very near our home. That left the 4 Deaf siblings. I told my dad I didn't want to stay home again; I became angry at the thought of having to stay home again. I told my dad I wanted to go to school. He thought about it and told me he didn't know but let him think about it. So, he asked his 2<sup>nd</sup> cousin if she knew about a Deaf school. So, his cousin went to the high school where my hearing siblings were going and asked if there were any Deaf programs or schools. There she was referred to the program in the unified school district, but my dad said it was a little bit too far, so he wasn't sure about it. I told him I really wanted to go to school. They told my dad they would offer transportation; he didn't have to drive there every day, so he was relieved. (Interview with Hala August 6, 2020)

In addition to Hala's identities as a Deaf woman, cultural beliefs and customs created more barriers to her education. She had seen her older Deaf siblings grow up without an opportunity for education and she was determined to change that pattern. As a young woman, Hala had the strength and courage to fight for her right to an education.

Really, for a few months I was not really enrolled in school yet, just training (this was in February) then in the fall I started 7th grade. I remember I entered school with Deaf peers, but it was different – we were on different levels. They placed me in that class because they thought I would learn slowly. I was learning reading, writing, numbers, etc., but I learned really quickly, faster than the other students in the class. The other students needed a lot of repetition to remember things and the teacher noticed I didn't fit in that class, so I was placed in another class. I graduated from middle school and decided to go to H. High School. I was in the Deaf program for one year then mainstreamed for three years. At that time, I really enjoyed school. It was my first experience going to school and I was so excited. But I was bullied a lot because I wasn't fluent in ASL, I didn't know how to write well, and I had moved from another country. The other students really made fun of me a lot. It was frustrating and there was a lot of drama, but I decided to focus on school. (Interview with Hala, August 6, 2020)

Hala's experience of being bullied and teased reflects the experience of many migrants who have resettled in the United States and other countries. They often face discrimination, xenophobia, and bullying. In spite of these negative interactions, Hala's drive for an education motivated her to continue on and stay focused throughout high school and college.

After I graduated the teachers really encouraged me to go to MHS, but I chose to go to HHS because it was closer to home and I didn't have time for the drama. I wanted

to focus on finishing my education. I graduated and went to CSUN and got my BA in Deaf Culture/Deaf Studies. In college I enjoyed going out with my Deaf friends and going out away from school. Really, I wanted to go to Gallaudet<sup>3</sup>, but my family didn't support it because it was so far away. They weren't rooted in American culture yet and said I had to stay with the family because I was a woman and am Deaf. My parents didn't feel I could live independently. We didn't agree for many months and I got advice from my teacher, who recommended CSUN. I applied and was accepted so I went. I really wish I had gone to Gallaudet because many of my Deaf friends went there, but none of my friends went to CSUN. When I was in college, I was in such a hurry to finish, I didn't stop and think about enjoying the experience. Now I realize I should have slowed down and enjoyed myself instead of being in such a hurry. (Interview with Hala, August 6, 2020)

Hala's dream of receiving an education came true, and she herself is now an educator, teaching American Sign Language at a local university. She is considering returning to school in the future to get her teaching credential and become a teacher for Deaf children.

Rihana did not have the opportunity to attend school either in Somalia or in the resettlement camp in Ethiopia because of her disability and gender. She came to the United States when she was 18 years old and attended high school for two years as a student in an English as a Second Language Program. At the time of this study, Rihana is studying for the Graduate Education Development (GED) exam. Currently, Diu is working on his BA in Early Childhood Education in hopes of someday returning to Ethiopia and teaching deaf children there.

<sup>&</sup>lt;sup>3</sup> Gallaudet University, in Washington, D.C., is the first liberal arts university for Deaf and Hard of Hearing students.

Gopal and Jacques shared their hopes to continue their education in the United States, Gopal to study psychology and Jacques to be a counselor or mentor for others.

Education can help break the cycle of poverty, improve health, and bring about social change and stability. The UN's Sustainable Development Goal 4 (SDG4) aims to ensure inclusive and equitable quality education for all (UN, 2015). The 2030 Sustainable Development Goals are a set of shared goals adopted by UN Member States as a call for action working towards peace and prosperity. Despite these calls for free and inclusive education for all, the participants' experiences both as refugees and as disabled people tell the reality of education for disabled displaced people and highlight many areas needing change.

# Theme 2: Inequities in the Resettlement Camps

If you are disabled, you are dependent, and you will accept anything that comes to you. If you are disabled, you cannot work. (Interview with Jacques, November 10, 2020)

Participants who lived in camps all spoke about the difficulty of life in the camps for everyone, but especially for disabled people. Common experiences that came up were lack of food and feelings of hunger, terrible living conditions, and financial difficulty.

In the previous section I discussed the educational experiences of the participants. The disparities in the education for the disabled and non-disabled camp residents are glaring. Participants shared other instances highlighting disparities and inequities between disabled and non-disabled camp residents. Some situations included in the participants' narratives are opportunities to work and earn money, difficulty accessing food, and accessibility and mobility barriers which caused increased dependence on others.

Gopal remembered not always having enough food to eat and being hungry, but he couldn't leave the camp to work and earn money to support his family because he is Deaf.

Life in the camp wasn't easy. It was really hard. The World Food Program (WFP) and another agency — I can't remember the name, but it was connected with the UNHCR — helped with food. They gave us food for 15 days (at a time). They gave us kind of a container of food, one for each member of the family. But the food ran out after one week, ten days. So, for five days we barely had enough to eat. It was really hard.

Sometimes we just had rice we cooked with water, bananas, the same for three months. Then they'd change it for another three months, maybe give us pumpkin. It was not enough food. We didn't have milk or meat. That was too expensive. Some people went outside of the camp to work, get money to support their families. But some people had no parents, they were disabled, Deaf, maybe their parents died, they were children, so they couldn't work. Life in the camp was really hard. (Interview with Gopal, December 12, 2020)

Jacques is the only participant who experienced life in a resettlement camp both as an non-disabled person and as a disabled person. After he was paralyzed Jacques used a wheelchair; he shared the difficulties he experienced accessing camp facilities and losing his independence, but also the support he received during that time.

After I became paralyzed, I lived in the camp health center because I had no way of living in those tiny houses for refugees. They are very little houses 2 ½ meters by 4 meters for every family. And the roads are really dirty and pits, stones, they are not good. So then living in there (the health center) I could have somebody help me. Because I couldn't handle life on my own. I needed to have someone push me every time if I wanted to go somewhere. I couldn't get in my house with my wheelchair. I arrived at the front door I had to have someone lift me and take me to the room. The doors were too

small for my wheelchair. Each time I need to go around the camp to relax I need to have someone push me. Because I can't push myself because the way the roads are really dirty and full of pits. So, I stayed in the health center for a while. I stayed in the healthcare center for one year. In 2010 I lived in Kanombe Military Hospital until the end of the year. Then in 2011 they built me a house near the hospital so I can get out of the hospital. Maybe live my life, take a shower whenever I want and sleep. So, nobody is pushing me around or standing beside me. To make me more independent. (Interview with Jacques, November 11, 2020)

Jacques explained that the UNHCR recognized his need for independence and they ordered his house built as a medical directive from the doctor. This step towards independence was very important for Jacques's mental and emotional health. Jacques shared his feelings of despair and depression, but he didn't have words to put to those emotions and feelings until he arrived in the United States. Not being able to work and support himself or one's family increased those feelings of despair and inadequacy.

I knew so many other disabled people there in the camp. The biggest problem is that what makes them feel bad is those who are not disabled are allowed to work in the refugee camp for money or outside of the refugee camp. That is how it is over there. If you are disabled, you are dependent, and you will accept anything that comes to you. If you are disabled, you cannot work. They are just walking around just taking a trip for fresh air. So, they had no way to get money. Rwanda gave them access to everything that they can do. Those who are not disabled, they do work for money. And in the refugee camp UNHCR didn't provide enough money or enough food so maybe they can save a little bit for their clothes. So, to get clothes it's like selling one piece of your food and

you can get a shirt or pants or some shoes. If I tell you that time 2008-2013 I had only two pants, made out of tissue, and another one made out of cotton – I don't know how it's called in the US, but it's those pants made for sports. So, I would clean my pants during the night aiming to wear them the next morning. Finding each and every way that my pants can get dry so the next morning I can wear it. If it doesn't get dry, I kept sleeping until my pants get dry and then I will wear it. It was a difficult life. And those who are in charge to find food for you, when you see them every day, sometimes they say today we had no food, you have to be patient, maybe tonight you will eat, so you feel more depressed. (Interview with Jacques, November 10, 2020)

I found it both surprising and hopeful that the UNHCR recognized Jacques's need for independence and found a way to make that happen. Jacques's mention of feeling bad and depressed is important to note because these issues are taboo in many cultures and often are not addressed but are extremely important issues that many displaced people experience.

Rihana's experience as a single, disabled woman with no family to support her shows the inequities and oppression she faced as a result of her intersecting identities. She also shared that, like Jacques, she had to depend on friends for support because she was a young, disabled, single woman.

I didn't have any money, but I survived by staying with some friends.

We shared a little bit of food. And in the refugee camp, people who work there they give you some rice, some oil, without no tomato no onion. You have to figure it out how to cook or share with a friend. Some friends I met in the refugee camp called Awbare.

I was in the camp in Ethiopia for five years. If you don't have family, it's very difficult. You're single, you're handicapped. And I left my country I lost everything. When I got

there, I used my crutches. Ethiopia is very cold sometimes. It's very difficult. So, yes. For people like me is very difficult. You are woman. And you are scared of the men and they want you to get married young. I say I'm lucky. Very lucky. (Interview with Rihana, November 1, 2020)

Rihana was only 13 when she fled Somalia and resettled in the camp in Ethiopia. Without any family to support her or take care of her, she had to rely on the help of others; however, this wasn't easy because she didn't know anyone and was scared and overwhelmed. However, she explained that others in the camp looked out for her. She met another young girl whose family took Rihana in and helped her when she needed it the most.

I almost give up on my life and everything I lost; I didn't know people. They'd been there before. They went when the civil war started. So, a lot of people were there ten years, twenty years in the refugee camp. And I was new, and I didn't want to share with everyone. But the people are nice, and the people check on you. So, I was sharing with my friend Halimo and we became friends. So, I was very lucky. I stayed [with Halimo's family] And I shared one packet of rice and little bit of oil. No gas, no tomato. Halimo said don't share your things. You can sell them and get clothes. (Interview with Rihana, November 1, 2020)

Like Jacques and Gopal, Rihana spoke of not having enough food, inadequate clothing and shelter, and the difficulties of life in the camp, especially for disabled people. Rihana's friend's family shared their food and cooking supplies with her and encouraged her to sell her allotment for clothes, because she had no other way to earn money.

The things you have, you sell them because you need oil and tomatoes, and a plate for how to cook. We didn't have dishes. For single people it's very hard in a refugee

camp. But Halimo's family was 12 people. So, they can sell some, and they change (trade) like the oil. We lived in a tent. There were no houses, just tents. It was very cold. Some people have money, so they have jackets. And some people who don't have, they give you blankets. (Interview with Rihana, November 1, 2020)

These narratives speak of inequities, oppression, and exclusion for disabled people living in the camps. Already terrible living situations are made worse by not providing opportunities for work and earn money to be more independent, provide for themselves and their families, and improve their living conditions by any means possible. However, throughout the narratives also came stories of hope, compassion, and perseverance. In circumstances where everyone had very little, the participants found others who were willing to share what they had and support each other in whatever ways they could.

# Theme 3: Lack of Knowledge and Training of Resettlement Workers

IOM sponsored my family when they came. International Organization of Migration.

They didn't understand my needs as a Deaf person at all. (Interview with Gopal,

December 17, 2020)

This theme emerged throughout the course of the oral history interviews. As participants shared their stories of arrival and resettlement in various regions of the United States, I asked them to explain their experiences with the resettlement agencies that assisted them. More specifically, I asked them about the agencies' and caseworkers' knowledge of the participants' unique needs related to their disabilities and whether or not those needs were met. The common experience among the participants was that their caseworkers did not know how to accommodate for their needs, and often it was volunteers, friends, or family members who assisted them in accessing the services and accommodations they needed.

Of the three Deaf participants, only Diu knew some ASL when he arrived in the United States. He was also the only one who had experience using interpreters and understood that he had a right to request one. However, interpreters were not always provided, and Diu shared that he struggled finding work because he couldn't complete the job interview without an interpreter.

When I first arrived, I didn't have interpreters, but later the Catholic church realized I was Deaf and needed interpreters and then I had them for when I go to the hospital. But sometimes I have to call, and I use VP (videophone) with interpreters. When I arrived in America, I found it hard as a Deaf person because I didn't have interpreters. I'm ready to work and I went to some interviews but there wasn't an interpreter. The company didn't give me an interpreter. In that way I lost work, because there wasn't an interpreter. In MN I worked in a hotel and there was a girl who knew ASL and she interpreted for me. (Interview with Diu, December 9, 2020)

Deaf people require specialized technology such as videophones, doorbell lights, and alarm clocks that shake the bed. These devices can be acquired free through various organizations and agencies, but if Deaf refugees aren't aware of these services, they don't know how to access them. Diu attended a local ASL class and saw the teacher use a videophone<sup>4</sup>. He let the instructor know he wanted a videophone to use at home so he could call 911 if his kids were sick, communicate with other Deaf people, and use a video relay service to make calls. The instructor helped him apply and after waiting for two weeks someone went to Diu's house to install the videophone and train him how to use it.

Gopal had the same frustrating experience of arriving in the United States and having difficulty communicating, which impacted his resettlement experience overall.

<sup>&</sup>lt;sup>4</sup> A videophone can be used by Deaf people to communicate with each other over the phone, or with hearing people through a sign language interpreter.

I went to a workshop related to refugees who just arrived in America. They couldn't communicate with me, so I just went home. In that workshop they taught how to pay rent, how to pay bills, no one taught me any of that. When I was home for eight months, I was trying to figure out how to pay bills, it was confusing. Later when I learned to sign well, I went back to that workshop and let them know I never learned any of that. I told the teacher that Deaf people need to learn all of that, too. Later I went to the New Hampshire Deaf Agency and learned sign language for two months. I learned some sign at the ASL classes, and I watched YouTube videos to learn. When I went to college classes I had an ASL interpreter and I watched and learned a lot. (Interview with Gopal, 12/17/2020)

Gopal's experience of frustration, isolation, and confusion when he first arrived motivated him to learn ASL quickly and to become a mentor for other recently arrived Deaf refugees. Gopal changed the resettlement experience for future Deaf migrants by letting the leaders of the workshop know how frustrated he was at not being able to learn the very important skills and information they taught and that he needed to know. He explained how he started working with the hearing teachers of the workshops and recruited Deaf newcomers to attend the classes.

After I learned a lot of ASL I went back to that newcomer's workshop to teach. I went to the Deaf refugees' homes and told them to come to the workshop. At the ESL class another Deaf student came. So, they asked me to help and I said yes, I was willing to help. So, there was a Deaf teacher and a hearing teacher. The hearing teacher spoke, and I used gestures and ASL to explain. Then another Deaf student came, then another. Then it expanded to 12 Deaf students! Then they got a grant and taught American

culture, the workshop, also when they had presenters, they had ASL interpreters. It was really great because they improved, got a job, and were independent. It was hard because I had to go to the Deaf people's houses and explain to them to come, sometimes I had to pick them up and drop them off after the workshop. (Interview with Gopal, December 17, 2020)

Not only did Gopal experience frustration and communication barriers when he arrived in the United States, he and his wife had a similar experience prior to leaving Nepal. The sponsoring organization did provide cultural workshops and training in Nepal, but they did not provide interpreters or accommodations for Gopal and his wife.

IOM (International Organization of Migration) sponsored my family when they came. They didn't understand my needs as a Deaf person at all. They hosted a workshop in Nepal to teach about culture, life in America, how to call 911, what to do at the hospital. That was in Nepal three days before we flew to America. There were no interpreters, just speaking, and it all went over my head. I didn't understand anything. A person from Nepal who had lived in America taught that workshop. There were many hearing people, all who were scheduled to fly at the same time as me. My wife and I were the only two Deaf people. We just sat there because we didn't understand. We understood a little bit of the writing and they showed some pictures, which helped. For example, they showed pictures of different celebrations, what Americans do if someone dies, about the food, that kind of thing. (Interview with Gopal, December 17, 2020)

When Hala's family arrived, she remembers a woman coming to their home to teach Hala and her siblings ASL, to prepare them for school and work in the United States.

I remember there was a woman, I can't remember her name, but she was a hearing woman, not Deaf, came to my house to teach us basic sign language. I really wish a Deaf woman had come instead of a hearing woman. I wish they had sent a Deaf model [language model] instead of a hearing one. Let me back up – that hearing woman came to teach us some sign language. The four of us, my Deaf siblings and I, sat down and my hearing sister, my older sister, interpreted for us. We knew home signs and didn't understand what the woman was teaching us. For example, she signed "apple" and my sister interpreted it into our home language. I learned really quickly. My older brothers and sisters were slower to understand. They kept asking what it meant, it was harder for them to learn. At that time, they were 30, 21, 15, and me, 12. It was really easy for me to learn ASL quickly. (Interview with Hala, August 6, 2020)

At the age of 12 Hala and her older Deaf siblings learned a formal language for the first time. Hala's older siblings struggled with learning ASL and the concepts they were taught. This is a common experience for older deaf people who have never had access to a formal signed or spoken language and is a result of language deprivation. They have passed the critical window for language development and this can impact other areas of their lives. Because Hala was still young it was easier for her to learn both ASL and the academic material taught at school.

Jacques and Rihana required accessible apartments but both explained that the resettlement agencies and caseworkers either were not aware of their needs or did not know how to provide what they needed. At first, Jacques didn't say anything to his caseworker about this because he was happy to have a nice place to live. However, he later realized he had rights as a disabled person and that he needed to have living accommodations that allowed him to be safe and independent.

The agency (Catholic Social Services) here is in charge of finding an apartment, they know everything about your situation. They know you are in a wheelchair, you are sick, this and that. But I was surprised I came here, and my case manager did not find a good apartment for my situation. But I didn't think anything about that because I saw that it was pretty different from my house that I was living in Rwanda in the camp. I see it's nice. Later, I realized after finding out that I have rights, to accommodate my requirements. (Interview with Jacques, November 10, 2020)

In Jacques's case, when he first arrived, he had to rely on the support of his brother for his daily needs because their apartment was not accessible to him and Jacques could not work. He spoke of being completely dependent on his brother and not being able to do anything except wait while his brother was at work. Jacques explained what it was like for him when his brother went to work every day.

Those agencies need to know that. I was not able to go to the toilet by myself. I need a chair. I was surprised. It was a tiny house. I came with my brother, but I was surprised. I could get in the door it was wide enough. But going in the shower, toilet, problem. Cooking – I couldn't cook. It was really high. When he went to work, I would suffer, stay hungry. Going to the toilet, too, I could wait for him. They need to know about that. And when they get here, those who are strong enough are required to go to work in three months. But what about those people who they take care of? Who will take care of them? They need to know about that and prepare something. They need to change it for sure. I just sit there and wait (for my brother to come home). (Interview with Jacques, November 10, 2020)

Shortly after he arrived in the United States Jacques met a volunteer with one of the local refugee agencies. She was very experienced and knowledgeable about the needs of the disabled refugees because her brother is quadriplegic. Both Rihana and Jacques met this volunteer and spoke of how much support she gave them and how she fought for them to get accessible accommodations.

I met Mia in the very first weeks. She talked to me. I didn't know any English. Since I met Mia, she talked to me and I told her how depressed I was in Rwanda. She asked me, "Do you know you can drive?" In my heart I said, "What's wrong with this woman? Can she see I am disabled? How can I drive?" But she had a secret. Her brother drives a car, and he is paralyzed, legs and arms. His name is Mark, and he is a good guy. He helps to fix my wheelchair. When I need a tire for my wheelchair, he purchases it for me and helps to change it. He lives here in the winter season and in the summer, he goes to Oregon. Six months in Oregon and six months in AZ. Whenever he goes to Oregon, he makes sure I have everything I need for six months to take care of my chair. (Interview with Jacques, November 10, 2020)

Jacques spoke of Mia with great admiration and gratitude. Her actions helped him realize that, even though he is now disabled, he can still have hopes and dreams and do anything he puts his mind to. Meeting other disabled people who are successful, can drive, and are independent was life-changing for Jacques.

When I was about to answer the question about driving, she said, "Now Jacques, listen, in the US you can do anything you can think of. Don't say you're disabled I can see you're disabled. You can do whatever you want. You can become whoever you need to be". Then I said, "How is this possible?" She said, "Next week I will take you

somewhere and you will meet some people living with disabilities." She took me to the wheelchair basketball team then after playing sitting basketball she asked people to talk to me. They talked to me and shared their stories, and I was impressed that everyone has a job. Everyone has a job. Even those who are not strong like me. Those who have trouble with their arms, those who cannot push themselves up a hill, they are not that strong to push themselves. But they can go around the city going everywhere. These people are really seriously injured, and they have a job. I didn't know that having a job is not about being disabled or strong or physically fit but because of my brain. This is one of my biggest barriers here, because of my thick head. Then she said, "You know another thing, all of them they drive". Somebody said, "You see Jacques I can't bend my fingers like this, but you can do it. You have a strong brain, why can't you drive?" He said it is about your brain not your legs. You can control the steering wheel with your arms. You have good eyes. You can drive. I said, "Wow! I can see myself driving." Mia helped me to get the first car with hand controls in it. A friend bought a new car, and he sold the old one to us. I learned how to drive with that car. I became an expert driver, now I can drive and earn money. This is amazing. I do it as a source of my income. People here are impressed I can drive. (Interview with Jacques, November 10, 2020)

Rihana had the same experience that Jacques had with a different resettlement agency and was given an apartment that was inaccessible to her. Through the help of a volunteer, she was able to procure wheelchair that was the right size for her and, eventually, an accessible, safer apartment.

Mia helped get a new wheelchair. IRC didn't know how to help with that kind of thing. When they taught me how to cook, how to make fire (use the stove), because I'm

handicapped, I need a little bit easier. It was very dangerous. (Interview with Rihana, November 1, 2020)

Rihana went on to explain that the volunteer advocated for an accessible apartment for Rihana, even though that meant waiting almost five years.

My apartment, the shower I love it. It's bigger and I use my wheelchair. The kitchen, I can use my wheelchair when I wash the dishes. It's very easy. Mia did everything. Mia understands because she has her brother, so she said, "No small bathroom, she has to use her wheelchair!" So, when she looked at the apartment, she said, "It's too small we have to wait". We waited a long time. This one is low income. I was waiting like five years. I think now they (IRC) understand people like me, now they changed. (Interview with Rihana November 1, 2020

Masuod had a different experience with yet another resettlement agency. He explained about the discrimination he faced in Afghanistan, not only by strangers but by his own family members stemming from cultural beliefs towards disability. His caseworker in the United States was also Afghani, but still Masuod experienced similar discrimination by him.

The Afghani caseworker discriminated against me. I went to the agency and the Afghani guy who worked there told me he won't support me. Only for one month. But I was introduced to an American woman, a caseworker, and she supported us more than one year. That is his job, but he never wanted to help me. (Interview with Masuod, August 7, 2020)

Every participant in this study went through different resettlement agencies; however, they all had similar experiences with not getting the accommodations and supports they needed. This demonstrates the need for training and increased awareness for resettlement workers about

the unique support needs for disabled refugees, as well as awareness of laws such as the Americans with Disabilities Act (ADA) that require accessibility and accommodations such as interpreters, access to information and services, and public spaces. Gopal is the only participant who specifically mentioned learning about ADA at a conference, after which he realized he has the right to ask for interpreters. Disabled refugees and migrants generally come from countries where they do not have any rights as disabled people; therefore, they need to be explicitly informed about their rights in the United States upon arrival and how to make sure those rights are implemented in every aspect of their lives.

## **Theme 4: Human Rights Realized**

The United States is a good culture. They are good to me. Everyone respects me. My human rights here are better. My rights are high. (Interview with Masuod, August 7, 2020)

As I interviewed the participants and got to know them, they became very comfortable sharing their stories and experiences with me. Most were open and honest about sharing their positive stories, hopes and dreams, and successes. They also shared feelings of frustration, despair, and human rights violations. This theme of human rights realized emerged as the participants shared their stories of realizing they have rights as human beings, as disabled people, as women, and as refugees.

Hala explained what her future would have been had her family stayed in Iraq and how she longed of a life different than what her Deaf siblings had.

Really, if my family had stayed in Iraq, I would have just been an old sister, I would have stayed home. I don't think I would have an education or a job, and probably not get married. I guess I would have lived with my family until I died. Growing up I did

dream about having a degree and working. I wanted people to see I could do it. Growing up I always dreamed of that and prayed about it. At night I always looked at the stars and prayed please get me out of this area. I loved that area, it was so beautiful, but sometimes I prayed to be able to leave that area because I knew my future if I stayed there. I couldn't put up with that. My older brother could handle it, he grew up there for 30 years and didn't mind it. But I couldn't, I didn't have the patience. (Interview with Hala, August 6, 2020)

As mentioned previously, Hala's dream of getting an education came true when she migrated to the United States. She shared about her rights and opportunities as a Deaf woman that had previously been denied in Iraq.

Here in America, I have a lot of benefits and privileges. A lot of opportunities. And I notice people who grow up here always complain about every little thing. I want to tell them they are really lucky; they should appreciate it. They are really lucky they grew up here. Overall, I am really happy to be here. I have an education, a job, maybe in the future I will marry or have children or maybe adopt. (Interview with Hala, August 6, 2020)

Not only did Hala finally experience basic rights, such as the right to education and to language, but also her relationship with her family began to change as they recognized her rights as a Deaf woman.

Before my brother really tried to control things, but that has changed. We used to fight a lot because I felt we were equal, and we argued a lot. But after we moved here, he started to change and respect me. He didn't say anything about my clothes anymore. I told him I didn't want an arranged marriage; I didn't want to be forced into marriage. I

want to make sure I meet someone I love, who has a good personality, who isn't abusive, etc. I want to make sure I pick the right man. I asked my brother if he wanted to be able to choose his wife and he said yes. Now we have a good relationship, we're close. (Interview with Hala, August 6, 2020)

Similarly, Jacques spoke about what his future might have been like had he not left the Democratic Republic of Congo.

If I were in DRC now my life will be really bad. Because there in the DRC there is no human rights. 100%. Not even a little human right because people abuse the human rights, no matter who they are. The government, police, military, leaders, they abuse human rights in general. My life would be worse because I can't get anything to help me. They would tell me to do my best. There is no help from the government. Maybe the private agencies, like MSF. If I live near there maybe I will get a little help from them. Maybe the churches or other organizations, maybe when they visit, they can buy me a wheelchair, they can give me some food. Maybe the church can give some soap or some body lotion or something but no help from the government. I can't work. People are still fleeing Congo every day. In Rwanda there is a camp that is not older than four years. Why? Because people are still leaving. Neighbor countries have so many Congo refugees. (Interview with Jacques, November 10, 2020)

Jacques first experienced human rights violations as a young refugee child when his family had to flee due to violence. In the resettlement camp in Rwanda, he continued to experience this lack of human rights as both a disabled person and a refugee. He spoke with pride and emotion about finally being seen as a human being and having human rights as a United States citizen.

I am a U.S. citizen. I got my citizenship last year. I voted this year. That made me proud. My first time in my entire life. That is my right. I just want to say thank you to America because they try to treat people equally. They try to apply equal rights. They try their best even if it's not 100%, but it's way better compared to ours. God Bless America. I didn't know if I will drive; now, I can drive. And my children were born here. Since I came here almost 7 years nobody pushed me around nobody threatened me. And I got help. I didn't have a dream. I can compare my life in Congo if I am there right now and the life I am in right now, I can't take this chance for granted. Because I saw so many things, I experienced so many things, I saw how people killed each other. I know how it is painful to be outside of your country. I know that it is painful when your country hates you and tells you that. I wish it can't happen to another person. If you are alive, if you can sleep, if you can eat, if you can say what you want to say, then say thank you to God. I'm happy with my life today. (Interview with Jacques, November 10, 2020)

Rihana spoke about how her rights and opportunities as a disabled woman changed once she moved to the United States.

I think America has a lot of opportunity. And you can change. Whatever you want to be. You have a lot of freedom; you use your force. Women like me, strong women, you learn, you get an education and go back to your country and share with people like you. Like, women there do not have an education. It's very difficult. And they marry young and if you're handicapped, your life is very difficult. But if you're like me and say no marriage, I had to change my life. It depends on your situation. A lot of people stay in Somalia, it's their country, it doesn't matter if we have a civil war. It's their country. I

hope that one day it will be a safe place. I miss the people, culture, the food in Somalia. (Interview with Rihana, November 1, 2020)

Throughout my interviews with Masuod he talked about the discrimination and prejudice he experienced as a disabled man in Afghanistan, not only at work and in his community, but also by his own family members. He shared that he did not have rights as a disabled person in Afghanistan but that changed when he moved to the United States.

The doctors here are better. In Afghanistan they don't cover anything. There aren't specialists. Here, the insurance picks me up and drops me off at dialysis. Maybe my family has a good future here. I can't work here because I go to special dialysis three times a week. I came here, the United States is a good culture. They are good to me. Everyone respects me. My human rights here are better. My rights are high. (Interview with Masuod, August 7, 2020)

Gopal explained that Deaf people in Nepal didn't have rights and were not respected. He didn't realize that laws and policies in the United States exist to both give and protect his rights as a Deaf refugee until he attended a conference and learned about the Americans with Disabilities Act (ADA).

In Nepal there were no interpreters, disabled people didn't have rights. Deaf people can't get a driver's license. In Nepalese culture those who have more money have more respect. Disabled people weren't respected. When I moved to America, I didn't know anything about ADA, rights, interpreters, nothing. When I went to the doctor with my brother, I didn't have an interpreter, so I didn't understand what was happening. Then I went to the deaf center and they asked if I have interpreters for the doctors and other things. I said no and they asked when my appointment was, and they called and told them

I need an interpreter. Even though I didn't know much ASL I understood some things like my name, birthday, etc. Later I knew to ask for an interpreter every time. Later I went to an open house at the DRC (Deaf Refugee Conference) and saw a presentation on ADA and understood my rights as a Deaf person. I was shocked! Later I went and learned more about it and the law. (Interview with Gopal, December 17, 2020)

Each participant who mentioned human rights spoke with gratitude at the opportunities they have had since arriving in the United States and with surprise and thankfulness at the realization that they have rights as disabled people, as refugees, as women, and as human beings. These stories demonstrate that human rights are not practiced worldwide as they ought to be and that many marginalized identity groups encounter violations of their rights on a daily basis. Not only were their human rights violated, but also in many cases the participants didn't even know they had rights in the first place, so they did not know how to change their situations.

# Theme 5: Changing the Narrative around Disability and Refugees

Refugee people are just human beings. (Interview with Rihana, November 1, 2020)

Some participants brought up this hope of changing the narrative around disability and refugees on their own; others, I asked for their feelings and perspectives on this topic. All of the participants shared instances of discrimination, prejudice, and human rights violations because of their disability, refugee status and, in some cases, gender. Their hopes by participating in this study are to start to challenge these narratives of pity, dependence, and helplessness and shift them towards stories of hope, respect, and courage.

Hala explained with pride how graduating from college not only changed her life, but also changed her family's and community's beliefs about Deafness and disability. Not only did she (my mom) blame herself (because her children were born deaf), but that culture tends to blame the woman, thinking she did something wrong to cause it. But they don't blame the man. My mom doesn't still blame herself. A lot has changed. She saw that I earned my degree. That really had a big impact on her. The Chaldean culture has changed, too, in how Deaf people are perceived. Now we're perceived as human beings. And my parents are proud now. When they go to church many people praise them because their Deaf daughter finished school and they ask what I'm doing now. When they say I am working everyone is so happy and proud so now my parents feel a sense of pride. (Interview with Hala, August 6, 2020)

Not only is Hala changing the narrative around Deafness within her family and community, but around disability in general. In a culture that blames the mother for past wrongdoings if a child is born deaf or disabled, Hala is showing them that disabled people have hopes and dreams and deserve the opportunity to achieve those dreams.

I'm showing them that Deaf people can do anything. A lot has changed. Also, I feel a lot of pride because I am influencing how they think, their perception of Deaf people. And now in the Chaldean community, many people have disabled children, not only Deaf, but other disabilities and they are not hiding that like before. In the past, children with disabilities were hidden away. Everyone looked down on the family and criticized them. It makes the family feel embarrassed and they don't want everyone to look at them, so they keep that child away. Now they see me, I graduated, I have a degree and a job, I can go to parties, I go do many things with my family, I don't just sit around. I use ASL and sign language to communicate with my family and other people. That

really helps other (Chaldean) community members feel confident that they don't have to hide their children anymore. (Interview with Hala, August 6, 2020)

Rihana spoke about changing the narrative around refugees and her religion of Islam, emphasizing that the media portrayal of refugees is very different from their actual experiences.

What I want people to know about refugees, I think when you see the country explosions and they say, "Who did it?" and they say the Muslim group - those people are not representative of our religion, you know. Some media is bad, like when you talk about the Middle East everything have problem, yes, we have problem, but I think those people use their own power. If you are Muslim or not Muslim you know, you are not killing. We don't agree. I think if my country is safe, I will stay in my country. Even if I didn't have opportunity, why am I refugee? Because it's not safe, my family died, I need to change my life. Refugee people are just human beings. You should look at them and what the situation is. But if you compare it to media and the refugee people, it's a big difference. (Interview with Rihana, November 1, 2020)

Rihana and Jacques both shared that they and other refugees do not leave their countries out of choice, but because they are seeking safety. If their home countries had been safer, they would have chosen to stay. That is an important point they wanted to emphasize – people are not fleeing their countries because they want to but because they have to. As Jacques explained,

People come here not because they are poor. Not because they need money. I don't need money. I lived in my culture; I know to eat I go to hunt. I'm happy with that life. But if someone threatens me, I need to go somewhere to be safe. If you can dig deep into that story you can find out something else. If you can see some refugees from Libya, they come to the US, what are you going to think about France and the US involved in

the war in Libya? Americans need to understand those people don't come here to take their jobs. They come here for security. Because where we live, people don't like each other – not because they don't but because of something else. It is corrupt. It looks the same way as why some Americans think refugees come here to take their jobs. They don't know the story behind it. That can create another hate. You hate that nation that is coming here. For sure they are not coming here to take their jobs. (Interview with Jacques, November 10, 2020)

Jacques and Rihana talked about the story of what is really happening that causes people to flee their countries, their lives, and their families. They want people to know the real story and not only what is portrayed in media.

Masuod's experience in changing the narrative around disability and disabled people was very stressful and difficult. He was unable to find work and faced discrimination when he tried to find work. Eventually, he had to offer to work without pay to show the company he was capable of doing the work and would not cost the company their project.

They don't respect these kind [disabled] of people. There is a lot of difficulty. People don't trust disabled people. I graduated from the university; I went to one company. They saw me and asked, "You can do the work?" I said, "Yes, I can do it." I found some people to go there. They recommended me. After that they hired me. It was difficult. Maybe other people, their body is okay, but they are not talented like me. They hire them. But they asked me, "You can do it? We have a big project. Maybe we will lose our project because of you, if you are here." That's not good. I'm disabled but I can do it. I told them not to pay me any money and see my work, then pay me. It was very difficult. (Interview with Masuod, August 7, 2020)

Over and over again Masuod talked about the culture in Afghanistan and the disrespect and discrimination disabled people encounter. After he became disabled Masuod lost friends and lost the respect of his family. However, he spoke with pride when explaining how he accomplished his goal of graduating from college and being employed.

In Afghanistan no one respects disabled people. They never respect me. People never invite me to be their guest. They think about me only as a disabled person, not as a person. But I showed everyone I can do anything. I came to the United States. If they see the United States in their dreams, they are happy. I came to the United States to provide for my family. I showed everyone I can do anything. (Interview with Masuod, August 7, 2020)

Similarly, Gopal described how he was treated as a Deaf person in Nepal and how he wanted to show people that their perceptions of Deaf and disabled people were wrong.

So many people lived in the camp. They didn't want to use sign language. They think if you're deaf it means you're dumb. That's their issue. That's the culture. I'm Deaf and I want to use sign and can speak a little. People called me dumb and asked why I used sign language. That really hurt my feelings. I confronted them and explained I have a job, I earn money. You think sign language is just gestures but it has vocabulary and grammar. There are many different sign languages, don't call me dumb. In Bhutan they still don't use sign language. They still think that if you're deaf it means you're dumb and they don't want to use sign language. In that culture if you're born with CP, a disability, can't walk, anything, they blame the mother. They think maybe before she had some bad behavior or actions that caused it. Sometimes they divorce and send the mother away.

Sometimes they don't want to take care of the child and neglect it. They look down on

someone with a disability, they can't go work and earn money. (Interview with Gopal, December 17, 2020)

He went on to explain the oppression Deaf people experienced in Bhutan and how he wasn't called by his family name the way his hearing siblings were because he is Deaf. This failure to acknowledge and use a Deaf person's given name serves to further dehumanize and oppress an already marginalized population.

Before in Bhutan deaf people couldn't go to school or college. They just stay home, take care of the cows, they don't earn money. They think they're dumb and call them "lata" which means "dumb". For Deaf women they call her "lati". If there is a deaf person, they don't call them by their name, they just say "lata" or "lati" (for women). They don't call them by their given name. There's a lot of oppression. It's really awful. They look down on Deaf people. Your first, second, third, fourth family names – they don't use. They don't call me Gopal. Many people still call me Kancha. My hearing brothers and sisters have the same last name but because I'm Deaf they don't use the same name for me. I thought about it a lot, all of my other hearing relatives use the same name. Why is mine different? (Interview with Gopal, December 17, 2020)

A common narrative around disability is one of pity, brokenness, and incapability. The narrative around refugees is often fear, difference, and less desirable beings. As we have seen woven throughout the participants' oral histories, these single stories rob people of dignity, create dependence on others, and emphasize our differences as human beings. The participants in this study are changing the narrative in their own lives, their families, and their communities as they continue to seek humanity, equity, and healing.

# Theme 6: Hope for the Future

I want to go back to Africa and help Deaf kids there. (Interview with Diu, December 9, 2020)

Not only did participants share their past experiences, fears, and trauma, but also many freely shared their hopes and dreams for the future. Almost all of the participants expressed their gratitude and appreciation for the chance at a new start in the United States and the opportunities they have that they might not have had if they had stayed in their home countries. However, a common theme was the desire to return to their countries in the future and work with others in similar situations as they had previously experienced. While their home countries were often dangerous and they experienced discrimination and human rights violations, they spoke of missing their countries, the culture, and pride in where they come from.

Woven throughout our interviews, Rihana talked about the lack of rights that women, especially disabled women, experience in Somalia. While extremely grateful for the opportunities she has had since arriving in the United States, Rihana hopes to someday return to Somalia to reunite with her brothers and sisters. She has not seen them since her parents died and they were separated to different caregivers. Currently, Rihana is studying for her GED and hopes to be a counselor someday. "Now I am studying for the GED. In the future I would love to study social work and go back to my home to help women. Be a counselor or something".

Diu recognized the high quality of education he and other Deaf and disabled children received in Kenya but that it is not the same for Deaf children in neighboring countries. While in the camp in Kenya he crossed the border into South Sudan and attempted to establish an educational program for the Deaf children there. However, he was caught and arrested after authorities realized he was not Sudanese. Currently, Diu is studying for a bachelor's degree in

Early Childhood Development with the hopes of someday returning to Africa as a teacher of Deaf children.

Now I'm studying ECD (Early Childhood Development), my BA again. In Kenya now the education is good. Deaf people can go to university. But in Ethiopia it's low. In South Sudan it's low. In North Sudan, low. Somalia, too. I want to go back to Ethiopia and train teachers so they can return to Somalia, North and South Sudan, and other countries in Africa. So Africa can develop because Deaf people can learn sign. I want to teach Deaf kids. I want to go back to Africa and help Deaf kids there. (Interview with Diu, December 9, 2020)

Jacques shared his hopes of using his personal experience as a disabled refugee to mentor and counsel other young, disabled men. He highly values the mentoring he received from other disabled men when he arrived in the United States – men who told him he could drive, work, have a family – all the dreams he had given up on. He hopes to encourage and inspire others in similar situations. Meeting these people changed Jacques's life and gave him hope for him and his family. As Jacques explained:

After dreaming about teaching and the dream did not come true, because of my experience, that bad life, if I can get some special training maybe I can be a mentor.

Maybe I can help people. You may see a psychologist, someone who did go to school and learned about psychology and how to talk to people. But he cannot be as good as I can be because I lived that life. I know the feelings. I know the way he feels, and I know something that can heal his thoughts. So maybe if I get the opportunity, I can be a counselor, something like that. I just like to talk to people. I can be a volunteer if they give me some training. I can do it with all my happiness. Because if I can tell somebody

and his depression can get reduced, I don't need the money. (Interview with Jacques, November 10, 2020)

Many participants spoke of their hopes and dreams when they were younger – dreams of education, family, respect, and to be valued as human beings. Participants shared what their lives would have been had they stayed in their home countries and some had given up on their dreams. After resettling in the United States, they felt safe to dream again and are taking advantages of all the opportunities they have here to pursue those dreams. A common thread among participants is using their experiences here and returning to where they came from to give others hope for the future. This leadership by those most affected is one of tenets of disability justice and through this work they are changing the narrative for disabled people around the globe.

#### **Summary of Findings**

This oral history project explored the narratives of disabled refugees to better understand their experiences as told from their perspectives and in their own words. Some of the participants had very similar experiences in the refugee camps and resettling in the United States, while others differed greatly. Six common themes emerged from their stories: 1) claiming education as a human right, 2) inequities in the resettlement camps, 3) lack of knowledge and training of resettlement workers, 4) human rights realized, 5) changing the narrative around disability and refugees, and 6) hope for the future. The themes and findings that emerged from this study reveal the conditions for disabled people living in resettlement camps and shed light on the challenges and barriers they experienced during the resettlement process. The participants' stories provide insight and implications for improving the resettlement experiences for disabled refugees in both policy and practice. These recommendations for current practice and ideas worth exploring through future research are discussed further in Chapter Six.

#### **CHAPTER VI:**

# SUMMARY, DISCUSSION, RECOMMENDATIONS, AND CONCLUSION Summary

This oral history study examined the lived experiences of six disabled refugees who have resettled in various regions of the United States. The results of this study highlight six common themes that emerged from the participants' stories: 1) claiming education as a human right, 2) inequities in the resettlement camps, 3) lack of knowledge and training of resettlement workers, 4) human rights realized, 5) changing the narrative around disability and refugees, and 6) hope for the future. Findings from this study suggest that barriers exist that impede independence and self-determination, both in the displacement camps and upon resettling in the United States.

Participants shared freely how these barriers created feelings of isolation, dependence, and frustration. All participants had the shared experience with the resettlement agencies and caseworkers in terms of their lack of knowledge and resources to provide appropriate supports and meet their needs as disabled people. Participants emphasized the support they received from family and friends during flight, while living in the camps, and when they arrived in the United States. This community support played a key role in each participants' lives and created a more positive resettlement experience for them overall.

This chapter begins with a discussion of key findings by answering the research questions that framed this study and contextualizing the findings within the existing research presented in the literature review. In the subsequent section I offer recommendations for practice and future research. Results of my study have important implications for current practice and future research, based both on my own interpretation and analysis of the data along with

recommendations from the participants themselves. Lastly, the study concludes with my own personal reflections as the researcher.

#### Discussion

In this section, I revisit the research questions that guided this study and answer each of these questions by synthesizing the data and findings from this study and comparing it to the existing literature outlined in Chapter 2. The participants in this study willingly shared their experiences, both positive and negative, as disabled refugees at different stages of their flight and resettlement. They openly discussed the hardships and barriers they encountered and their feelings of frustration, isolation, trauma, and despair. But each participant also described their gratitude towards the people who helped and supported them along their journey, the opportunities they have in the United States, and their future hopes and dreams.

# **Lived Experiences During Displacement**

The first guiding question for this study was, "How do disabled people describe their experiences living in displacement camps in regard to accessing programs, resources, health care, education, and other services?" The four participants who lived in resettlement camps each described how difficult life was for everyone living in the camps because of inadequate food supplies, poor living conditions, and lack of money. Disabled people experienced even more difficulties and barriers in terms of accessing education, physically inaccessible spaces, and language and communication barriers for Deaf participants. As disabled people, they all have unique support needs and require specific accommodations or specialized equipment which were often not available in refugee camps or other emergency placements. The infrastructure of resettlement camps does not support accessibility and independence. This stems from lack of funding and resources, insufficient knowledge of the needs of disabled camp residents, and often

the immediate urgency to construct a camp, which does not allow for sufficient planning and development. Resettlement camps are constructed to meet the immediate, basic needs of those who live there.

However, as we have seen in this study, what is meant to be a short-term solution often becomes a way of life for the residents. Gopal grew up in a resettlement camp and did not remember another way of life prior to coming to the United States. Jacques entered the resettlement camp in Rwanda as an non-disabled child and had to learn how to navigate life as a disabled adult while living in an environment that was not equipped to support this transition either physically or emotionally. These narratives demonstrate the need to plan not only for disabled people' immediate needs, but also for the long-term situations in which they find themselves. Providing appropriate support and accessibility is key in supporting the independence and self-sufficiency of disabled people, which in turn leads to them becoming active, contributing residents of the camp. The participants in this study did not become dependent on others out of personal desire or lack of motivation; rather, they had no other choice because it was the only way to get both their basic needs met and to survive in an already difficult living situation.

## Intersectionality – Gender and Disability

The two women participants experienced further discrimination as a result of their intersecting identities of gender and disability. Rihana spoke openly about how women in her culture do not have any rights, and the situation is even more dire for disabled women. As a disabled teenager with no family to support her, Rihana faced the decision of being forced to marry or to flee Somalia. Hala's family had difficulty supporting her choices to be an independent Deaf woman, but with time she proved to them that she was determined to fulfill her

dreams of getting an education and having a career. Rihana's and Hala's stories show us that it is not only policies that create further discrimination towards women, but also deeply rooted cultural beliefs about gender roles and disability.

# Leadership by the Most Impacted

The second tenet of a disability justice framework is leadership by the most impacted (Sins Invalid, 2019). Both Diu and Gopal demonstrated this leadership by using their negative experiences in the camps to support and advocate for other disabled residents. Gopal asked for employment in the camp disability center, not a volunteer position. He personally related to the needs and experiences of the other members in the center and used that knowledge to create change. Diu took his own negative educational experience and became a teacher so he could improve the educational experience for Deaf children in Kenya and South Sudan. Both participants saw a need within their communities and took on leadership roles to fill those gaps and change the experience for other Deaf residents. By doing so, they also met the personal need of earning an income to provide for their families. These examples of leadership by the most impacted demonstrate that when disabled refugees are empowered and supported, they can and will work to make change within their communities.

## Barriers Hinder Independence

Findings from this study align with existing research that noted how the infrastructure and layout of camps often impeded access to facilities (Shivji, 2010). This includes dirt roads with stones and potholes, narrow doors, and long distances to schools and other facilities. These inaccessible spaces reduced independence for all participants in both Shivji's (2010) study and this one, causing them to become passive, dependent residents of the camp. They were forced to rely on others for their basic needs such as food and self-care.

Not only physically disabled participants experienced this dependence on others, but

Deaf participants were also forced to rely on the help of family and friends to access information.

Diu and Gopal experienced the same linguistic barriers to education as the Deaf participants in

Elder's (2015) study, where Deaf participants were required to attend school but were not

provided interpreters or teachers who knew sign language. Deaf participants in both studies were

held responsible for the content of the lessons in order to pass their classes; however, no supports

or accommodations were in place to help them. This caused frustration and increased stress,

which almost led Gopal to give up on his education.

One issue this brings up is inadequate resources and training for teachers on how to educate and support disabled learners. Diu mentioned inclusive education in the camp in Kenya; however, it raises the question of what inclusive education encompasses. Inclusive education is not simply allowing or requiring all students to attend school without providing appropriate support and accommodations for the students and staff. Teachers need training, resources, and support on how to include all learners. Diu mentioned there were people from many countries residing in the camp where he lived. The linguistic and cultural needs of the learners, gender, religion, and other identities all need to be taken into consideration, as well as the support needs of any disabled learners.

The female participants' experiences in this study corroborate Pittaway and Bartolomei's (2001) report that refugee women face increased discrimination and that resettlement policies discriminate against women through the use of gender blindness. This gender bias and discrimination is further outlined in Erevelles and Minear (2010) who use Critical Race Theory to illustrate how individuals located at the intersections of race, class, gender, and disability are viewed as non-citizens. Treating disabled refugee women as non-citizens grossly violates their

human rights and further emphasizes the discriminatory practices that view them as less desirable citizens and human beings. Hala and Rihana both expressed their personal encounters with this, and that they were viewed as less than simply because they are disabled women.

Previous studies (Abuya and Ikobe, 2010; Kett & van Ommeren, 2009; Mirza, 2011c; Shivji, 2010) cited the challenges and difficulties disabled people experienced living in resettlement camps. Participants in the studies listed here and in this current study report that barriers existed in all aspects of life, including environmental, institutional, and attitudinal barriers, which hinder independence and self-reliance for disabled people living in the camps. Shivji (2010), Sivunen (2019), and Handicap International (2015) outlined these same barriers in their respective studies. In order to begin to eliminate and dismantle these barriers, disabled refugees need to be at the forefront of refugee and displacement discourse and decision-making. Their unique needs are often overlooked in humanitarian and emergency contexts; therefore, these barriers will continue to exist if their perspectives and experiences are not taken into consideration going forward.

#### Empowering Disabled Refugees to Create Change

Mirza's (2011b) study on grassroots and disabled refugee-led efforts in displacement camps found that these efforts, led by the most impacted, have the potential to be the most successful. Disabled refugees understand firsthand what needs are not being met, the barriers that exist in having their needs met, and the discrimination and oppression this population experiences in daily life. Gopal's efforts in the camp in Nepal further support Mirza's (2011b) study. He took his own experience, recognized what needed to be changed for other Deaf and disabled residents and acted on it. The perspectives and ideas of the disabled camp residents are invaluable and need to be included in the discourse and in policy making. Excluding their unique

perspectives leads to further marginalization and human rights violations, because without them we cannot truly understand their lived experiences and unique needs.

# Improving CRPD Compliance

The results of this study also support Duell-Piening's (2018) recommendation of a global approach to improve CRPD compliance in resettlement programs, including the establishment of a Resettlement Submission Category for disability. As of February 2020, 181 States have ratified the CRPD, meaning these States have committed to be held responsible by the global community for the obligations outlined in the Convention (Disabled World, 2020). Of the participants' home countries and their countries of refuge, the only State which has not ratified the CRPD is the United States. Therefore, what these States have committed to and the reality of what is happening are in stark contrast. More global accountability and improving CRPD compliance on a global level by establishing guidelines, providing training to agencies and organizations, and reallocating resources would improve the resettlement experiences of disabled displaced people regardless of which country they migrate to.

Article 11 of the CRPD recognizes that disabled people are at greater risk in situations of emergency, conflict, displacement, or a combination of these (Smith-Khan et al., 2014). The CRPD advocates for disabled people to be treated with respect and dignity and the fulfillment and enjoyment of their human rights, rather than viewing them as objects of pity or needing charity. We see from the participants' narratives in this study that this is not the reality of what is happening for disabled displaced people. This is reflected in both Jacques's and Rihana's stories. Because they are disabled, they were not allowed to work and were forced to rely on others to meet their basic needs, not only as disabled people but as human beings. Jacques was even forced to rely on others to bring him food, which is dehumanizing and increased his feelings of

inadequacy and depression. Neither participant had wheelchairs that fit appropriately which would have allowed for more independence. Diu and Gopal did not have interpreters, which forced them to rely on friends to access their education. All of these barriers caused additional stress and frustration for every participant, and also decreased their feelings of self-worth.

The four participants in this study who lived in the resettlement camps - Jacques, Rihana, Gopal, and Diu - all wanted to support themselves and their families, contribute to their communities, and be independent and self-sufficient. However, their needs as disabled people were overlooked and unmet, and multiple barriers existed that prevented them from achieving this. The systems, policies, and cultural norms around gender and disability all work together to create further oppression and marginalization of disabled residents in the displacement camps. The global community needs to work towards humanizing the systems, policies, and procedures that serve to further exclude disabled refugees in the resettlement camps and beyond.

## **Lived Experiences in the United States**

The second question that guided this study was, "How do the participants describe their resettlement experiences upon arriving in the United States and the ease and/or difficulty of accessing programs, resources, health care, education, and other services?"

Every participant in this study reported experiencing barriers during their resettlement process as a result of their disability – the same barriers outlined in Handicap International's 2015 study discussed in Chapter 2. Deaf participants faced informational and institutional barriers because they did not have access to interpreters, nor did they know that they had the right to request interpreters. Because of this, Diu lost out on work opportunities which led to added stress about how to support his family. Gopal described his feelings of isolation and confusion because the resettlement classes he and his wife attended both in Nepal and in the

United States did not have interpreters. Therefore, it took him longer to learn how to navigate life in America than the other refugees in the class, who learned important information, customs, and cultural norms. Rihana and Jacques experienced environmental barriers leading to inaccessible and potentially dangerous living spaces. Masuod described his experience with attitudinal barriers, not only by members of his own refugee community, but also by the resettlement caseworker assigned to work with him. Hala shared a similar experience as a high school student and being bullied by others because she did not know ASL or English well. Each participant expressed their gratitude at the opportunity to resettle in the United States and feel safe and secure; however, these negative experiences caused by systemic barriers created additional stress and feelings of inadequacy.

# **Exclusive Systems and Practices**

Each participant had friends, family, and volunteers who helped them access resources, information, and the specialized equipment they needed. It's hard to know how or if the resettlement experiences of these participants would have been different had they not found support in their communities. One of the common narratives around refugees and disability is of need and dependence; however, I argue that this is caused by failures in the system and exclusive policies and not because of personal values or the desire to depend on others. Participants in this study all expressed the desire to work, get an education, support their families, and be independent. What hindered them in doing so was not their personal drive and motivation, but lack of appropriate support and accessibility that allowed them to be independent and self-reliant.

# Refugees as Agents of Change

Since resettling in the United States, each participant has become involved in their local refugee and disability communities and have worked to change these narratives around disability

and refugees. Hala graduated from college and works full-time as an ASL instructor. Through this, she has shown others in her family and Chaldean community that disability does not mean helplessness and dependence. Jacques has a family who he works to support and has become a leader within both the refugee and disabled communities. For the first time in her life, Rihana has the opportunity for an education and is working hard to obtain her GED. She is heavily involved in her state and local wheelchair basketball associations and is the first, if not only, Muslim woman to join. Once Gopal became more settled and learned ASL he returned to the resettlement workshops to explain the impact his experience had on him, and he now works to change that experience for other Deaf newcomers. All of these stories speak to the participants' strength and perseverance and prove that, with the appropriate support and resources, disabled refugees can have a more positive resettlement experience.

Sivunen's (2019) study on Deaf asylum seekers in Finland reported similar findings; linguistic barriers prevented participants from taking part in activities and services. Participants either were not aware of activities and programs because the information was not announced in an accessible language, or the programs themselves were not accessible, as we saw with Gopal and Diu. Hala was the only participant who resettled in the United States as a minor; therefore, her experience differed in comparison to other Deaf participants because she was under the care and guidance of her parents. Because she will still a teenager, she did not have the added stress and pressure of trying to find work to support herself and her family.

#### Refugees as Knowledge Producers

Shivji (2010) found that displaced people are often seen as passive recipients of aid and assistance, versus active participants who may be able to contribute ideas, skills, and expertise. As stated earlier, I argue that this misperception is due to systems and policies that hinder

independence and self-reliance, versus the individual drive and desire. One of the core tenets of a Critical Refugee Studies framework is how to access this refugee knowledge (Espiritu, 2014) and welcome the knowledge and skills they bring to our communities. When the stories of disabled people and refugees are amplified and their perspectives are welcomed and taken into account, the barriers that exist to allowing for full participation in society are more likely to be dismantled.

Many refugees have successful careers in their home countries before being forced to flee. They bring with them invaluable expertise and skills that can and should be sought out in their countries of resettlement. Masuod is currently undergoing dialysis treatment and on the list for a kidney transplant. While he appreciates the financial support he receives from the government during this time when he cannot work, he wants to work and support his family independently. He mentioned security work as an option in the future; however, Masuod has a degree in Computer Sciences and experience in the field of Information Technology. If he can find a way to work in his career field, it would be much more sustainable for him and his family, thereby decreasing his need for government dependence and support.

#### Disability Rights Awareness

Diu's experience of missing out on work opportunities because of not having interpreters is reflected in Mirza's (2012) study on disabled refugees' access to occupational participation. Mirza's (2012) study suggests that the lack of appropriate supports and services needed to develop occupational skills can lead to further feelings of inadequacy and isolation. Most refugees resettle in a new country with hopes and dreams which often include getting an education and having a career with which they can support themselves and their families. Since

government support is finite, when it runs out resettled refugees must find a way to support themselves independently.

However, this challenge becomes even greater when supports and services are not in place that allow this to happen. Not only do disabled refugees need to understand laws such as ADA when they resettle in the United States, but they also need to know what their rights are as human beings, and as disabled human beings, and what to do when those rights are being violated. While all educational and employment settings should be aware of ADA and follow the laws, that is often not the case. More training and accountability need to occur within these settings as well, to make them more accessible and welcoming.

Human rights are fundamental rights that cannot be earned or taken away. However, the responsibility to ensure their rights are being upheld should not fall solely on the disabled and refugee communities; it is our responsibility as a society to transform these exclusive systems and practices that hinder full participation in society. We need to work on making systematic changes towards inclusive practices in all aspects of society. A human rights-based approach considers disabled people as decision makers, citizens, and rights holders. As such they need to be centered in the decision-making processes around policy and practice.

## **Resettlement Experiences**

The final question was, "How do the participants assess their experiences with resettlement agencies and caseworkers in terms of being able to meet the unique needs related to their impairment?"

The overarching consensus among participants was that the resettlement workers from the various refugee agencies that sponsored them were not knowledgeable in how to meet their needs or did not have the resources to do so. Most participants relied on the help of volunteers, family, or friends to assist them with gaining the specialized equipment and services they needed. In both Jacques's and Rihana's experiences, the resettlement workers did not have training or resources in how to provide safe, accessible housing or a wheelchair that fit them properly. Both participants relied on the knowledge and expertise of a volunteer who advocated for them to get an accessible apartment. This volunteer also connected them with other disabled people in their community, which was key in helping them realize not only the opportunities available to them, but also increased their own ideas of possibility that had previously not been conceivable. Coming from cultures that view disability as a curse or disabled people as unable to be self-sufficient, participants had to shift their own mindsets into realizing they have opportunities and the ability to be independent, support their families, and pursue their goals. Jacques spoke candidly about this realization when he met other disabled people in his community who work, drive, and have families. It was the first time he felt hope about his own future.

## Community Support

Without the guidance and mentorship of the disabled community, Jacques's experience would have been very different. Resettlement agencies and caseworkers should have knowledge of the unique needs of disabled refugees, not only their physical and linguistic needs, but their social-emotional and mental health needs as well. In Jacques's case, he became disabled as a young adult and was grappling with the depression and stress that accompanied the realization that his life was not going to be how he had envisioned. Being connected with the disabled community changed his outlook and his life, and therefore changed the future for himself and his family.

Similarly, Diu and Gopal turned to friends, family, and their local Deaf communities to help them transition into life in a new country and culture. Diu received assistance from his ASL instructor with getting a videophone – something that is free to any Deaf person in the United States, if they know how to access it. Resettlement workers need to be aware of these services in order to better assist refugees throughout the resettlement process. Deaf people often need specialized equipment such as doorbells, videophones, and alarm clocks. These are often provided free of charge through local Deaf agencies; however, if Deaf refugees don't know how to access these resources it may result in a delay in receiving them.

Most larger communities have a Deaf agency that can provide these and other resources to Deaf community members. Collaboration between the Deaf and resettlement agencies will make the transition to life in the United States easier and less stressful for Deaf refugees.

Services often provided through these agencies are specialized equipment and technology, ASL classes, counseling and mental health services, and interpreting services. Deaf refugees most likely will not seek out these agencies and services on their own, because similar support systems did not exist in their home countries or in the resettlement camps; therefore, they need to be guided and supported in accessing and utilizing these community services and resources available to them.

For Rihana and Jacques, safety was a concern. Rihana mentioned the dangers of trying to cook on a high stove from her wheelchair. Jacques was left alone hours a day, unable to use the bathroom or cook for himself while his brother was at work. Without a videophone Deaf refugees may be unable to call 911 or other emergency services if necessary. These concerns are not simply matters of access and making life easier, but of safety and overall well-being.

Connecting disabled refugees with members of both their local disabled and refugee

communities is an integral part of the resettlement process as we have seen from the participants' narratives in this study. Each participant expressed how important this piece was for them and almost every participant is now doing their part to provide a similar experience for other disabled newcomers in their communities.

# Disability Rights Are Human Rights

In many countries around the world disabled people have very limited rights. The participants' narratives reflected this fact, as they described realizing they had rights for the very first time. When Gopal learned about the ADA, he realized he had the right to request interpreters for the doctor, meetings at his children's school, and job interviews. Gopal is the only participant who mentioned attending a resettlement workshop when he arrived at the United States; however, its inaccessibility due to language barriers left him feeling frustrated and confused. Since these workshops are part of the resettlement process for all displaced people upon arrival in the United States, a discussion about ADA, rights as a disabled person, and how to access available resources needs to be included. It begs the question whether or not they are physically accessible- for disabled refugees unable to drive: Is transportation provided so they can attend? Are accommodations and supports in place for visually impaired participants? Holding the workshops and providing the information are not enough and essentially ineffective if participants cannot access and understand the information being presented.

This dependence on others limits one's ability to live self-determined lives. Participants in Elder's (2015) and Roberts and Harris's (2002) shared similar stories of inadequate accommodations which created barriers to independence. Disabled people experience difficulty accessing assistance programs, largely due to societal, environmental, and communication barriers (Pearce, 2015). Recurrent themes in both this and Roberts and Harris's (2002) study on

disabled refugees and asylum seekers are: inadequate housing, difficulty with communication, and feelings of isolation. Gopal described the isolation he felt when trying to learn to navigate life in the United States. He later recognized that same isolation in other Deaf newcomers in his community, so went out into the community to meet with them, encourage them to attend classes, and even picked them up if they needed a ride.

Roberts and Harris (2002) found that service providers do not have the training and knowledge of needs of disabled refugees; therefore, they struggle to meet their needs appropriately. We see this come up again and again in the participants' narratives. Gopal took action by returning to the teachers of the workshop and explaining his experience, and then working with that same organization to change the experience for others. This form of advocacy is critical in effecting change in both policy and practice. Gopal recognized a problem and need in his community; as part of the solution, he became a leader in his Deaf refugee community. Now he is working to mentor and encourage other Deaf refugees to take on more leadership roles and become active in the process of making change.

This study highlights the experiences of disabled refugees throughout their journey of flight and resettlement in the United States. Each participant expressed feelings of gratitude for their opportunities in the United States and for those who helped them along the way, as well as their hope and dreams for the future. Yet they also repeatedly noted the difficulties and barriers they experienced during each stage of their journey. These barriers exist because of cultural beliefs around gender and disability, systems and policies in place that impede full participation and access, and violation of the basic human rights of disabled refugees in their home countries, countries of flight, and in the United States.

This study is unique because of its use of oral history to explore the lived experiences of disabled refugees. Oral history allowed for much deeper, more personal narratives and interactions with the participants because they were provided a space to share freely and openly. This oral history study is a collaborative project *with* disabled refugees; therefore, they had the power to control the narrative and tell their stories in their own words. Compared to more traditional qualitative interview methods, oral history gives primary agency to the narrators and serves to honor their voices and stories. As an oral history project, this study fills a gap in existing literature and humanizes the participants to a larger degree than may have been possible using more traditional interview methods.

This study corroborates existing research that identify the challenges disabled refugees experience both in the resettlement camps and upon resettling in the United States. These challenges are a result of environmental, attitudinal, language and communication, and societal barriers. What separates this study from existing literatures is that it also highlights the resilience and resistance the participants demonstrated throughout their journeys and continue to demonstrate through their resettlement in the United States. In spite of these barriers and obstacles the participants described that caused dependence on others in almost every aspect of their lives, each participant emphasized their desire for autonomy and dignity. Their narratives speak to each participants' resilience and resistance and how they used their experiences to become agents of change within their communities.

### **Recommendations for Practice**

Participants in this study entrusted me with their stories not only of trauma, despair, and loss, but also of hope, gratitude, and triumph. Their willingness to share their lived experiences came from the desire to create awareness of the situation of disabled refugees and change the

narrative around disability and displacement. This research study aims to fill a gap in existing literature on disabled displaced people, but more research in this area is still needed. While participants in this study may be considered successes among their families and communities, many untold stories still need to be heard in order to truly understand the reality of what is happening both in the camps and through the resettlement process.

# **Cross-collaboration between Resettlement and Disability Organizations**

This first recommendation stems from an emergent theme in the interviews and was a recurring recommendation from the participants themselves. Participants shared their experiences with resettlement workers who did not know how to support their needs as disabled people, whether by helping them find accessible housing, providing interpreters or teaching participants how to request interpreters, or assisting with adaptive equipment such as wheelchairs. More training and cross-collaboration are needed for both humanitarian staff and disabled person's organizations, as well as increased awareness and understanding of disability and the needs of disabled displaced people. This recommendation is essential to help provide better access for disabled people, overcome barriers that impede independence and self-sufficiency, and facilitate a better resettlement experience.

Current policies and practices often overlook the unique needs of disabled displaced people, and lack of resources or inadequate distribution of resources contribute to continued marginalization and oppression of this group. Additionally, disabled people need to be aware of their rights and how to recognize when these rights are not being upheld. Resettlement workshops should include discussions on ADA and IDEA (Individuals with Disabilities Education Act) for parents of disabled children.

## **Prioritizing Inclusion and Accessibility**

Only one participant mentioned inclusive education in the camps; however, ensuring inclusion for all children must be a priority - not only in education but in all aspects of the camp and resettlement processes. Providing an inclusive and quality education for everyone has the power to create knowledge, reduce social inequities, and break down barriers to opportunity. Inclusive education means providing not only physically accessible spaces, but also adapted curricula and training and supporting teachers to meet the needs of their students. The participants who received an education in the camps were grateful for that opportunity, because it was not available to everyone. However, they also shared their frustrations with the educational system as well as with lack of access to instruction and information because there were no interpreters or trained teachers of the Deaf. Teachers in the camps need to receive training, resources, and support in how to make education accessible and equitable for everyone.

When considering inclusive education, the differing needs of disabled girls and women, religion, impairment type, and other intersecting identities must also be taken into account. These intersecting identities lead to increased exclusion and marginalization and one cannot be separated from the other.

# **Mental and Emotional Well-being**

Refugees and migrants flee their homes to escape violence, persecution, and human rights violations. Many have seen death, experienced torture, left behind family members, and been injured or disabled themselves. All of these experiences can cause severe trauma, depression, and other emotional distress. Participants in this research who mentioned their mental and emotional distress, depression, and feelings of despair did not receive services or help to work through this trauma, either in the camps or upon resettling in the United States. The mental health needs of all refugees and displaced people must be prioritized by providing

trauma-informed care, counseling, and access to mental and emotional health providers and services. In many cultures, discussion of mental and emotional health is taboo and displaced people who need support in this area may not know how to ask for it, or even how to recognize and name it. Part of the intake process should be to address trauma and emotional wellbeing. This is especially true for displaced children who may have lost parents, been separated from their parents or siblings, or experienced violence or abuse.

# **Address the Root Causes of Migration**

Perhaps most importantly, the international community must address the root causes of migration. People are fleeing their homes and countries out of desperation and as a last resort as they seek safety and well-being for themselves and their families. These root causes of migration, many of which were outlined in Chapter 5, must be addressed at the local, state, and international levels. Militarization, human rights violations, and violence are driving forces for migration. Governments must be held accountable for upholding human rights for every citizen as outlined in the UDHR, CRPD, and other human rights treaties and conventions.

One facet of this is human rights education for all citizens. In order to recognize when one's rights are absent or being violated, one must first understand that they have rights and what those rights are. Incorporating human rights education in all school curricula is an important start. However, adults need to be aware of their rights and the rights of their children and other family members so that they can work towards change in their communities as well.

### **Recommendations for Future Research**

# **Training and Cross-Collaboration**

Mirza (2011b) and Handicap International (2015) reported on the knowledge of resettlement workers regarding disability and meeting the unique support needs of this group of

refugees. However, as evidenced from this study, resettlement workers lack sufficient training, knowledge, resources, and expertise in this area. Current policies and practices often overlook the unique needs of disabled displaced people, and the lack of resources or inadequate distribution of resources contribute to continued marginalization and oppression of this group. Conducting more in-depth research on this topic would shed light on specific areas of need and work towards changes in policy and practice. It is critical to include the perspectives and experiences of disabled displaced people in this research.

In Handicap International's 2015 Disability in Humanitarian Contexts survey, 56% of humanitarian workers recommend prioritizing improved coordination between mainstream actors, specialized actors, and DPOs (Disabled Person's Organizations). Eighty five percent of responses by humanitarian workers recognized the increased vulnerability of disabled displaced people, but 92% feel that the needs of this group are not taken into account in humanitarian situations (Handicap International, 2015). This data is reflected in the participants' narratives as well and further supports the need for change.

# **Parent Perspectives**

My interest in this research stems from my work as a special education teacher in a region of the United States where a large number of refugees have resettled. As a teacher, I attended many intake meetings for students who had recently arrived who had disabilities. Listening to their parents' stories and their experiences having disabled children in their home countries, in the resettlement camps, and now as they are resettling in the United States, I realized this is an area that needs more research and awareness. Parent perspectives would provide important insight for professionals, educators, humanitarian workers, and resettlement

workers on what the needs are of disabled children and how to work collaboratively to meet those needs.

When families with disabled children resettle in the United States, they have to learn to navigate not only an unfamiliar educational system, but also a complex special education system. Many families come from countries where cultural norms trust the teacher and the system and parents do not question or challenge the services their children receive. Some children may have never experienced formal education at any time; therefore, parents are learning not only how to live and adjust to a completely different culture, but also how to learn how to support their child's education for the first time. Additionally, families may come from countries where their disabled child could not go to school and are now in a country where it is mandatory. This may require a shift in perspective and attitude from one of believing their child is not capable of learning to one of believing their child can participate and learn. In order to facilitate these shifts and transitions it is important to understand the parents' perspectives and experiences and take those into account when working with refugee and immigrant families of disabled children.

### **Conclusion**

It was an honor and privilege to collaborate with the participants in this study and be entrusted with their stories not only of trauma, despair, and loss, but also of hope, success, and perseverance. When I began my doctoral career at the University of San Francisco I had no idea this would be the end result. The topic for my dissertation did not reveal itself until almost the end of my coursework as a result of my work and a course I took in Disability Studies. This course completely changed my perspective on disability and caused me to challenge how I think and interact as an educator in the field of special education.

Conducting such personal, intimate interviews in the midst of a global pandemic was especially challenging. Face-to-face interviews were not possible, and the intimacy was lost through technology. However, I gained the trust and friendship of some of the participants and continue to be in touch with them, in some cases working together on a committee for the first World Deaf Refugee Day event that will take place in June 2021. Gopal is one of the visionaries of this event. After he learned about World Refugee Day, he wanted to plan an event that focuses specifically on the unique needs and perspectives of Deaf refugees. He is working tirelessly with local organizations and the Deaf community to make this vision a reality.

No one chooses to be a refugee. People become refugees not by choice, but by circumstance. My purpose in conducting this research study was to provide a safe, brave space for disabled refugees to share their stories. The participants in this study have shown that they are changing the narrative around disability and refugee and, in doing so, working to dismantle existing barriers that hinder independence and self-reliance.

Yet I caution us to be careful when considering the representation of disabled refugees and the common refugee tropes that are prevalent in society. While the stories we read in this study are inspirational and the participants have shown us resilience and perseverance, we need to be careful not to take their stories as "trauma porn" or "inspiration porn." For participants and disabled refugees around the world, their resilience and trauma are not for our entertainment and inspiration. They are more than stories about pain, suffering, and resilience. Their stories deserve to be told to change the narratives around disability and displacement. Every disabled person is unique. Every refugee is unique. However, understanding their shared experiences is instrumental in supporting the success and self-determination of disabled refugees.

#### **EPILOGUE**

I want to take this opportunity to further highlight the work Gopal is doing not only in his own community but also in the greater Deaf refugee community. Every year in June, refugees are recognized worldwide through World Refugee Day. When Gopal learned about World Refugee Day, he reflected on his own experiences as a Deaf refugee and saw the need for a similar event that focuses on the unique needs faced by Deaf refugees and vulnerable Deaf immigrants. Gopal, along with another Deaf refugee and a Deaf refugee advocate, is organizing the first World Deaf Refugee Day (WDRD) which will be held in Lancaster, Pennsylvania, in June 2021. One of the primary goals of WDRD is to foster an understanding of strategies and programs that promote inclusion and collaboration with various agencies. This aligns with one of the needs identified by this study.

I met Gopal through a friend who was previously involved with the WDRD planning committee. After meeting Gopal and interviewing him as a participant for this study, I was asked to join the committee and have since become the program coordinator in charge of presenters and workshops. Through weekly planning committee meetings, I have seen firsthand the grassroots work Deaf refugees are doing to create awareness about the situation for Deaf refugees and immigrants and also to fill the needs that were not met in their own resettlement experiences.

The role of the WDRD coordinators is to mentor and teach the Deaf refugee committee members the various roles and responsibilities that go into coordinating a conference or event, with the goal of them taking the lead for the 2<sup>nd</sup> annual event. Many of the workshops and presentations will be led by Deaf refugees from countries around the globe, most of whom do not have previous experience even attending an event such as WDRD let alone presenting or leading

one. This event gives primary agency to the Deaf refugees themselves and they have been involved in the planning and decision making from day one. This is a perfect example of leadership by the most impacted and viewing refugees as knowledge producers.

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**APPENDIX: ORAL HISTORIES** 

**Diutay** 

AGE: 36

OCCUPATION: Teacher

HOME COUNTRY: Ethiopia

Diu shared his life story matter of factly and openly. Although he primarily used ASL throughout the interview, now and then some Kenyan Sign Language was thrown in; however, it did not hinder our communication nor my understanding of his story. Diu prefers to be called Ustaz Diu, Ustaz meaning teacher in Arabic. Diu's story is filled with tragedy and loss — of his seven family members, only he and one of his brothers are still living. After seeing his parents and brother brutally gunned down by the Ethiopian police, he and his remaining brother fled to the city, only to be arrested and tortured. They knew the only way to survive was to flee Ethiopia. The Catholic church assisted them in getting to the refugee camp in neighboring Kenya. In college, Diu studied to be a teacher and later returned to the refugee camp to teach the Deaf children there. Now resettled in the United States with his wife and four children, Diu's passion for teaching continues and he hopes to return to Africa someday to continue teaching there.

My name is Diu N. I was born in 1984. I'm married and have four kids. I was born hearing. From one-eight years old I was hearing. Then I became sick. I had pain in my wrists and head, my body was very hot. Then I got better but I became Deaf. I could speak and lipread.

My family had seven people. Five kids and my parents. The firstborn was a girl. At that time, we stayed near the border of Sudan and Ethiopia. My sister married a man from Sudan and moved there. Then Sudan started a war and my sister, and her family moved back to Ethiopia as refugees. That was in 1991. The camps were destroyed. North and Tigray closed, and all the camps were destroyed. So, my sister crossed back into South Sudan to go home. An airplane from North Sudan flew over South Sudan and dropped bombs. My sister and her two kids were killed. The third sibling was also girl. She was married, too, and lived in Sudan. She had four boys and two girls. When North and South Sudan separated, she stayed in the North. Later she went to South Sudan. When war started again in 2013, she fled to a refugee camp in Ethiopia.

She became sick and had a cough. I believe she died around 2017-2018. Her husband was sick and died, too. I took care of her kids in the camp until I came to America.

My second brother, we grew up together. We were close in age and we stayed with our mom and dad. Until 2000 we stayed with our parents near the Ethiopian border. In 2005 there was not a war in all of Ethiopia only in my region. Why? Because of my second brother. He was a rebel and fought against the government. My brother tried to get out of the Army, so he hid in a tree and stayed. He couldn't come home. Why? The government was listening and there was fighting. Then he came home to visit my family.

I was there. The government heard he was there. My brother stayed a short time then left. The government came to our house. They brought many soldiers from the Army. He asked my father if my brother was coming to the house. My father said no. Why? If he said yes, he knew they would shoot him. They knew he already came. And they didn't talk anymore. They shot my parents and my second brother. My other brother was a businessman, and his house was near my parents' house. He heard the guns and he and I ran and escaped. So now there are only two living siblings. I am the youngest. My brother is in London and I came to America.

### WE THOUGHT WE WOULD DIE

When the rebels shot my family my brother and I ran to a city named Gambella. We thought maybe the government wouldn't find us there. We arrived and my brother, a businessman, decided to sell cows to earn some money. We sat outside and waited for the clients to come and buy cows, but while we were selling cows the government soldiers came. They saw me and my brother and knew about our family and that they were already killed. So, they hit us with the butt of their guns.

They hit us in the neck, in the head, everywhere. They beat us and beat us. I was bleeding from my nose and ears. Some people died. They put us in their car and drove us to the jail. I woke up 2-3 hours later in jail. I had a little bit of money from selling cows. The police thought I stole the money. They took us from our cells and put us in a dark room and tortured and beat us then put us back in the cells. The next day they did it again. For seven days. My brother and I thought we would die. We had to think about how we could survive. My brother said to negotiate with the jailers. To give them some money so we could go free. So, we talked to them in private and they accepted the bribe. They let us out. But the other prisoners saw us leave and they forced their way out. They broke the door and escaped. They called the army, and they came and started shooting at us. My brother was shot in the leg. He couldn't walk. I carried him into the jungle, and we hid. The soldiers didn't see us, and they left. We hid in the forest until dark. We left the jungle and walked to the road and waited for a car. A car from the Catholic church stopped and asked if we had a problem. I explained and they helped me with my brother.

They put us in the car and drove us to Addis Ababa. It's a very big city. There we went to a hospital named Kenya University Hospital. We went in and they gave my brother so many shots. We stayed for one month until his body healed, and he was healthy and strong. He had surgery on his leg. They took out a bunch of metal from his leg. They told us don't go home. The government lit our house on fire and burned it. They told us we were not safe in Ethiopia and we should leave.

My brother and I decided to flee Ethiopia for a safer life. The Catholic church helped us, they got passports for us. They said goodbye and told us to go and they drove us to the border with Kenya. We crossed the border into Kenya. It was very dangerous when my brother and I

escaped from Ethiopia to Kenya. The UNHCR was there in Kenya. We stayed in Kenya from 2005 until 2019. We felt a little safer in Kenya. When my brother and I fled in 2005 I was 21.

# THE LIFE THERE IN THE CAMP WASN'T GOOD

There were two camps in Kenya. One was called Ifo/Dadaab. That is the biggest one. The second largest one, where I stayed, in Kakuma. In the camp in Kenya there were people from many, many different nations in Africa and also the Arab world. It was sunny, very, very hot. There were no farms. Getting food was hard. In the camp people change, steal food, kill too. There was not enough food to satisfy us. Some people felt bad and hung themselves from the tree and died. Suicide. We told the UN to look, many people are dying. It's better if you give them a good life. But Kenyans controlled the UN. They would take the money. We wrote a letter and said the police were arresting kids, but they ignored it.

There was one Deaf girl, 16 years old, from Somalia. Her home was near the school. Her parents went to the store to buy food. She stayed home to take care of the children. Someone entered the house and abused her. When the girl saw they were coming she put the chairs up to block the door. But the men broke the door down, so she ran to the school. I was there teaching. I asked her what happened. She said they abused me. It was scary. We asked the UN what can we do? We wrote a letter to the UN and the parents went to talk to them and three months later the family went to America. Now they're safe. The UN helped the family. This kind of thing happened many times.

But Trump, the President now, blocked people from coming. So, I had to stay in Africa until 2019. When it was time the UN called and told me no, I couldn't go. The people here (in America) were waiting and waiting for me and trying to figure out how to help me. Many people went to Australia, Canada, many places. Why? The life there (in the camp) wasn't good. The UN

paid for the refugees' food, but the Kenyans stole it. They just gave us a little bit and we were so hungry. But school was good. There were a few deaf people. The first time I stayed, there was no work. Later, I finished school and I became a Deaf teacher.

### **INCLUSIVE EDUCATION**

They have inclusive education there (in the camp)— all the kids went to school. Now there are teachers there. But there is no support. Nothing. Why? The UN gives money, but the Kenyans steal it. There was only a little bit of work. Maybe I work every day, 8 hours and in 1 month they paid me \$50. It's the same for all the teachers. For the Deaf students it was their first time to go to school. We started at Class 1 or 2 until middle school. For high school, the UN picked some students and sent them to the city. College was hard. The students came home and stayed (when they finished school). They looked for jobs but if there were no jobs they stayed home. College is hard. The interview is hard. Deaf people can pass? Not really. Only me because before I was hearing and went to hearing school.

The camps in Kenya were good. There were two camps and people signed. The camp in Kenya had inclusive education. It was public, not private. The UN paid the teachers. They couldn't deny kids. They required the refugee kids in the camp to go to school. All the school buildings were together. The Deaf kids had five or six classes. But they socialized with the hearing kids sometimes. For example, for music class they all came together. But for class they were separate. But if a Deaf student wanted to join the hearing class they could. And if a hearing student wanted to join the Deaf class it was ok. So, there was a lot of socialization. There were two schools in the camp where Deaf and hearing students went. One was called Fashoda. I was a teacher there. The other was called Nasibinda. It was far. By bicycle it took maybe one hour. But Deaf kids could go to school there too. When middle school was finished the UN chose some

students to go to high school in the city. At my school there were two kids, one used a wheelchair, the other lost a leg and he used crutches. They went to school. They weren't separated.

But at the school some of the teachers were bad because there were different tribes. There were tribal rivalries in the schools in the camps. Some teachers oppressed students from the other tribes. Teachers preferred to teach the students from their tribes. The UN sent teachers, one from New York and another from South Korea, others from America, from London. They came to Kakuma camp where I was. They taught us for four days. They told us we have to teach all the kids not just those from our tribes. They told us if we had any problems in the camps with the kids, problems that were hard to solve, to call them in America. They gave us a certificate and a phone and told us to call them if we had any problems or difficulties while we were teaching. They said to call them outside of Africa and they will help us solve the problems. It was that way for three years. The problems between the tribes lessened. Now the camp is really good. That was in 2017. Since then, it's been good. The kids get along, hearing and deaf interact with each other.

The roads were bad in the camp. If the kids in wheelchairs lived close to the school, we could go help push them and bring them to school. But if they lived far, we couldn't help. The roads are really bad. Why? The people there control the UN things. They don't give us the full services (to the camp people). The UN gave full services, paid for things, but the people stole it and the people in the camp were so poor. In the camp they posted advertisements to let us know when things were happening, like food distribution and other news. Everyone looked at those and saw the day and week. I didn't have any problems getting information in the camp. It was good.

In 2008 I finished middle school. I was an adult but in school with kids. I finished middle school in Ethiopia when I was 21 years old. When I arrived in Kenya, I found that the education in Ethiopia is lower. In Ethiopia I finished class 7. When I went to Kenya, I started in class 5 again. The kids start school young. I was in school with kids who were 13 and 14 years old. In middle school I was with hearing students. Communication was hard. Why? They spoke English, a different language. Writing was okay, why? Because I copied the teacher, and I went home and studied. At the hearing school I tried to lipread, but it was hard, so I wrote. The education was free. The UN paid.

I started learning sign language in 2012. ASL and KSL (Kenyan Sign Language) both. But ASL is lower because in Kenya they pushed it aside and changed the language to KSL. I'm very fluent in KSL. KSL and ASL are different, but not a lot different. A little different.

Then I went to college. My friend in America who is Deaf, his name is James N, he came to America in 1998. In 2011 he helped me go to school. He paid \$1300 for one year of college for me. Then when I finished college, I went back to the camp to be a teacher. There were many deaf kids in the camp from many different nations. We had to teach them Kenyan Sign Language (KSL). I taught them that. But later, little by little, we taught them ASL. Why? It's illegal there. We were only allowed to teach KSL. When I went to college it was mixed, KSL and ASL. But for middle school and high school it was only KSL. I started to learn KSL in 2011. There was a teacher but not a good one. They didn't have a license. They told me to go to the city and the government will teach me better. So, I went but it was mixed, KSL and ASL. At college I had interpreters. There were three interpreters. They were good! They knew both ASL and KSL.

I saw for Deaf kids it was good in Kenya. But near the border of Kenya and South Sudan there was no school for Deaf kids. I saw their skin was dark like mine so I thought I will go help

build a school in Juba. The people have black skin like me, we look the same, so I thought I will go. I crossed the border and arrived and saw there were many Deaf people. I asked the government if they will build a school for Deaf people. They can have language and I will teach. The government accepted but said wait a little bit. We will get money and then call you to come. So, I waited and waited but before that happened a war started again. And they caught me. See these lines on my forehead? That's from my tribe. My tribe is Nuer. So, they caught me. But the people came and saw me and told them that I am Deaf. They told them I came to start a school for Deaf kids in South Sudan. Please don't kill him. Let him go. So, the government let me go. I went to the UN for protection. I went to the UN and stayed for four months. They protected me. After 4 months I heard things were better now. People could cross into Kenya. My family was there. So, I thought about it and decided to go. I arrived safely in Kenya. My brother was there. His family was there. The UN called and told me I needed to leave (to go to America). But I said no, my family is here. My wife and two kids. It was better if we stay together and go together. The UN told me I had to start the process again. Why? I got married in 2010. I started the process in 2009. And it was successful. But they told me if I want my family to join me, I have to start again. I accepted that and started again. It took until 2019. That means my brother and his family went to London in 2014. They were already gone but I stayed with my family. But we waited and finally in 2019 we came to America.

I went to college three times. The first time for six months then for one year. The last time for two years. Two times to be a teacher and one time to study ICT. Around 2017 I went to college again and studied ICT, Information Communication Technology.

## WHEN I FIRST ARRIVED IN AMERICA, I WAS SO CONFUSED

The first time I started the process to come to America with the UNHCR. They worked together with the government of America through the Catholic church. When everything was finished the Catholic church bought our tickets to come to America. First, I came to Minnesota, St. Paul It's very cold. I lived there July 2019 – May 2020 then I moved to Nebraska.

When we arrived, they helped us get a house, beds, food, for about 3 months they helped us. Then we got SSI. They asked me if need CIs (cochlear implants)<sup>5</sup> I said I don't know. I've been Deaf for a long time, 28 years. Will CIs help? But I discussed it with the doctor, and we decided they won't help. So, I didn't get them. After three months we started getting SSI checks and I looked for work. We were disconnected from the Catholic church services, only the caseworker guided us and helped us. For example, if we had to go to the hospital the caseworker came and picked us up and took us. They helped us look for work. Then we decided to come here (Nebraska) because my wife has relatives here. But I think we will go back to Minnesota soon. My wife is hearing, and she doesn't have a lot of education. When we were in St. Paul, she thought maybe Nebraska would be better for us. But I remember during orientation in Kenya they told us life in America is hard. If you have money it's easy to move but if you don't, it isn't. I advised my wife about that, but she really wanted to go to Nebraska. I gave in and we moved. Now my wife is working, and I take care of the kids, do laundry, sometimes cook, and go to university. Life is hard here. My wife and I discussed it, and we think it's better to go back to MN. I applied for a house and was accepted so we will go.

<sup>&</sup>lt;sup>5</sup> A cochlear implant is an electronic device that partially restores hearing. It can be an option for people who have severe hearing loss from inner-ear damage and who receive limited benefit from hearing aids.

When I first arrived in America, I was so confused. Communicating at the hospital was hard. Then I met a Deaf person who taught adults at a college. Since I was new from Africa I went to that class. They taught sign language, but it wasn't good. I saw they had a videophone and I really wanted one. I waited two weeks and they sent one to my home. They brought an iPad to my house and it took one hour to set it up then they left. Now if I'm home and the kids are sick, I can call 911. So, the communication is better now. But one time I applied for a job and I went to two interviews but there wasn't an interpreter. I know that in America they must have interpreters. But I know the job counselor didn't think to get an interpreter. So, I failed to two interviews because of that. One job I really tried and tried, and I wrote during the interview and I got a job at a hotel.

When I first arrived, I didn't have interpreters, but later the Catholic church realized I was Deaf and needed interpreters and then I had them for when I go to the hospital. My college courses I just do the work and send it and the teacher sends it back. I don't need interpreters. But sometimes I have to call, and I use VP with interpreters. When I arrived in America, I found it hard as a Deaf person because I didn't have interpreters. I'm ready to work and I went to some interviews but there wasn't an interpreter. The company didn't give me an interpreter. In that way I lost work, because there wasn't an interpreter. In MN I worked in a hotel and there was a girl who knew ASL and she interpreted for me.

My brother who I escaped with is in London. His family went there. I came to America. I am looking for money to bring my brother here but because of Corona virus I can't.

When I first arrived in America it was so different! In Africa people are always outside, walking, selling clothes, I always saw so many people outside. It made me feel happy. But when I came to America, I saw that all the stores were inside, people weren't out walking, everyone

was driving. I didn't see people. It made me feel sad. But slowly it started to change and now I feel a little better.

I feel the American people accept refugees. I wasn't the only person to come. In many countries there are wars and people are coming to America. Americans must accept refugees and give them an easier life, advise us, guide us.

Now I'm studying ECD (Early Childhood Development), my BA again. In Kenya now the education is good. Deaf people can go to university. But in Ethiopia it's low. In South Sudan it's low. In North Sudan, low. Somalia, too. I want to go back to Ethiopia and train teachers so they can return to Somalia, North and South Sudan, and other countries in Africa. So Africa can develop because Deaf people can learn sign. I want to teach Deaf kids. I want to go back to Africa and help Deaf kids there.

# Gopal

### AGE: 35

OCCUPATION: Deaf Interpreter, Deaf Refugee Education Instructor

HOME COUNTRY: Bhutan and Nepal

Gopal is a funny, enthusiastic man who loves to share stories and chat with anyone who will listen. He explained that whenever he meets someone who knows ASL he loves to chat and tends to go on and on. Gopal was a young boy when his family was forced to leave Bhutan and move to a refugee camp in Nepal, where he lived for 20 years. Gopal admitted he still doesn't understand why so many Nepalese were forced to leave Bhutan. Gopal has a great sense of humor and shared many funny stories about when he first arrived in the United States, such as seeing traffic lights for the first time and experiencing his first Halloween. However, he also expressed openly his feelings of confusion and isolation due to language barriers. Not wanting other Deaf newcomers to go through what he did, Gopal is now actively involved in Deaf refugee education classes and teaches other Deaf refugees what he wished he had known when he first arrived.

When I was about 6 or 7 years old the government of Bhutan forced us out of the country. I went with my parents to Nepal. I grew up in Nepal. In Bhutan I only went to elementary school. I learned the alphabet and a little bit of their language. I forgot some of it. I can write my name. I understand a little bit of the written language, but that's all. I only went there about 5 months then the schools closed. I don't know what happened. Maybe a war, politics. Then the government forced us out and we went to a camp. We lived in the refugee camp in Nepal for 20 years. I grew up in the camp. I learned Nepalese language. I know more Nepalese language than Bhutanese. I can read easily and sign both. I also learned English. I went to a mainstream school, there was no Deaf school. Before, in Bhutan, I was hearing. When I moved to Nepal, I lost my hearing and became deaf. I had no way to communicate. I went to the doctor. He wasn't a professional. He was not a good doctor, just a camp doctor, but it was free. He put water in my ear to try to clean it. But I continued to lose my hearing and became completely deaf by the time I was about eight years old. I couldn't hear anything.

## LIFE IN THE CAMP WAS REALLY HARD

Life in the camp wasn't easy. It was really hard. The World Food Program (WFP) and another agency – I can't remember the name, but it was connected with the UNHCR – helped with food. They gave us food for 15 days (at a time). They gave us kind of a container of food, one for each member of the family. But the food ran out after one week, ten days. So for five days we barely had enough to eat. It was really hard. Sometimes we just had rice we cooked with water, bananas, the same for 3 months. Then they'd change it for another 3 months, maybe give us pumpkin. It was not enough food. We didn't have milk or meat. That was too expensive. Some people went outside of the camp to work, get money to support their families. But some people had no parents, they were disabled, Deaf, maybe their parents died, they were children. Life in the camp was really hard. I grew up in a really poor family. My mom died and my dad married another woman. It was really hard.

Our houses were very small, not really a house, but small. And they were connected. All the roofs were connected, and we had dirt floors. One house started on fire and burned all the houses. We lost all of our things. That happened two times, my house burned down. One time there was a flood, and it destroyed our house.

### I WAS READY TO GIVE UP

The school in the camp was outside under the trees. There was no building. If it rained, we couldn't have school, we had to go home. If it was a good day we could learn. Sometimes it was really cold. We didn't have tables or chairs. We used our shoes to sit on.

I tried to go to the hearing school, but the teacher spoke, and I couldn't understand any of it. I failed and failed 3<sup>rd</sup> grade so many times. I was ready to give up, go find a job or something. I couldn't understand and I didn't learn anything. But my family, my brother, said no, you're still

young, 11, 12, 13 years old. An education in important. They really encouraged me to continue. So, in 1996 (I moved to the camp in 1992, I became deaf in 1994, around then) and for 2 years I failed 3<sup>rd</sup> grade. But in 1996 I went to the sign class and started learning Nepalese sign language.

In 1996 Nepal had a Deaf agency named NDHSS or something like that. They heard there were many deaf people in the camp who could learn sign and they brought the agency SCUK (Save the Children Fund, UK). They came to help in the camp, to teach us sign. They brought teachers from Kathmandu, from the Nepalese deaf agency/association. So, the deaf people in the camp learned sign. It wasn't a school. They just taught us some vocabulary and words. I joined that class for six months and learned a lot. I was really able to communicate well. The teachers saw that and gave me a test and I did really well. So, I volunteered to help teach the other deaf people. I wasn't paid, but I was like a teacher assistant. When I graduated college, I worked in the disability center in the camp. Like assisting the manager/director. While the teacher was teaching sign I would help, watch the students, etc.

# I AM SMART, JUST DEAF

Sometimes at school (hearing school) the teacher didn't come, or it was break time or whatever, I tried to teach my friends who lived near me sign language. They picked it up fast, I could read lips a little bit, so we could communicate. I understood them better than the teacher who just talked and talked, told stories, I didn't understand any of that. During breaktime or after school I asked my friends to help me. I asked them what the teacher said at school, what they talked about, about the homework. My friends were willing to help me, so they explained it and I understood, and I passed the classes. It's not the same as America where if you fail you can still move to the next grade. In Nepal if you fail you stay in the same grade, so I stayed in 3<sup>rd</sup> grade two times and I really felt bad and was depressed. I wanted to quit. But I taught my friends sign

and they helped me, and I really improved a lot. I was able to pass the classes. My friends were like my interpreters, they helped me to communicate and understand. I am smart, just Deaf. The agency that taught us sign language left but I volunteered to keep teaching the other deaf people sign language.

After I graduated from high school, I went to college for two years. I went out of the camp for two years to go to college. After I finished, I came back to the camp and worked at the disability center as a professional worker, not a volunteer. Deaf people would go to the camp disability center and it was very fun. We would all join and play games, play soccer, volleyball, art, different things. I really enjoyed it. Other deaf people lived near there so we could meet each other every day. But living was very, very difficult and a lot of problems. We didn't have money, no meat, milk, my parents were poor. We went to school with sandals, we didn't have shoes. It was a hard life. When it rained we didn't have umbrellas. Sometimes we would slip and fall in the mud and our books went everywhere.

I lived in a really big camp, about 7,000 people. We had a small disability center to help people with disabilities – physical disabilities, Deaf, blind, mental health, CP (cerebral palsy), all different disabilities. They helped with things like problems at home, family problems, if they needed a wheelchair, sign, therapy. Small babies with CP came to the therapy room at the center. I learned how to help in the therapy room. I went to different cities to learn and came back and volunteered in the therapy room. They taught different skills like haircutting, knitting, sewing, tools, art/painting, more vocational skills so when they left the camp, they had some training. Sometimes the center referred people to go out of the camp and learn skills like carpentry. My camp taught haircutting, knitting, art to deaf people. When I finished high school, I went to the center and told them I wanted them to hire Deaf people and they did. We didn't have other job

opportunities or ways to earn money and we had experience with the center. So, they hired about four deaf people to work there. There were seven different camps but mine was the only one that taught sign to Deaf people. I worked at the center. Later more Deaf people came to my camp because they heard there were Deaf people there working and teaching. We could communicate and chat, it was fun. Every year we hosted a Deaf festival, gave awards, sports, etc. Later we set up a formal Disability Day in the camp. We invited people from all seven camps to come. We played sports, soccer, races, different things. It was really fun, all day. Workers from the disability center visited the homes of the disabled people to see what support they needed. They went one or two times a week. Maybe they needed their wheelchair fixed or wanted to learn more, we went to their homes to see how they were doing and to help. For blind people they learned how to walk with a cane. I tried to help but I'm Deaf and they're blind, so communication was hard. They talked and I couldn't understand. So, I helped in the therapy room instead. It's more visual and I learned really quickly. Caritas ran the disability center. A long time ago it was run by Save the Children Fund.

School was free until high school. I went to college when I was 22, 23 years old. In college I studied Humanities. I went to college for 3 months then had 2 months off. At that time, I worked in the fields, digging, etc., to save money to pay for college. When I went to college a fire destroyed our house and we lost everything. That created more pressure, more mental pressure, trying to figure out what to do. Food was free, school was free, the hospital was free. They were run by organizations which were under UNHCR. The schools were run by Caritas, the hospital by AMDA – Association of Medical Doctors of Asia. I didn't have interpreters at college. I learned more of the Nepalese language and in college I studied English. I had the same book in English and Nepalese, so I read the book in Nepalese then in English and I quickly

understood. It's the same now in America, for example, if I search for something in Google it shows up in English. If I don't understand I translate it to Nepalese.

#### LATA

So many people lived in the camp. They didn't want to use sign language. They think if you're deaf it means you're dumb. That's their issue. That's the culture. I'm Deaf and I want to use sign and can speak a little. People called me dumb and asked why I used sign language. That really hurt my feelings. I confronted them and explained I have a job, I earn money. You think sign language is just gestures but it has vocabulary and grammar. There are many different sign languages, don't call me dumb. In Bhutan they still don't use sign language. They still think that if you're deaf it means you're dumb and they don't want to use sign language. In that culture if you're born with CP, a disability, can't walk, anything, they blame the mother. They think maybe before she had some bad behavior or actions that caused it. Sometimes they divorce and send the mother away. Sometimes they don't want to take care of the child and neglect it. They look down on someone with a disability, they can't go work and earn money. Before in Bhutan Deaf people couldn't go to school or college. They just stay home, take care of the cows, they don't earn money. They think they're dumb and call them "lata" which means "dumb" For deaf women they call her "lati". If there is a deaf person, they don't call them by their name, they just say "lata" or "lati" (for women). They don't call them by their given name. There's a lot of oppression. It's really awful. They look down on Deaf people. Your first, second, third, fourth family names – they don't use. They don't call me Gopal. Many people still call me Kancha. My hearing brothers and sisters have the same last name but because I'm Deaf they don't use the same name for me. I thought about it a lot, all of my other hearing relatives use the same name. Why is mine different?

I had a very big family. But in my culture the last son to get married takes care of the parents, so I live with my parents now. I take care of them, it's my responsibility. But I go to work and earn money, so my wife takes care of my parents, cooks, cleans the house. My father is on oxygen and has breathing problems so he can't work. If we were in Nepal, I would have to take care of them.

## WE COULDN'T COMMUNICATE

My family arrived in New York or California – I don't know where, really, and there were no tickets available to fly to New Hampshire, so we had to wait for 5 days. I thought the food would be the same as in Nepal. We traveled for 3 days and we didn't eat anything. They brought different kinds of food and it smelled really different to us, like tacos and some other food. They showed us a list and asked what we wanted. We didn't know how to communicate so I just pointed at something. They showed us soda and I didn't know what it was, but it was brown, so I said no, but I was so thirsty. They just gave us a little bit of water, but it wasn't enough. I wanted a big glass of water. We got to the hotel and they gave us the key card, and the room was beautiful. We were hungry so we went to ask if they had any food. I knew how to write the word "milk" in English, so I wrote it and asked for milk for my son, not for me. So, they gave me milk, but it was cold. We are used to warm milk, not cold. So, I wrote "boil" and asked them to warm it up. They pointed to the microwave. We didn't know what that was or how to use it. My son put the milk in and closed the door, I saw the numbers flashing and we were so afraid we were going to start a fire. We were really afraid we would start a fire or something so we went to get the person who worked there but we couldn't communicate. We didn't understand. So, we just gave my son the cold milk, but he was used to warm milk and didn't want it.

One person came up to me and asked what we wanted to eat. I asked for chicken and rice. I thought it would be the same as Nepal. They brought four containers of food and we opened it. There was no seasoning/salt on the chicken. The rice had no flavor. We just closed them and didn't eat. My wife opened hers first and when we saw her reaction we didn't want to eat. So, we asked for apples and for five days we ate apples.

A woman came and told us she would take us to the airport, so we went with her and got on the plane. Finally, we went to New Hampshire. My brother picked us up at the airport and brought us to his home. I told him we were hungry. I told him that for five days we just ate apples and we wanted to go back to Nepal and not be here anymore. He said at his house they had Nepalese food. So, we got in the car, I was sitting in the front seat. On the highway he just kept driving and driving, but then we got on the small streets and he kept stopping and stopping. I thought he was crazy, I asked him why he kept stopping and waiting why he didn't just go. He pointed at the light, but I didn't understand why he kept stopping. I yelled at him that we were hungry and to hurry up! Later I finally understood. So, we went to his house and ate, and we felt so happy. My brother moved to New Hampshire 4 or 5 years before me.

I really love TV! I love to watch different YouTube videos and watch TV. I brought some DVDs from Nepal. In Nepal we use DVDs, we don't use the Internet or YouTube. My brother told me I didn't need the DVDs here. We arrived on October 21 and our apartment wasn't ready yet. For 15 days I stayed in my brother's apartment and watched TV. Then October 31, Halloween evening, I had no idea about that. We don't have that in Nepal. I'd never seen it before. I was watching a movie and my family was eating dinner. Someone knocked on the door. In Nepal at night everything is closed, people don't go out. Where my brother lived there were a lot of refugees and people always came and went, it's part of the culture. So, I debated whether

to open the door or not and thought maybe it was some family members visiting or friends of my brother's. So, I opened the door and I saw scary masks, swords, costumes, and I freaked out! I ran to where my family was eating and explained what happened, I thought maybe they were going to kill us or something. My brother laughed and gave them candy.

Then we finally moved to our apartment. We learned how to use the microwave, how to use the doorbell. A funny story, one time we went to the neighbors' house and kept ringing the doorbell. We're Deaf so we couldn't hear it or what they said to us. We rang it over and over again. We learned that to cross the street we had to push the button and stop and wait. I didn't know that; we don't have that in Nepal. So, I just started walking into the street and they explained I have to stop and wait.

# DEAF PEOPLE NEED TO LEARN THAT, TOO

I went to a workshop related to refugees who just arrived in America. They couldn't communicate with me, so I just went home. In that workshop they taught how to pay rent, how to pay bills, no one taught me any of that. When I was home for eight months, I was trying to figure out how to pay bills, it was confusing. Later when I learned to sign well, I went back to that workshop and let them know I never learned any of that. I told the teacher that Deaf people need to learn all of that, too. Later I went to the New Hampshire Deaf Agency and learned sign language for 2 months. I also went to English as a Second Language classes and the taught me the ABCs. It was fine but I already knew that, so they suggested I go to the advanced class. That included college classes and I passed all the tests. I earned 19 college credits but then I moved to PA. Now I'm not going to college, I have work and my family, I'm busy.

I learned some sign at the ASL classes, and I watched YouTube videos to learn. When I went to college classes I had an ASL interpreter and I watched and learned a lot. After I learned a

lot of ASL I went back to that newcomer's workshop to teach. I went to the Deaf refugees' homes and told them to come to the workshop. At the ESL class another Deaf student came. So, they asked me to help and I said yes, I was willing to help. So, there was a Deaf teacher and a hearing teacher. The hearing teacher spoke, and I used gestures and ASL to explain. Then another Deaf student came, then another. Then it expanded to 12 Deaf students! Then they got a grant and taught American culture, the workshop, also when they had presenters, they had ASL interpreters. It was really great because they improved, got a job, and were independent. It was hard because I had to go to the Deaf people's houses and explain to them to come, sometimes I had to pick them up and drop them off after the workshop.

Before I didn't have a license. I asked my brother how I can get a license, but he said, "You're deaf, how can you drive?" He told me to ask the other Deaf people to help me. I studied and studied the book from the DMV, but I just didn't understand. So, I asked another friend, a hearing friend, to help me. He showed me on the computer the DMV website and told me to study those questions. I practiced and got 50%, 70%, 80%, 100%. I kept trying and when I got 100% again and again, I went to take the test. I called the interpreter on VR (video relay) and asked to interpret for me so I could take the test and I passed! But when I went to take the driving test the person looked and couldn't find the VR interpreter. Then my permit expired after 1 year, so I had to do it again. My son told me that all the other fathers drive and go fun places like the store and the park, but I don't. He wanted me to learn to drive. I tried and failed and failed. It really hurt me. My family (hearing) was discussing going to the apple orchard My son heard them and told me he wanted to go but I didn't have a car. He cried and cried because he wanted to go. I asked my family if they could bring him, but they didn't have room in the car. Later I found a car and got my license.

### I STAYED HOME, ISOLATED

I have two jobs. I work at a store stocking in the dairy department and in my other job I help support refugees who just arrived. I've worked there about one year. When I moved to New Hampshire I saw Deaf people (refugees) sitting at home doing nothing, isolated. I had the same experience. For eight months I stayed home, isolated. I went to the doctor with my brother and my brother talked about me to the doctor. I just sat there; I didn't understand anything. There was no communication. There was no interpreter, and I didn't know ASL.

IOM sponsored my family when they came. International Organization of Migration. They didn't understand my needs as a Deaf person at all. They hosted a workshop in Nepal to teach about culture, life in America, how to call 911, what to do at the hospital. That was in Nepal 3 days before we flew to America. There were no interpreters, just speaking, and it all went over my head. I didn't understand anything. A person from Nepal who had lived in America taught that workshop. There were many hearing people, all who were scheduled to fly at the same time as me. My wife and I were the only two Deaf people. We just sat there because we didn't understand. We understood a little bit of the writing and they showed some pictures, which helped. For example, they showed pictures of different celebrations, what Americans do if someone dies, about the food, that kind of thing. When I arrived in America the caseworker came and picked me and my family up. Some people have family here to teach them how to use things, what to do. Some people don't have family here. The caseworker has to teach how to start a fire, how to flush the toilet – in Nepal we didn't have toilets that flushed so some people don't know about that. I had experienced it before a little, so I knew but some people don't. Before we got on the airplane, they didn't teach us anything about what to expect. I went to the bathroom

and I knew to flush the toilet, but it was so loud! And at the same time the plane bounced a little. I thought we were going to crash! It was really scary!

In Nepal when you go to the store to buy something we negotiate. It's different here. In Nepal we used only cash. Here we got a card and a pin number. I didn't understand what a pin number was. I remember I went to the store with my brother's family and he was putting a bunch of stuff in his cart. I asked him if he had money, how was he going to pay for everything? He told me he had a card. When I got my card, they told me I need a pin and I didn't understand – I thought they meant a real pin! I really didn't understand how the card worked. I learned six months later! I always watched my family and slowly started to learn how to do things. I'm smart and I learned in six months. Other Deaf people, it sometimes took them 5 years and they still didn't know. And at the bank we need an account, to cross the street we have to push the walk button and wait for the light – we all need to learn those things. Now we have a class on Fridays, Rob and I teach it, for refugees who have come to America. We teach it on Zoom. We used to go to people's homes and teach them but now because of Corona virus we teach on Zoom.

I told my caseworker I wanted to learn ASL. When I went to the ESL class there was a volunteer who came sometimes who knew a little ASL. I understood a little because I have a Deaf friend who came to America before me and learned ASL, so I understood a little bit. One time I was home alone, and someone came over. I didn't know who it was, and they were very direct and asked me my name. I didn't understand and the sign for "name" in ASL is very similar to "cut" in NSL, so I thought they were talking about cut. I didn't understand what was happening. She wrote "name" and showed me, and I understood. The alphabet in ASL and NSL are very similar, just a couple letters are different. That woman was Jehovah's Witness. I didn't

know what that meant before. She told me she was Jehovah's Witness, but she told me her name and I saw someone who signed, and I was happy. She sat down so we could chat and then she got out a pamphlet and gave me a DVD. I watched the DVD, and it was a JW signing, talking about God, the temple, etc. I didn't understand it but I enjoyed seeing someone signing. I didn't really care about the religion, but I wanted to learn ASL, so I started learning with that woman. She taught me some vocabulary, but I was ready to dive in and really wanted to learn. I wrote down some questions and things I wanted to learn but she kept telling me to wait and only taught me some basic things. I didn't like that way, so I went to Deaf services and told them I wanted to learn ASL. They gave me a tutor for two months and I learned better with that person. The first woman, the Jehovah's Witness, wanted to teach me signs related to her religion. I didn't want to learn from a book. I wanted to chat and have conversation. Then a husband and wife started coming. I don't know what happened to the first woman. They were all hearing. When they showed me books about their religion, Adam and Eve, that kind of thing, I told them about my religion, Hindu. They taught me about their religion, and I taught them about mine. For example, I have pictures on the wall, so I showed them and explained about the gods. I am not in contact with them anymore but I'm happy they taught me some ASL. But it was interesting they tried to change my religion. My religion was passed down to me by my ancestors. But with the tutor I learned things I wanted and needed to know.

## DISABLED PEOPLE DIDN'T HAVE RIGHTS

In Nepal there were no interpreters, disabled people didn't have rights. Deaf people can't get a driver's license. In Nepalese culture those who have more money have more respect.

Disabled people weren't respected. When I moved to America, I didn't know anything about ADA, rights, interpreters, nothing. When I went to the doctor with my brother, I didn't have an

interpreter, so I didn't understand what was happening. Then I went to the deaf center and they asked if I have interpreters for the doctors and other things. I said no and they asked when my appointment was, and they called and told them I need an interpreter. Even though I didn't know much ASL I understood some things like my name, birthday, etc. Later I knew to ask for an interpreter every time. Later I went to an open house at the DRC and saw a presentation on ADA and understood my rights as a Deaf person. I was shocked! Later I went and learned more about it and the law.

I have two kids. They're 13 and 7. My kids are hearing. In NH when I went to meetings at the school, they knew I needed an interpreter and provided one. Anytime I went somewhere and didn't have an interpreter I texted Julia at the DRC (Deaf Refugee Center) and she called them and demanded an interpreter. Here in PA, I don't have someone like that. For parent meetings I've let them know I need an interpreter and they put the responsibility on me.

I have not experienced discrimination as a refugee because I'm tall and White and people think I'm American. When people ask where I'm from sometimes I say Bhutan, sometimes Nepal. Someone asked me where I am from and I said Nepal and they didn't believe me because I don't look like it. I have heard that other Deaf people have experienced that because their skin is darker, but my skin is light, so I haven't experienced that. But I've heard other Deaf people's stories and maybe they go for a job interview but don't get hired because they're Deaf or they're from Nepal.

I want to go back to college and study Psychology. When I went to school, I got good grades. But it's hard and I have to take care of my family and work. I learned a little about crisis psychology and it helps me in my job now, but I want to learn more in-depth.

### Hala

## AGE: 23

OCCUPATION: American Sign Language Instructor

# HOME COUNTRY: *Iraq*

Hala's warmth and friendliness was apparent as soon as I met her. As the only participant who came to the United States with her parents and siblings, she gives us a different perspective on life in the United States as a refugee. Hala passionately shared about her family, her love of Iraq, and her desire for an education. As a Deaf girl in Iraq Hala knew that if she stayed there, she would have no opportunity for an education, a career, and a family. With four older Deaf siblings, she had a glimpse into her future and didn't want the same for herself. Hala has changed the narrative around Deafness, disability, and gender not only in her own family but in her Chaldean community. Parents of disabled children see her as hope and possibility for their own children.

My name is Hala. I am 23 years old. I was born in the village of Batnaya, in Iraq. Really, I was born in Mosul, which is near my village, because my village didn't have a hospital. Batnaya is about 15 miles from Mosul. There was a doctor for minor things, like a cut or other small thing but that's all. Iraq is a really beautiful country. My village was so beautiful, and I really miss it. I'm the youngest of 12 children. I have seven hearing siblings and there are five of us who are Deaf. I didn't learn sign language in Iraq. My family uses visual language. My dad was the principal of an elementary school. I have dual citizenship so maybe in the future I want to go visit.

### THERE WAS MUTUAL RESPECT FOR BOTH RELIGIONS

Really, it's a beautiful country. I love the food. There are many restaurants here but it's not the same. Iraqi food is good but really, I love Syrian food the best. Why? I was finally out of the farm life, I grew up on a farm in Iraq, and finally in Syria I was in a nice city, in Damascus there were a lot of people everywhere, a lot of traffic, and really it smelled so good. Let me back up – I grew up in Iraq, I had friends there, but now those friends are spread around the world in

different countries, we're not really close but I have those memories. I remember as a child working at the Red Tomato Tea House, harvesting things from the farm, I worked with my father in his business and helped my mom at home cooking, cleaning, the only thing was I wished I could go to school. But other than that, I really loved it there. It was a beautiful town. It was very peaceful, farm life, beautiful. It was a different lifestyle.

I wish you could have seen it before the war, it was even more beautiful. Very peaceful. Christians and Muslims got along, Christian churches and Muslim mosques were right next to each other, the people of both religions were together going to their churches without any problems. Really, when the war started is when Christians and Muslims started to become divided. Before that they weren't. It was so peaceful, and the people were so beautiful and friendly. Maybe there were problems in other cities and towns but in this big city (Damascus) there was mutual respect for both religions. They became divided during the war. I noticed the same thing happened in Iraq. The American government isn't honest with the people about what happens, they try to hide things and don't tell the whole truth. The American school system doesn't teach the truth, either. For example, with Indians [sic] they just taught us some surface information, like the Pilgrims wanted to come here, it was so nice they came and became friends with the Indians and ate together. Really that's not honest and they don't tell about the damage they (the Pilgrims) did and murdering. The history books really focus on white people and don't tell everything.

I did see other Deaf people in my village, maybe less than ten, and they were older.

Because we were varying ages it was impossible to establish a school for us. I did see other Deaf people, but we didn't communicate or chat ever. We kept our distance because we were from different families. And if we are talking/chatting the hearing people will tease us and make fun

of us. So many Deaf people didn't want to associate with other Deaf people. I thought it was cool, we're the same, we're Deaf, we can communicate. I wanted friends but it was hard to communicate. I had my brothers and sisters, and I was always with my sister. I never went to school until I came to the United States. I helped with my family business, which was a tea house. My hearing brothers and sisters went to school, but my Deaf siblings and I didn't. There's no school for Deaf kids.

I consider myself both a refugee and an immigrant. I am a refugee from Iraq to Syria and when I came to the US, I became an immigrant. I was 12 when I came here. That agency in Syria helped us with the paperwork so when we arrived here, we were here legally. But in Syria I was a refugee because I was forced to leave my home.

## MY FAMILY HAD THREATS AGAINST US

My family left Iraq for several reasons. Let me back up – really, the war had already started. I don't know all of the details in-depth, but I know the basics. I was young at that time. My dad was in the army and he ran away, changed his name, and it was as if he had died. Really, he was still alive, but he didn't want to be in the military anymore – he had seen a lot of blood, people suffering, war, and so he had to run away. He wanted to be with his wife and his children. If he had stayed in the army he probably would have been killed. He continued to live his life then sometime later a man recognized my dad and told the authorities he was still alive, that he had ran away from the military. That's when things started to get worse. Not only in my town but in neighboring towns and villages, too. Many women were raped, some women were kidnapped, and my family became very paranoid and scared. It was really dangerous at that time. If something happened, it had a big impact, and we knew in our gut that in time something would "steal

your beautiful daughters", they would shoot my dad, and other things. I don't know who said these things. My dad didn't want to explain more to us, he felt it wasn't appropriate to tell us these things. Also, because we were Christians and many other things it was dangerous.

My older brother went to Germany to avoid being recruited into the army. I really missed my brothers. Later, my other brothers went, too. The ISIS soldiers commented to my dad about his beautiful daughters and threatened to rape and assault us. So, my parents decided to leave. We drove to Syria because it was close. We could have gone to Lebanon, Turkey, or some other places but we chose Syria because it was close. And because my dad already had other relatives, some cousins, living there. When we arrived, it was easier because they could guide us, show us the area, help us, so it was easier.

We drove 24 hours when we left Iraq to reach Syria. We drove, only stopping for gas, to eat, and to use the bathroom, until we reached the border. We were taking a chance because when we got to the border, they could have denied us entry and made us go back. We arrived at the border and there were so many people! So many people waiting to cross the border. Not only Christians, but also Muslims. I remember that day so clearly. So many people had to flee their homes for safety, not only us. Many people were lined up waiting. If they approved you, you could cross the border. We had to wait so long – about five hours. We were finally approved and got the stamp to cross into Syria. I saw so many people waiting for so long, into the night, and they weren't approved. I really felt so bad for them. In Syria we lived in a very small room – all nine of us – no bedroom, just one room and a very small bathroom. After about three months we moved to a bigger house. We left Iraq in September 2007 and arrived in the US October 2008. We came to this area because there are a lot of people here from Iraq.

We really wanted to go to Germany to be with my brothers. My parents' first plan was to go to Australia, but our application was denied. Really, we thought Canada would be the quickest, but my parents didn't want to go there because it's so cold and we weren't used to the cold. They wanted a warmer, sunny climate. So, we tried Australia, but Australia denied us because there were too many Deaf people in our family. There were five of us, one brother had already gone to Germany so there were four left, which was too many. We could have split up, but my parents said no, they wanted to keep the whole family together. My dad got depressed when Australia denied us. My dad went to a Catholic church in Syria, in Damascus where we were living, and they offered to support us. They asked why we fled Iraq and my dad explained that it wasn't safe for us to stay there anymore. So, the church sent us to an agency which supported refugees and they could help us fill out the paperwork to go to America. They explained that America had better schools for Deaf children. My dad thought that was a good idea and because I was still young maybe I could get Cochlear Implants and learn to speak. That's how my family decided to come to America. So, we filled out the paperwork and sent it in, America approved our application and we moved here. America was Plan C. I didn't want to come to the United States. I was really angry. I really wanted to go to Germany to be with my brothers. We came to this city because there were already many Middle Eastern people here and we had support and a community.

Six of my brothers are in Germany. One is Deaf. And six of us are here – two brothers, one Deaf and one hearing, and four Deaf sisters. I wish we could all be together. My oldest brother can come here because he has German citizenship, but the other ones don't so they can't come here, not even to visit. Germany has a very strict system and American's immigration system prevents them from coming, too. Several times my siblings have gone to the immigration

office to explain their situation and that they want to come here and visit their parents, but they are turned down. So, they can't visit here. Last time I saw my brothers and sisters was in Syria, but then two or three years ago I went to Germany to visit them. My parents can go visit them, too, they just went last year for my brother's wedding. I really wish we could all live nearby in the same area so we could visit often. But now every two or three years I go to visit them, it's far.

#### I WANTED AN EDUCATION

For people with disabilities there was no education, no support or services. Maybe there was in Baghdad, but not in my village. In Iraq there is the belief that the parents did something wrong if their child is disabled or Deaf. My mom had a lot of guilt and grief for many years because her children were Deaf. They [Iraqi culture] blame the mom and think she did something wrong to cause this to happen to her child.

My village didn't have education for Deaf children. There was a Deaf school in Baghdad. I remember my friend went there and I asked her what she learned at that school. She told me the teacher wrote on the board and the students had to copy it. Then they had to try and memorize it, study it, and on the test the teacher would choose one paragraph and the students had to write it word for word from memory. That's really bad, it's not successful in helping students learn how to write. They just had to memorize it. They didn't understand the meaning the teacher showed the paragraph to them then erased it and the students had to write it exactly the same. When they showed it to the teacher the teacher would point out all of the mistakes. Then when the girls were around nine or ten years old, they started learning vocational skills like sewing, flower arrangement, cooking, more vocational training. My friend told me she enjoyed school for the socialization with Deaf friends. But I didn't want that. I wanted to learn. I wanted an education.

Those other skills I could learn at home. I already learned to cook at home, why did I need to learn them again at school?

We didn't have to pay anything when we came here, it was free. We were referred to the Catholic church and they helped us. My dad went to the office and they helped fill out the paperwork. They got all of our IDs and everything ready and then we had to wait a few months to find out if it was approved or not. After it was approved, we went to New York and stayed one night and changed planes then came here. We had many friends here, so we stayed with friends for three nights and rested. Then my dad went to the agency and let them know we arrived and made sure everything was in order. My dad's cousin helped find an apartment and get us settled. They got it changed to my dad's name, helped us get beds, furniture, everything we needed. My dad didn't have to work when we arrived. My parents were older when we arrived so they got a stipend from the government and because they had four Deaf children, they also received a stipend so we could help out with the finances and rent. My older hearing sister also helped out.

We found a place to live and then started the process of enrolling in school. There was a school very close to our home. My older siblings went to adult school and my other hearing siblings went to the high school that was very near our home. That left the four Deaf siblings. I told my dad I didn't want to stay home again; I became frustrated/angry at the thought of having to stay home again. I told my dad I wanted to go to school. He thought about it and told me he didn't know but let him think about it. So, he asked his 2<sup>nd</sup> cousin if they knew about a Deaf school. So, his cousin went to the high school where my hearing siblings were going and asked if there were any Deaf programs or schools. There she was referred to the program in the unified school district, but my dad said it was a little bit too far, so he wasn't sure about it. I told him I really wanted to go to school. They told my dad they would offer transportation; he didn't have

to drive there every day, so he was relieved. My parents wanted me and my sister to go to school together but were told no, we couldn't, because my sister was older and should be in high school. She couldn't go to middle school. So, we were separated for school and my parents were worried but with time they got used to it. So, I went to CPMA and my sister went to HHS then two years later when I graduated from middle school I decided to go to HHS.

I remember we arrived when I was 12, we got all the paperwork taken care of, benefits, and got settled a little. I remember there was a woman, I can't remember her name, but she was a hearing woman, not Deaf, came to my house to teach us basic sign language. I really wish a Deaf woman had come instead of a hearing woman. I wish they had sent a Deaf model [language model] instead of a hearing one. Let me back up – that hearing woman came to teach us some sign language. The four of us, my Deaf siblings and I, sat down and my hearing sister, my older sister, interpreted for us. We knew home signs and didn't understand what the woman was teaching us. For example, she signed "apple" and my sister interpreted it into our home language. I learned really quickly. My older brothers and sisters were slower to understand. They kept asking what it meant, it was harder for them to learn. At that time, they were 30, 21, 15, and me, 12. It was really easy for me to learn ASL quickly. I was able to learn reading and writing quickly, too. My sister who was 15 learned pretty quickly, but my older siblings were much slower. Another example, that woman taught us math. The three of them didn't understand math. I already knew and could understand math because I used to help my sister with her homework in Iraq, so I knew. After a while that woman felt I was ready to go to school because I could pick things up quickly. My 15-year-old sister also was sent to school. My older brothers took more time and they kept practicing and finally they were able to go to adult school at Deaf Community Services. They studied there for 2-3 years. My sister went to H. High School. I went to CPMA.

My first teacher there was hearing. She signed well, and she was really nice and a good teacher, but she was hearing. Then in 7<sup>th</sup> grade I had three teachers, one was hearing, one was hard of hearing – she liked to use SimCom<sup>6</sup>, which I didn't like, and the 3<sup>rd</sup> was Deaf. I was at that school for 7<sup>th</sup> and 8<sup>th</sup> grade.

Really for a few months I was not really enrolled in school yet, just training/practice (this was in February) then in the fall I started 7th grade. I remember I entered school with Deaf peers, but it was different – we were on different levels. They placed me in that class because they thought I would learn slowly. I was learning reading, writing, numbers, etc., but I learned really quickly, faster than the other students in the class. The other students needed a lot of repetition to remember things and the teacher noticed I didn't fit in that class, so I was placed in another class. I graduated from middle school and decided to go to H. High School. I was in the Deaf program for one year then mainstreamed for three years. At that time, I really enjoyed school. It was my first experience going to school and I was so excited. But I was bullied a lot because I wasn't fluent in ASL, I didn't know how to write well, and I had moved from another country. The other students really made fun of me a lot. It was frustrating and there was a lot of drama, but I decided to focus on school (this was in middle school). After I graduated the teachers really encouraged me to go to MHS, but I chose to go to HHS because it was closer to home and I didn't have time for the drama. I wanted to focus on finishing my education. I graduated and went to CSUN and got my BA in Deaf Culture/Deaf Studies. In college I enjoyed going out with my Deaf friends and going out away from school. Really, I wanted to go to Gallaudet, but my family didn't support it because it was so far away. They weren't rooted in American culture yet and said I had to stay with the family because I was a woman and am Deaf. My parents didn't

<sup>&</sup>lt;sup>6</sup> SimCom stands for Simultaneous Communication in which a spoken and signed language are used simulataneously.

feel I could live independently. We didn't agree for many months and I got advice from my teacher, who recommended CSUN. I applied and was accepted so I went. I really wish I had gone to Gallaudet because many of my Deaf friends went there, but none of my friends went to CSUN. When I was in college, I was in such a hurry to finish, I didn't stop and think about enjoying the experience. Now I realize I should have slowed down and enjoyed myself instead of being in such a hurry.

#### I PRAYED TO BE ABLE TO LEAVE

Really, if my family had stayed in Iraq, I would have just been an old sister, I would have stayed home. I don't think I would have an education or a job, and probably not get married. I guess I would have lived with my family until I died. Growing up I did dream about having a degree and working. I wanted people to see I could do it. Growing up I always dreamed of that and prayed about it. At night I always looked at the stars and prayed please get me out of this area. I loved that area, it was so beautiful, but sometimes I prayed to be able to leave that area because I knew my future if I stayed there. I couldn't put up with that. My older brother could handle it, he grew up there for 30 years and didn't mind it. But I couldn't, I didn't have the patience. I asked my parents why I was born Deaf and they said that's how you were made. I was angry, but later I realized I couldn't blame God, it could be hereditary. Both sides of my family have history of Deaf people.

Not only did she (my mom) blame herself, but that culture tends to blame the woman, thinking she did something wrong to cause it. But they don't blame the man. Really the man could be responsible, too. Maybe in Deafness is in his genetic history. My dad's great uncle is Deaf. Two of my mom's great aunts are Deaf. They didn't think about it when they got married, about the history of deafness in their families. My dad has brothers and sisters, they all got

married and had kids and none of their kids are Deaf. My mom has brothers and sisters, they all got married and had kids and none of their kids are Deaf. Only my parents' kids, they had five Deaf children, that's why my mom mourned. Why only me, she thought? Why not my brothers and sisters, too?

### DEAF PEOPLE CAN DO ANYTHING

My mom doesn't still blame herself. A lot has changed. She saw that I earned my degree. That really had a big impact on her. The Chaldean culture has changed, too, in how Deaf people are perceived. Now we're perceived as human beings. And my parents are proud now. When they go to church many people praise them because their Deaf daughter finished school (college) and they ask what I'm doing now. When they say I am working everyone is so happy and proud so now my parents feel a sense of pride.

I'm showing them that Deaf people can do anything. A lot has changed. Also, I feel a lot of pride because I am influencing how they think, their perception of Deaf people. And now in the Chaldean community, many people have disabled children, not only Deaf, but other disabilities and they are not hiding that like before. In the past, children with disabilities were hidden away. Everyone looked down on the family and criticizes them. It makes the family feel embarrassed and they don't want everyone to look at them, so they keep that child away. Now they see me, I graduated, I have a degree and a job, I can go to parties, I go do many things with my family, I don't just sit around. I use ASL and sign language to communicate with my family and other people. That really helps other (Chaldean) community members feel confident that they don't have to hide their children anymore.

There is still one situation that really touched me. I remember when I entered high school there was a student who had just moved here from another country. The mother had died, and

that student lived with her brother, sister, and dad, the four of them. She explained in-depth what happened in their own home. The mother was gone, the older brother blamed that student, abused her, beat her up, never let her go out or leave the house or have friends or anything until she finally went to school. Communication was very hard for her. Learning language was really hard. I really felt sorry for her but at the same time I wished she could have been placed in a better home, but she wanted to stay with her family because it's all they knew. Again, I was really upset because the brother abused her, the father didn't do anything. The sister tried to help but the brother felt it was his house, he was the man of the house, so she couldn't do anything.

Before my brother really tried to control things, but that has changed. We used to fight a lot because I felt we were equal, and we argued a lot. But after we moved here, he started to change and respect me. He didn't say anything about my clothes anymore. I told him I didn't want an arranged marriage; I didn't want to be forced into marriage. I want to make sure I meet someone I love, who has a good personality, who isn't abusive, etc. I want to make sure I pick the right man. I asked my brother if he wanted to be able to choose his wife and he said yes. Now we have a good relationship, we're close.

The situation in Iraq has not changed very much. Now there is a new president. Really, it's about money. And many of the people who still live there are farmers, live in rural areas, they're struggling to get food, water, there's no electricity, most evenings there is no electricity. I remember growing up there wasn't electricity many times. During the war it was worse. We had to heat up the water on the fire, sleep with a lot of blankets and wear layers of clothes to stay warm. We could maybe only take a bath every four or five days because these wasn't enough water. It was a hard life. Not like here in America – you can just turn on the switch and have light, hot and cold water anytime, a shower anytime, there it was so hot, and we didn't have AC.

I remember my dad would take a nap and I had to fan him while he slept to keep cool. I didn't like that. It was hard work, standing there for 1-2 hours fanning him. Here in America, I have a lot of benefits and privileges. A lot of opportunities. And I notice people who grow up here always complain about every little thing. I want to tell them they are really lucky; they should appreciate it. They are really lucky they grew up here. Overall, I am really happy to be here. I have an education, a job, maybe in the future I will marry or have children or maybe adopt.

The Iraqi government does not support disabled people. Well, maybe like \$50 a month or \$10 a month, but you must be over 16. I will ask my dad the specifics. I know my brother received some money, but I don't know the details. My dad would love to tell you stories. He loves to talk about the past. Recently I asked him, and he and my mom decided to get married. They didn't know each other well; they had only known each other for a week. Then they decided to get married and they been together for many years. They have such a good relationship I asked them how they do that because so many people don't have good relationships and are separated. They have a really good relationship when my mom goes out for one or two hours to buy groceries or something my dad always misses her, he asks where she is, when she'll be home. They go to church together, sleep in the same bed. Many couples sleep in separate beds. They are always together.

# **Jacques**

AGE: 33

OCCUPATION: Rideshare driver

HOME COUNTRY: Democratic Republic of Congo

Jacques is an enthusiastic, passionate person who was eager to share his story in hope that it will help others. He spoke of his two children with great pride, children he wandered if he'd be able to have after becoming paralyzed at the age of 20. Jacques's positive outlook on his experience and life showed itself again and again throughout our conversation. Meeting other disabled people in his community gave him a renewed sense of hope – hope that he could drive, work, and provide for his family. Now he wants to do the same for others because he can relate personally to their experiences. Jacques is a leader in both his disabled and refugee communities, mentoring, translating, and supporting others the way he was supported when he first arrived in the United States.

I am Jacques M. I am 33 years old. I am from Democratic Republic of the Congo. I've been in the US almost 7 years. I've been here since 2013, December. I've been in a wheelchair since 2008 due to a bullet shot in my hip and I was paralyzed. I will talk about anything; you can ask me anything. I have no secrets. Maybe my difficulties can be a source of help for others.

I was born in the Democratic Republic of the Congo, it's called DRC, Kinshasa, in the province of North Kivu. I was born in 1986 and now I think I am around 33 years old. I was born in a very large family of ten kids and two parents, so it was a really giant family. We were five boys and five girls. But now because of life we live separate, you know I live in the United States along with my sister but the rest of the family they live in Africa some in Rwanda others in the Democratic Republic of the Congo. But both parents are dead. My sister lives here in the same city but we don't live in the same house because she has her family and I have my own family.

I was born in DRC in 1986. I grew up like the other kids, I knew nothing at that time because we lived in the countryside where schools were not available for everyone. Yes, they

were available for everyone who can afford it and those who can get there. But maybe a child starts his journey to go to school when he is mature enough because the schools are far away. Me, I began my school journey when I was 9 years old. So, I walked more than 4 km there and back, like 8 km, every day. School was about 4 km from my home. That is an estimation, it could be farther. We would wake up at 5:30 am. School started at 8:30 am but we began our journey at 5:30 am and sometimes it was raining, and there are mountains and crossing the rivers. And some people don't know that DRC is a jungle country.

## A LOT OF PEOPLE DIED IN THAT TIME

At that time, we were poor, we didn't have a ride, just walking. I began school in 1995 and in 1996 we fled from Congo to Rwanda. I can't talk much about my childhood there because I don't know much. I started to know more in 1996 when the war started. What I know is that we were going to our crop fields. Since 1996 we fled from Congo to Rwanda after the Rwandan genocide. As you know in 1994 Rwanda had a really terrible genocide. After the genocide against Tutsi in Rwanda those that were defeated in Rwanda fled from Rwanda to Congo.

Arriving in Congo they caused trouble there which pushed us to flee from Congo to Rwanda. We shifted like that. And a lot of parents, a lot of people died in that time period. I stayed in Rwanda a long time in a refugee camp. I was in the northern province called the Gihembe Refugee Camp in Rwanda. At that time, it was called Byumba province, but it's now called Gicumbi District. I was in a refugee camp there since 1996, in the end of 1996 until 2013 when I came from there to United States. Maybe 17 years.

We walked from Congo to Rwanda. At that time there was a war, fighting, killing people everywhere in our province. We walked and we couldn't use the streets. That way was very dangerous. The killers stopped cars trying to see if there are refugees fleeing the country and

killed them. So, we walked. We went through the forest. We walked through the night and in the daytime, we took a rest in the forest. There were 30 families walking together because they were avoiding going somewhere with a lot of people. Like 20-30 families, they went. From our province, we walked two weeks in the forest. Then when we got to where there was a little bit of security, we were able to take a car. It was very near the border of Rwanda. We didn't bring anything with us. Men would try to go and get food anywhere they can get food, even if it means stealing it. Just find it no matter how you get it, for those who are more vulnerable. I was about 9 years old. It was really scary, and I didn't know what is happening. People were killing each other. I didn't know who was killing who. I knew that later, after a long time when I was in the refugee camp. I knew that so many years after that incident.

I have a younger sister; she was around seven and a young brother who was only five. The rest of them were older than me. We were ten kids but most of them were with their families because they were mature enough. They had families too. During that time walking to Rwanda, we were six kids. My mom was dead already. We were with my dad. In my village, so many people died because of the war. They got chopped with machetes like my uncle's families and so many people. It was so bad. We experienced bad stuff. The strong parents could try to keep building our confidence, even if they know we can be killed anytime. They said, "You're ok, we'll make it", like that.

Now I can feel the way my dad was feeling at that moment without his wife or anyone else who can join and try to add something and help him. Nobody was there and taking care of six kids by himself. At that time male parents didn't know how to take care of kids. Their jobs were going in the fields, grow food, give food for their family. But they didn't know how to take

care of kids. That's the job of the mom. He suffered in that moment. I can feel the pain he was feeling at that time. He died when I was around 17. We talked about it so many times.

# WE HAD NO WAY TO GO TO SCHOOL

The first couple years we were together (my family) in the refugee camp but in 2003 some of us decided to go back to DRC, probably in 2002, so they went back and as a result we are spread. Some are here, some are in Rwanda, some are in DRC. But my parents were dead already. In 2008 I went, maybe the end of 2007, I went to visit my uncle in Congo because in Gihembe we had no way to go to school. I will say until 9th grade we could go to school. There was not a chance to finish the high school diploma. So many students were going to Congo to find their dreams and a better living and to get a high school diploma. So, people were going back and forth, especially young people. I would say students. Because in Rwanda before 2005 students had a chance. When they finished the 9th grade they continued with progression.

UNHCR paid for their school fees outside the camp in Rwanda. They paid for their school fees, those who passed high school with good grades, they paid for their university. But the time came when they said no more school fees so when they finish the 9th grade they would stay home or go to learn, other stuff, I don't know how to call it, those things like making materials, carpenter, learn how to build a house, how to sew things, everything.

I was going to DRC each year for school and returned to the refugee camp for the holidays. I didn't go and stay for a couple of years. I went to go to school and after I completed a year, I came back to the refugee camp. I went back to the camp because all my family was there. Only my uncle was living in Congo. When I was shot, I hadn't finished high school, at that time. I finished 11<sup>th</sup> grade, if I compare it to the US program. I was in Senior 5. If you finish Senior 6 you finish high school. But in the refugee camp, after like 3 years, I started a program with my

friends. They were teaching me some necessary courses and I went to do the private candidate exam and then I got my high school diploma in Rwanda. I got a high school diploma in Rwanda three years after I was shot.

### WHY DID THIS HAPPEN?

I appreciate UNHCR if they were running out of money, but they tried to bring those people who can help them. But then you will be classified as someone who didn't go to school. So, in the end of 2007 there was a war in DRC, another war, of rebels against Congo government. There were M23 rebels, some other rebels called Mai Mai, all those rebels were against the government. So, in that way I was shot when rebels attacked the village. I was shot in my hip.

I was out with the cows. It was a war and boys were trying to flee. I chose to stay at my uncle's farm and see if I could leave the village for a while. The killers were attacking the village so much. Of course, the killers were trying to steal cows and everything that's how they got money. They took everything that could help them. We were four boys at that time. My uncle's workers. I was with one friend who was my classmate, then we tried to run away, and I got shot. My friend fled, alive, but his two workers were killed. One was around 17 years and the other was between 20-25 years old.

I was about 20 years old when I was shot. I woke up with my normal brain after some days. Maybe a week because I lost some memory. But after a while I came around with my normal thinking and I started the interviews (to go to the refugee camp) right away. I was suffering so much, and they met me at my bed, and they tried to ask me more than 20 questions and I was so sad. It was increasing my depression. And myself I am asking so many questions

when I'm awake, why did this happen? Am I going to die? How will I make it? There was a lot of anger and grief.

I stayed in DRC like a month. After I was shot, right away I lost consciousness and after a couple of hours people found me and took me to MSF (Medecins Sans Frontiers/Doctors Without Borders). They took care of me in the first two weeks and I was doing the interview during that time. Then they cooperated with UNHCR and relocated me to the refugee camp. Of course, they asked me why I was in Congo, because I was already counted as a refugee in Gihembe camp.

And then the MSF they tried to help me and the Army division from all over the world — India, France, maybe Belgium, they are in Congo to make peace. So along with Doctors Without Borders they tried to help me. They treated me and they figured out a way they can send me back to the UNHCR. They did it and the UNHCR did not hesitate to receive me. They treated me as a refugee and it was since 2008 in February that I lived in a camp there (in Rwanda) again as a patient, as a paralyzed man. So that time, February 2008, I lived again in a camp and they tried to make some transfers to see if I can get some better health care. They transferred me to Kanombe Miltary Hospital. I was treated there for one year then they returned me back to the refugee camp. Arriving there they saw there was no change, but I had no wounds, but I had pain because of the damage the bullet made to me. And I was paralyzed. So, they said this guy has no way to live here in a camp you can live there when you are strong enough to make your life. So, they decided to find a way I can be relocated from there to the United States.

So, they applied for me, the American Refugee Committee, applied for me as they do for other people there. So, they did it. They told me they're going to try and that if I have a chance I will go. After a couple months they called me and said your application has been approved and

now you are going to go through the interview. We did the interview, it's my background. They asked me questions since my childhood so then everything was processed, and the application had been approved by Arizona and then that is how I flew from Rwanda to the US. The time came and they said now you're ready now you're going to the US. So, I flew from Rwanda to the US and arriving here was another challenge. They began the application in 2010. It took 3 years.

## MAKE ME MORE INDEPENDENT

After I became paralyzed, I lived in the camp health center because I had no way of living in those tiny houses for refugees. They are very little houses 2 ½ meters by 4 meters for every family. And the roads are really dirty and pits, stones, they are not good. So then living in there (the health center) I could have somebody help me. Because I couldn't handle life on my own. I needed to have someone push me every time if I wanted to go somewhere. I couldn't get in my house with my wheelchair. I arrived at the front door I had to have someone lift me and take me to the room. The doors were too small for my wheelchair. Each time I need to go around the camp to relax I need to have someone push me. Because I can't push myself because the way the roads are really dirty and full of pits. So, I stayed in the health center for a while. I stayed in the healthcare center for one year. In 2010 I lived in Kanombe Military Hospital until the end of the year. Then in 2011 they built me a house near the hospital so I can get out of the hospital. Maybe live my life, take a shower whenever I want and sleep. So, nobody is pushing me around or standing beside me. To make me more independent. I was famous in the camp.

I did not tell you how a doctor discouraged me in Rwanda. He told me when I got to Rwanda the first time from Congo with DWB, the first doctor who saw me he was from France. He was a bone specialist. At that time, I was really sick, and the situation was really bad, but my brain was strong, and I could listen to people. But he saw me, and he told my people now you

can just take him out of hospital because I don't need him to die here. There is nothing we can do here. He is just going to die in 3 days there is nothing we can do. I was in a coma for two weeks, I didn't die. I was not able to rollover myself and switch sides, now I can do it. How can he say this?

The UNHCR built me that house. They helped me a lot. They couldn't help with everything I need but the basic needs to feel more independent. For me, they did it (the house) as a prescription from the doctor.

### I DIDN'T WANT TO FACE PEOPLE

I was really depressed and over there it seemed like, right now I will say that it seemed like nobody cared because they have a lot of things to do. I found out I was depressed when I came to the US. I said, "Oh my god I was depressed there". And many people must be living in a deep depression over there and nobody knows. When I got shot, I was 20 years old I was a strong young man. But finding out that I got paralyzed and no more walking with my legs, it could drive me in a deep depression, and it did. To the point that I was sleeping in the house and did not open for anyone, even who brings food to me. Like a house member. They could bring food for me for lunch or dinner, but I will never open for her or him. That is depression. Because of not walking the same as other people I was imagining the way I walked hundreds and hundreds of kilometers, it was amazing. I think I was a really strong young man. Then if you see yourself you will never walk again that is a really bad thing to experience. And then as I was living in that little house for me a time could come, and I would never open for anyone. I slept there not opening for anyone. Every day I had pain and they thought maybe he's having pain and they would come back, but I never opened. Then I had only one person who I could open the house and for him, for me to open for him he must call me first. If it's not him I'm not going to

open. He stayed with me; he was the one who could help me with anything I want. He was a friend who just loved me and said, "Now I'm going to stay with Jacques and help him with anything just to help him ease his life." He was the only person I could trust. He met me in the hospital, and he cared. He approached me and asked me about my difficulties. I saw that he takes my difficulties as his. He came to see me often day and night day and night. He didn't show emotion and at that time I didn't like people who showed emotion because I was suffering so much. I just needed people to take it as like it is. Because showing me emotion was one thing that gave me pain. Maybe they realize I am finished. That person (my friend) could say, "Stay strong. It happened. Just take it as it is and be there. By the grace of God it will be alright". And he did not share my story with other people. He could answer or try to find everything that I need. He couldn't say, "Why?". Now he is here in the United States, in Tucson. We visit each other and he is still helping me. Even though I have a family he is my forever friend.

I would pass one or two weeks without going outside because of my own decision. I didn't want to face people, I just stayed in the house, I didn't want to see people anymore. Just two weeks without going outside. That is a very deep depression. I didn't know but each day I was in the house I was thinking about my life. I had a little FM receiver radio just to follow news and entertainment I liked that because it helped to reduce my bad feelings. But in that time, I turned it off. I never listened to the radio for two weeks, without facing people. After two weeks when I faced people, they said they missed me, where have you been? I tried to laugh with them, but I knew it was not a laugh from my heart. It was a smokescreen, to make them happy.

Because I didn't need to show my negative side, maybe people will give up on me and maybe they will stop helping me. I didn't want that. I was just trying myself to make a smoke screen to show positive things, but inside me it was terrible. It was like a volcano that needed to erupt.

In my culture they don't talk about mental health. They really don't. Which I think some people commit suicide because of that. Because they don't have somebody to listen to them, to listen to their difficulties. I'm sure if somebody approached you and tried to ask you some questions and you trust that person, that person will try to help you. I think now if they start to approach people to talk about their feelings maybe they will save some lives.

## IF YOU ARE DISABLED YOU CAN'T WORK

I knew so many other disabled people there in the camp. The biggest problem is that what makes them feel bad is those who are not disabled are allowed to work in the refugee camp for money or outside of the refugee camp. That is how it is over there. If you are disabled, you are dependent, and you will accept anything that comes to you. If you are disabled, you cannot work. They are just walking around just taking a trip for fresh air. So, they had no way to get money. Rwanda gave them access to everything that they can do. Those who are not disabled, they do work for money. And in the refugee camp UNHCR didn't provide enough money or enough food so maybe they can save a little bit for their clothes. So, to get clothes it's like selling one piece of your food and you can get a shirt or pants or some shoes. If I tell you that time 2008-2013 I had only two pants, made out of tissue, and another one made out of cotton – I don't know how it's called in the US, but it's those pants made for sports. So, I would clean my pants during the night aiming to wear them the next morning. Finding each and every way that my pants can get dry so the next morning I can wear it. If it doesn't get dry, I kept sleeping until my pants get dry and then I will wear it. It was a difficult life.

And those who are in charge to find food for you, when you see them every day, sometimes they say today we had no food, you have to be patient, maybe tonight you will eat, so you feel more depressed. And I think I am a young man if I had my legs or if I was strong, I

could go for me and for my family, but look at the way I am. That feeling drives you into another depression. And then you will close your door again. So now I don't even need to eat or drink because I'm nothing. I'm nothing because I can't do anything to support my family, I can't do anything to support myself then if I can't support myself or somebody else who am I. That is a serious question that you can ask yourself or somebody else and he will not be able to answer it.

In our culture the women are dependent on their husband or boys. The males chase life for their families because females are dependent. So, if you are male and not that strong you start to degrade yourself. You start to bring yourself down because you feel like you're nothing.

In DRC they don't see disabled people as cursed. I never saw disabled people in Congo. Never. Those disabled that I could see are those who became sick and left them with some disability, maybe paralyzed. I don't know how it is called. But I never saw the paraplegic people, the paralyzed people. Because in Congo everybody walks. If you don't walk you will never be seen. Especially in the countryside where disabled people could not live. Maybe disabled people could go to live in the cities, like Goma, maybe I could see disabled people but not living in the countryside and that is where I grew up. I didn't see any disabled people there. But if it's like a child or anybody who is disabled, they don't see him as cursed, or the family. Because most of them are believers.

### I SEE DISABLED PROFESSIONALS

I drive for two rideshare companies. I don't like it. Let me say no because there is one reason that pushes me to say no. Because it's the only thing that I can do. I am not physically fit. I don't have that physical strength that can make me do a lot of jobs like build roads or work in the warehouse, lifting, or working at Walmart packing the shelves. It is a no choice job for me. I

never had another job before, and I can't use my legs. I love it because it's the only thing I can do.

So, let me tell you. I had a dream for a long time, but my dream got cut off. I had a dream of being a schoolteacher and it is what I was taking in my high school over there. I was taking methodology and other courses that would lead me to be a schoolteacher. I liked it and I did it as a student teacher for two weeks. I wanted so much to be a schoolteacher, but these dreams are gone. Here in the US, I tried to go to college to see if I can be a dental hygienist, but it required so many things to achieve and I said this is not going to end well because I have a family to take care of. Since I was shot in 2008 and paralyzed, I started to think am I going to have a family? Am I going to be able to make a child or am I going to die like this? I thought maybe not. But when I came to the US it was different. I can tell the way doctors tried to help me. And I got to the point where I can get married and have a child.

Let me begin with my experience in the US since I flew from Africa to the US. I can't dream about being a teacher anymore. But I think about maybe working in a library. I could have access to the internet and books. I have never seen a disabled person working in the library. How good that must be, working in the library. I can add some more knowledge that will help me to get a better job. I never see disabled people working, I see them working as professionals. I don't have that degree. I see disabled people working in the DES, helping us apply for food stamps, helping us apply for things. I have a friend who is disabled in the arms and legs and he works in the college. He has a degree. He is a professional. I can work as a librarian, giving the orientation, putting the books in order, that kind of thing.

### I LIVED THAT LIFE

After dreaming about teaching and the dream did not come true, because of my experience, that bad life, if I can get some special training maybe I can be a mentor. Maybe I can help people. You may see a psychologist, someone who did go to school and learned about psychology and how to talk to people. But he cannot be as good as I can be because I lived that life. I know the feelings. I know the way he feels, and I know something that can heal his thoughts. So maybe if I get the opportunity, I can be a counselor, something like that. I just like to talk to people. I can be a volunteer if they give me some training. I can do it with all my happiness. Because if I can tell somebody and his depression can get reduced, I don't need the money.

One time I drove somebody from the hospital. She was with her mom. She was a young woman, 23 years old. She was really depressed at the point of crying in the car. Her mom said she is depressed she has anxiety, everything. But when I started to tell my story, I drove them 23 minutes, when I started to tell my story it cheered her up and when we got to her home she was smiling. This is my gift.

### MY APARTMENT WAS NOT GOOD FOR MY SITUATION

In 2013 I flew from Rwanda to the US. Arriving in the US I found things are completely different. My first week in the US, I had nobody to take care of me. When we came here, we had a case manager who came to our house maybe every day to show me life in the US, to teach a little bit about the culture, to show how to ride the bus. Just basic things you may need to survive. For three months they should help. In the first week they came to get us at the airport they bring us home and then from that time I never saw them. And the problem is when you arrive here in the US, they said don't go outside you may be killed, if somebody knocks, look

through the door and if you don't know them don't open. For some point I can see they may be right, maybe you can be kidnapped, maybe you don't how to call 911, you don't know the environment or how safe your neighborhood is. Even if you go outside but don't get kidnapped maybe you will get lost and they will be searching for you. But things were different. Everything was different. People are hospitable. Not all Americans are good, there are some bad people. How do I know there are some bad people? I saw them. How did I see them? In Africa nobody insulted me. But in the US, even if life is better, the best compared to the one in Africa, I couldn't make money in Africa but here I do, and they take care of my family. But here just near my house when I was walking from my house to the library, somebody passed by. They were in a truck. It was the first two weeks of our arrival and somebody threw two eggs on me. Two fresh eggs, from the truck. I didn't know what to do. I didn't know why he did it. It was very bad. It happened to me. I told my friend Mia and her brother that somebody threw two eggs. I was with my brother and he said let's go home. I said, "Let's go on. These things come and pass, and life goes on".

The agency (Catholic Social Services) here is in charge of finding an apartment, they know everything about your situation. They know you are in a wheelchair, you are sick, this and that. But I was surprised I came here, and my case manager did not find a good apartment for my situation. But I didn't think anything about that because I saw that it was pretty different from my house that I was living in Rwanda in the camp. I see it's nice. Later, I realized after finding out that I have rights, to accommodate my requirements.

Those agencies need to know that. I was not able to go to the toilet by myself. I need a chair. I was surprised. It was a tiny house. I came with my brother, but I was surprised. I could get in the door; it was wide enough. But going in the shower, toilet, problem. Cooking – I

couldn't cook. It was really high. When he went to work, I would suffer, stay hungry. Going to the toilet, too, I could wait for him. They need to know about that. And when they get here, those who are strong enough are required to go to work in 3 months. But what about those people who they take care of? Who will take care of them? They need to know about that and prepare something. They need to change it for sure. I just sit there and wait (for my brother to come home).

But more life in the US. Markets – in Rwanda I was not able to walk around and go to grab some food somewhere. Here I can. Over there in the refugee camp to get a wheelchair you have to apply, and it can take maybe 1-2 years. And if you get a wheelchair maybe it's not your size. Maybe it's too big or too little. If it's little, like for children, they tell you to find somebody to switch with. But here, your health insurance, if you are approved to get a chair, they bring the experts to measure you and to make sure you get the right chair for you as prescribed by the doctor. Here I can buy a chair. Here in America so many people feel pity on other vulnerable people, and they help. If I don't have a chair and I say it to 2-3 friends soon I have a chair in 3 days. That is a good side of US. People are hospitable. When you ask for help so many people will help you. One time, it's like a testimony, my car got a flat tire. I took my wheelchair outside and sat on the side of the road. Two women passed by and stopped. They asked me, "Do you need help". I said, "Yes, I need help". They loaded me in their car and took me home. They bought me some soda. I had money. But they stopped at Circle K to buy soda for themselves and they bought one for me. That really touched me, seeing those good people.

Maybe some people say that same way they help is the same way you can be kidnapped.

And it might be. But what I believe in is this: whatever you will be that plan will not go away

from me. Each and every plan for you, you will go through that. Because there is a plan for their

life. That's what I believe in. If I get kidnapped that is my life. Maybe I protect myself, but I still get kidnapped. Why do people get in accidents? Because that is the plan. You can't avoid that. That's how I believe it. Whatever is your plan you will need the help of people. People need each other.

#### YOU CAN DO WHATEVER YOU WANT TO DO

I met Mia in the very first weeks. She talked to me. I didn't know any English. Since I met Mia, she talked to me and I told her how depressed I was in Rwanda. She asked me, "Do you know you can drive?" In my heart I said, "What's wrong with this woman? Can she see I am disabled? How can I drive?" But she had a secret. Her brother drives a car, and he is paralyzed, legs and arms. He is a good guy. He helps to fix my wheelchair. When I need a tire for my wheelchair, he purchases it for me and helps to change it. He lives here in the winter season and in the summer, he goes to Oregon. Six months in Oregon and six months in AZ. Whenever he goes to OR he makes sure I have everything I need for six months to take care of my chair.

When I was about to answer the question about driving, she said, "Now Jacques, listen, in the US you can do anything you can think of. Don't say you're disabled I can see you're disabled. You can do whatever you want. You can become whoever you need to be". Then I said, "How is this possible?" She said, "Next week I will take you somewhere and you will meet some people living with disabilities." She took me to the wheelchair basketball team then after playing sitting basketball she asked people to talk to me. They talked to me and shared their stories, and I was impressed that everyone has a job. Everyone has a job. Even those who are not strong like me. Those who have trouble with their arms, those who cannot push themselves up a hill, they are not that strong to push themselves. But they can go around the city going everywhere. These people are really seriously injured, and they have a job. I didn't know that

having a job is not about being disabled or strong or physically fit but because of my brain. This is one of my biggest barriers here, because of my thick head. Then she said, "You know another thing, all of them they drive". Somebody said, "You see Jacques I can't bend my fingers like this, but you can do it. You have a strong brain, why can't you drive?" He said it is about your brain not your legs. You can control the steering wheel with your arms. You have good eyes. You can drive. I said wow! I can see myself driving. Mia Hansen helped me to get the first car with hand controls in it. A friend bought a new car, and he sold the old one to us. I learned how to drive with that car. I became an expert driver, now I can drive for rideshare. This is amazing. I do it as a source of my income. People here are impressed I can drive. When I visit people in a nearby city they ask if I drive there. If I can have work even part time just to put a smile on some people's face that would be great.

I appreciate the life I live here. Because the US was one of the superior solutions and I love it because they do care about somebody's difficulties. They ask about depression; they like to share stories. Maybe you don't know where the answers will come from.

In 2014 I began to learn English. It was really a challenge. And learn about US culture. It was a big challenge. It's not an easy thing. English is one of the most difficult languages to learn. In 2015 I was single, doctors helped me to heal my body. I asked the doctor is it possible for me to get married, have children? He said yes. It was the first time I heard that. It was the first time to speak that word out of my mouth. He said why not? In 2015 I got married, in the beginning. In November 6<sup>th</sup>, 2015, I had my first child. A baby boy was born, and now he is almost 5 years. I said now I'm blessed; I have a child. In 2018 my second child, a baby girl, was born and I said ok.

#### THEY ABUSE HUMAN RIGHTS

If I were in DRC now my life will be really bad. Because there in the DRC there is no human rights. 100%. Not even a little human right because people abuse the human rights, no matter who they are. The government, police, military, leaders, they abuse human rights in general. My life would be worse because I can't get anything to help me. They would tell me to do my best. There is no help from the government. Maybe the private agencies, like MSF. If I live near there maybe I will get a little help from them. Maybe the churches or other organizations, maybe when they visit, they can buy me a wheelchair, they can give me some food. Maybe the church can give some soap or some body lotion or something but no help from the government. I can't work. People are still fleeing Congo every day. In Rwanda there is a camp that is not older than 4 years. Why? Because people are still leaving. Neighbor countries have so many Congo refugees.

I am a US citizen. I got my citizenship last year. I voted this year. That made me proud.

My first time in my entire life. That is my right.

I came in 2013, before Trump. I know so many people in the camp who were going to come to the US but now they are stopped. That time was not good for refugees. I know it was not only for my nation but all over the world. He changed a lot of things. People cannot ignore it.

Now their applications are stopped.

# I'M HAPPY WITH MY LIFE

People come here not because they are poor. Not because they need money. I don't need money. I lived in my culture; I know to eat I go to hunt. I'm happy with that life. But if someone threatens me, I need to go somewhere to be safe. If you can dig deep into that story you can find out something else. If you can see some refugees from Libya, they come to the US, what are you

going to think about France and the US involved in the war in Libya? Americans need to understand those people don't come here to take their jobs. They come here for security. Because where we live, people don't like each other – not because they don't but because of something else. It is corrupt. It looks the same way as why some Americans think refugees come here to take their jobs. They don't know the story behind it. That can create another hate. You hate that nation that is coming here. For sure they are not coming here to take their jobs.

I just want to say thank you to America because they try to treat people equally. They try to apply equal rights. They try their best even if it's not 100%, but it's way better compared to ours. God Bless America. I didn't know if I will drive; now, I can drive. And my children were born here. Since I came here almost seven years nobody pushed me around nobody threatened me. And I got help. I didn't have a dream. I can compare my life in Congo if I am there right now and the life I am in right now, I can't take this chance for granted. Because I saw so many things, I experienced so many things, I saw how people killed each other. I know how it is painful to be outside of your country. I know that it is painful when your country hates you and tells you that. I wish it can't happen to another person. If you are alive, if you can sleep, if you can eat, if you can say what you want to say, then say thank you to God. I'm happy with my life today.

#### Masuod

AGE: 34

OCCUPATION: Information Technology

HOME COUNTRY: Afghanistan

Masuod spoke with pride about his four children and his dreams of a better life for them in the United States. He became emotional throughout our two interviews when he spoke about how he was treated by others in Afghanistan, including his own parents and family. Over and over again he had to prove himself as a disabled man, even offering to work without pay to show that he was capable of doing the work. While he's grateful that he can receive the medical services he needs, he looks forward to the day when he can return to work and support his family independently.

I'm Masuod, I come from Afghanistan on February 9, 2019. At that time, I had three kids and Yusuf was born here in March 2019. When I was a child, maybe 10 years old, I fell playing sports and broke my hand. Two years later I had pain in my legs. I have six sisters two brothers. Two are in Afghanistan one is in Kansas. Manhattan, KS. One is in Maryland. And other one lives in India, three of my sisters are in Kabul. Two are at home. One is married in Kabul. Two brothers are both engineers. One is civil engineer one is power engineer. He has master's degree of engineer.

# THE TALIBAN CAME AGAIN

That time in Afghanistan was good, when I was a child. We lived in Kabul. My father worked in government at that time. He brought me to the children's hospital in Kabul because that time the services were good because the Indian government covered many things. The name of the children's hospital is Indira Gandhi Hospital. The doctors were good, the facilities were good, good medication, like that. They did one operation and found maybe an infection in my legs. After one or two months I can walk good with no pain. Then the government started fighting. They started fighting, the hospital couldn't do anything, there was no money, my father lost his job, there were no jobs, from the capital we went to our village. There wasn't good food,

no medication, and my body was infected again but my dad and mom tried to find doctors. At that time there wasn't any good facilities, no complex hospital, there was just one doctor to write prescriptions. No testing, no specialists, just one doctor. That time was a little better but after two or three years the Taliban came again.

In 1996 the Taliban came again. I was a young man, maybe 17 years. Again, my dad lost his job. They (the Taliban) took everything from my home in the capital, removed the rugs and everything from my home. My dad worked in resistance against the Taliban. My father was military. His rank is Colonel. But he also worked in the Afghanistan army but is now retired. We went to our village again, and again the Taliban took everything from my home. We moved because there was no work, no medication. I was in bed for one year shouting and crying in pain. I had a lot of pain in my body, sometimes in my stomach. But I cried a lot. My mom cried with me. They massaged my body, but they couldn't massage my body all the time. I had a lot of pain. At that time after one year, I stood up and my bed was bent, my spine fused, I was disabled. Arthritis caused this. Because of the war, no doctor, no medicine, after one year my body is bent. I needed good food, good weather, good life, maybe this wouldn't happen.

At that time, things were bad because the Taliban was bad. My dad tried to fix my body, but they couldn't because there we no doctors and no money. We couldn't go to doctors outside of Afghanistan we don't have any money. Around 9/11 the coalition forces came to Afghanistan; they came to the capital again. My dad joined the military again, but my dad said, "You are now disabled. We can't do anything.". But I told my dad I can start school again. I went to school. I finished two years. I had to leave school and class for two years. After I came back, I started two years again then I graduated from school and went to University then finished University. Then I worked on a big project of the Coalition forces. I worked there.

When I was in school my body was a little better. But in 2004 the Coalition forces brought me to Turkey and put steel in my leg. But I started University again in 2008 and when I graduated University I worked on this project.

I studied Computer Sciences. That was the first time with computers. People didn't know about computers. We knew a little about computers, but we started a big project for the United States military in Kabul, for the Afghanistan government. We supported the military of Afghanistan, like the Ministry of Interior, the Ministry of Defense. The two ministries started a big NOC – Network Operation Center. I worked there as a manager. I started their first as IT support and worked up to manager. This was for the Afghan government. We contracted with the US Army but worked for the Afghan government. That kind of project.

# NO ONE WOULD MARRY ME

In 2011 I wanted to be married but no one would marry me because I am disabled. When I wanted to get married, I requested from my classmates, but they told me your body is bent, I can't marry you. In Afghanistan it is a different culture. Some people want good faces, good bodies, but my face is good, but they said they can't marry me. I asked my relatives, like my aunt's daughter or my father's sister's daughter. Anyone. But uncle found Lailoma's (my wife) uncle and asked if she can marry me.

I went to my village to find my wife and one year later there is my kid. Second year my other kid was born. The 4<sup>th</sup> year my daughter was born. And after seven years the youngest. I came in 2019 because I think how difficult their lives will be because I am disabled.

In Afghanistan no one respects disabled people. They never respect me. People never invite me to be their guest. They think about me only as a disabled person, not as a person. I knew some disabled people in Afghanistan. There is one organization I worked there sometimes as a

volunteer IT. They sometimes introduce to people about disabled people. But I showed everyone I can do anything. I came to the United States. If they see the United States in their dreams, they are happy. I came to the United States to provide for my family. I showed everyone I can do anything.

#### PEOPLE DON'T RESPECT ME

I didn't have support in Afghanistan. A lot of people are injured during the fight, like bomb explosion, rockets, pistols, now they are disabled. Maybe their leg was cut off, maybe they couldn't walk. A lot of people had polio there. There was no vaccination, no immunization. A lot of people have CP (Cerebral palsy). The Taliban use a lot of rockets, bombs, and chemicals, so a lot of people are disabled now. It is bad because there are no facilities, no government help for the mom and dad. It is very difficult for mom and dad. Maybe if there is one disabled person in the family the family is poor because they can't take care of the child. There is corruption.

Everyone knows about Afghanistan. It is difficult to find food. For us, a long time my dad was a simple government worker. The simple workers can just find bread, a little food, not good food. Good food is sauce from potatoes. That is good food. Better than that is maybe green beans.

Sometimes my family, my dad, also call me disabled. I applied for the United States, but my dad told me, "Maybe you will never go to the United States. You are a disabled person. You will never go". I said, "Dad, the United States has human rights. Human rights are there." He said, "No, they just need the good-bodied people, not like you."

There is not special education because I told you the mental attitude there they never go to school. Because people's laughing? Like that. Look at my son. He also has a problem. He couldn't speak and there is no speech therapy, no facility like that. People laugh and there is no respect for people. People like me, with a disabled body, it is a big problem. People call to me

and don't respect me. Like my friends they call me "disabled people", not Masuod, because the culture is different there. The people are different. They are not educated there. No respect.

If they go to school maybe they have a lot of problems. They may be crying every time. Because they don't respect these kinds of people. There is a lot of difficulty. People don't trust disabled people. I graduated from the university; I went to one company. They saw me and asked, "You can do the work?" I said yes, I can do it. I found some people to go there. They recommended me. After that they hired me. It was difficult. Maybe other people, their body is okay, but they are not talented like me. They hire them. But they asked me, "You can do it? We have a big project. Maybe we will lose our project because of you, if you are here." That's not good. I'm disabled but I can do it. I told them not to pay me any money and see my work, then pay me. It was very difficult.

I got a special immigration visa just for family members like children and my wife. Everybody knows I worked with the US Army so maybe we will be killed in Afghanistan. They asked why we worked with these people (the US Army)? We told our director that we were threatened. Maybe they will kill my daughter or my sons. The director said, "It is not good for you, you should go to the United States." It was not good for us. A lot of problems started. My wife was pregnant. I didn't have a car. I didn't have friends who could help me.

#### MY HUMAN RIGHTS ARE BETTER

When I first came to the United States it was very difficult. No one helped me. I looked for a car. I didn't have friends. Now it is better because I know things but at that time, I was so worried and stressed. I had a lot of stress about things. Because it was a different life, different work, different things. My family is good, but I lost both my kidneys. I go to dialysis now.

The doctors here are better. In Afghanistan they don't cover anything. There aren't specialists. Here, the insurance picks me up and drops me off at dialysis. Maybe my family has a good future here. I can't work here because I go to special dialysis three times a week.

I came here, the United States is a good culture. They are good to me. Everyone respects me. My human rights here are better. My rights are high. My body is different. I can't work. The government pays money for us. I have medical. No one can tell me anything. I respect everyone. In Afghanistan, to get one food I have to respect everyone. My rights are high. There, somebody is good but never says hi to me. I am so happy I am here. I have a lot of difficulty because I started a new life from zero. It was difficult because I am disabled but I can do anything. My children have more opportunity. They can do anything. In Afghanistan there are no design for ramps or anything. They accepted workers' rights but did not do it they need a budget. There is corruption. The government pays maybe \$40 per month for disability. If you were injured in a fight, in war, not if you were born disabled. There is no polio disability, nothing like that. If you were injured in the war maybe they pay \$40 a month. \$40 is not much money.

I paid my own money to come to the United States. The organization, my Afghani friend works there, and connected us. They helped us to apply for citizen, medical, everything like that they applied. But for me it is also so difficult because Lailoma is uneducated. I went to IRC, I started driver's class, I got my permit and lessons, now I drive. I applied for my visa in 2016, I got it February 2019.

My kidneys got worse here. Before, maybe they were working 20%. Now about 4%. After a kidney transplant maybe, I can have surgery on my back and legs. Then maybe I can work. Maybe I can do security or something. Here I am waiting for my kidney transplant. I've been waiting one year, maybe four years more. Because if I don't have my kidneys my body

isn't strong, so I can't have surgery. In Afghanistan there is no facility for medical. When the baby is born there is delivery space. In Afghanistan, some people come with us with the mother delivers. I just went by myself. I stayed at the clinic a long time; I couldn't enter the clinic. When Yusuf was born, me and Lailoma were in the same room. In Afghanistan it isn't like that. The mom enters the clinic, the family and the husband wait outside the clinic. They're waiting. They call you to bring the soap, the gloves, you bring a lot of things. There I should be doing everything, listening to what they say, but no one helped me. No brothers, no relatives, nobody helped me because I am disabled. People don't want me. No brother wanted me; no sister wanted me. Because I am disabled, I am not good. They think he is disabled maybe he's not good.

Here, no Afghani come visit me. No Afghani come talk with me. Maybe they think about me, he isn't working, he doesn't have money. They don't go to picnic with me, nothing That is a problem. They think, "he is disabled, he will maybe make problems for us" so they don't talk to me.

My parents are the same. Because sometimes they say bad things about me. I came to the United States, now they think, "Oh now you're our son." Before they didn't talk like that. They overlooked us. There was tension. I think about my future life. I am so worried about my family. Because after the government support stops, what should I do? My house, rent, my wife is uneducated. My kids are small and can't work. But I respect my god, he can do anything.

# I AM STRONG. I CAN DO ANYTHING

The first time when I came here was difficult. No one will walk with me no one will talk with me. They didn't do anything. In Afghanistan like that same, I told you before, I wanted get jobs, my classmates all got jobs but just the HR manager see me, "You couldn't do it" like that. That's prejudice!

Other Afghani refugees they come from Afghanistan they think the same. Like my friend to went to his house, they blocked my phone, they blocked my Facebook messenger, they never talk with me. I couldn't talk with them. They say I'm not their friend. Like that. I have a lot of stress about that. But I am strong. I can do anything. I am disabled but I have good ability. I can do anything. I am a refugee but soon after I came, I got my driver's license. If I didn't lose my kidneys, I can do anything. I can work in business. But my kidneys make me weak. And the Afghani caseworker discriminated against me. I went to the agency and the Afghani guy who worked there told me he won't support me. Only for one month. But I was introduced to an American woman, a caseworker, and she supported us more than one year. That is his job, but he never wanted to help me.

I don't really miss Afghanistan. I have a bad experience there. I had a lot of headaches. At work, the bazaar, everywhere, some people called to me like, "Disabled person, where are you going?". Sometimes I was ashamed. My dad was also ashamed. He never walked with me. I asked my dad to go to the wedding hall together. He said no, people are watching. He was ashamed of me. I told him I am disabled. I am not an alcoholic. I don't do drugs. But now they are proud because I came to America. They tell people their son came to America.

### Rihana

AGE: 25

OCCUPATION: Student, Wheelchair basketball player

HOME COUNTRY: Somalia

Shy and soft-spoken, Rihana quickly warmed up. She spoke with pride about her accomplishments as a wheelchair basketball player, working towards her GED, and learning English. Orphaned as a child and separated from her siblings, Rihana met a family in the refugee camp who took her in. As a young, disabled, single woman Rihana described how cultural beliefs and norms viewed her as a lesser human being without rights, and what her future would have been had she stayed in Somalia. Rihana is changing the narrative around gender, disability, and religion by getting an education and becoming involved in her local disabled community.

My name is Rihana. I'm from Somalia, Mogadishu. I'm 25. I walk with crutches. I had polio since I was born. I can't walk without crutches. In Africa we didn't have a polio vaccination. It's too bad. In Somalia it's very difficult for a person with a wheelchair or that uses crutches because Somalia does not have sidewalks. It's desert and people like me they only stay home, no education, not a lot of opportunity. It's very tough for women. As handicapped and no family there, it's very difficult.

In Somalia, they started a civil war in 1992 maybe. The group was called Al Shabab. They want to control women. There was no freedom. And they fight with everyone.

When the people help you, they kill them. It's still happening now, every three months, six months, explosions, kill innocent people.

My mom passed away when I was five years. She was killed in an explosion at the marketplace. My father passed away in 2006. He was killed by Al Shabab militants. And my mom, her best friend, she adopted me. I was living at her house and she died. After she died, my mom's best friend, her son was asking me to stay to be his wife, or he said I had to leave his house. I was 13. I said no and he beat me in the head. I have two brothers and one sister, but I

never saw them because we grew up in different families. Because my parents died. In the future I will go back to Somalia and find them. I don't know where they are now.

#### WOMEN WITH DISABILITIES HAVE LESS RIGHTS

In my culture women get married young and depend on a family. That is how it has been for a long time. Now young people don't understand. Women have a choice. So before, you have to stay with your family and the married family member. I said no, I don't want to stay with the man. I grew up with him. He was like my brother. When his mom died, he said if you stay you will be my wife. I said no because I was young. I didn't have experience. I didn't want to get married as a young woman. When you get married and you're handicapped your life is very difficult. No education, you have to stay with the man, so I said no. I left the house and went to the neighbors. And we raised money for a better life. Like, we had to escape. Otherwise, we will be dying. If I had stayed in Somalia it would have been very difficult. I didn't see other women; I saw women without handicap get married young and their situations were very bad. Men use their power to control women. I don't agree with that in my culture. I think women have a choice. Some women understand some women have no choice. They have no options. They die or get married. Maybe to someone they never met before. Women in my culture don't have rights. Women with disabilities have less rights.

I never went to school. If I didn't have a disability I could go to school. There it is not the same for people like me and people without disabilities, because they have more options. I think it depends on your family. Your family decides. And my family died when I was young, so I didn't have a lot of opportunity.

# IT'S VERY DANGEROUS FOR WOMEN

People in my neighborhood said we are going to be refugees, like go to a different place. So, I went with some people as a refugee for a second chance and to be safe because Somalia is very dangerous. To me, it's very dangerous because I don't have my family. So, I left the home. After that I became a refugee in Ethiopia. We didn't have money to take a car and we walked all the way. Sometimes we had to beg for a ride. It took six months to go from Mogadishu to Ethiopia because we didn't have money, so we have to beg for some rides and walk. In the road it's very dangerous for women, some of them are killed and some are raped. So yes, it was very dangerous, but we made it.

So, it took me like six months to get to Ethiopia. So, after I got to the Ethiopia refugee (camp) I had to explain why I was here to the refugee agency. After I explained they accepted me to come to America, but I had to wait five years.

#### I LEFT MY COUNTRY AND I LOST EVERYTHING

So, um, I didn't have any money, but I survived by staying with some friends.

We shared a little bit of food. And in the refugee camp, people who work there they give you some rice, some oil, without no tomato no onion. You have to figure it out how to cook or share with a friend. Some friends I met in the refugee camp called Awbare.

I was in the camp in Ethiopia for five years. If you don't have family, it's very difficult. You're single, you're handicapped. And I left my country I lost everything. When I got there, I used my crutches. So, they give me a little bit in town with the plastic, everything, a blanket, but Ethiopia is very cold sometimes. It's very difficult. So, yes. For people like me is very difficult. You are woman. And you are scared of the men and they want you to get married young. I say I'm lucky. Very lucky.

I almost give up on my life and everything I lost; I didn't know people. They'd been there before. They went when the civil war started. So, a lot of people were there ten years, twenty years in the refugee camp. And I was new, and I didn't want to share with everyone. But the people are nice, and the people check on you. So, I was sharing with my friend Halimo and we became friends. So, I was very lucky. So, I stayed. And I shared one packet of rice and little bit of oil. No gas, no tomato. She said don't share your things. You can sell them and get clothes. The things you have, you sell them because you need oil and tomatoes, and a plate for how to cook. We didn't have dishes. For single people it's very hard in a refugee camp. But Halimo's family was 12 people. So, they can sell some, and they change (trade) like the oil.

We lived in a tent. There were no houses, just tents. It was very cold. Some people have money, so they have jackets. And some people who don't have, they give you blankets.

In the camp it was cold and rainy. It was hard to go places with my crutches. So, I had an infection in my feet. The doctor said I have to cut (amputate) but I said no, I don't want to give up my feet. So, I couldn't walk. Because when I walked all the way to Ethiopia. I was walking with crutches and bad shoes. The doctor who took care of my feet was Ethiopian. An agency, they paid for everything I needed. So, I didn't pay any money because I didn't have any money. He just sent me the medicine. So, I took the medicine and I stayed, I didn't walk for like three months, and it was fine.

In the camp the school was very far, like two hours. And you have to pay some money. If you want to learn English, that is money. The guy who teaches you is not free.

My friend Halimo was looking at the paper when they accept people in America. You have to read your name (on the list). So, I was sleeping in the afternoon. When I eat I like to sleep. She said, "Oh Rihana! You're going to America!". I was like, "Oh, you're kidding me. I

don't want to go to America". When I saw my name, I couldn't believe it. And people say, "Oh you'll survive. You're a very strong woman". And people were happy for me. All my friends, they came before Trump. They went to Seattle, Ohio, Minnesota.

# I WAS YOUNG AND ALONE

I came to America in 2014, April 30. After that, the refugee agency, called IRC (International Rescue Committee) accepted me. IRC is a good agency. When I came it was late. I was very tired. They said I had an appointment. So, the women are fast, like boom, boom, boom, Check-in, and go get food stamps. I was like, "What are food stamps?" I came April 30. They had an apartment and a lot of Somali visited me. I had support and help when I moved here.

Coming to the United States it was very scary. I was young and alone. I didn't speak English. I was 18. I was confused when I came to Tucson because there is a lot of Spanish. You know, when I watched the movies and you see like New York is big, California is big, but Tucson is a little bit small. It was my first time to hear Mexican people. And we watched the football (soccer) but we only hear people speaking Spanish from like Argentina. I couldn't even speak English. I went to the high school, I spent time, two years, to learn how to speak English.

### THE IRC DIDN'T KNOW HOW TO HELP

After that I met Mia. She was a volunteer at IRC. Mia helped me a lot. She taught me, um, how to live in America, how to go shopping, how to use a wheelchair, how to learn English. And I really am grateful. And 2019, June 20 I became an American citizen.

Mia helped get a new wheelchair. IRC didn't know how to help with that kind of thing. When they taught me how to cook, how to make fire (use the stove), because I'm handicapped, I need a little bit easier. It was very dangerous. Now when I go to school and shopping, I use a wheelchair. When I came to the United States, they gave me a big wheelchair. I can't even push

it. Like you see at the airport when people are waiting? Like that one. My crutches were made of wood. So, these are made of metal.

My apartment, the shower I love it. It's bigger and I use my wheelchair. The kitchen, I can use my wheelchair when I wash the dishes. It's very easy. Mia did everything. Mia understands because she has her brother, so she said, "No small bathroom, she has to use her wheelchair!" So, when she looked at the apartment, she said, "It's too small we have to wait". We waited a long time. This one is low income. I was waiting like five years. I think now they (IRC) understand people like me, now they changed.

When I met Mia, we met the coach for the university basketball team, who is coaching wheelchair basketball. It was the first time. That one, it was tough. To play three years, no English. Now I play in the community, women and men. I play defense for the local and state teams.

My teammate, her name is Jennifer, she asked me, "How did you get to America?". I said, "By airplane. Do you think I walk all the way?". I said I had a visa as refugee. She asked, "What's a refugee?". So, I have to explain to people. Now they understand.

I have basketball so we travel a lot. We drove to California, Las Vegas, one time we went to Wisconsin, Chicago, IL. I'm very good at basketball. I can't shoot rebounds but I'm very good at defense because my arms are long. I'm fast. People shout, "Go African girl! Go Somalian!". When I met Mia, I was hand cycling at the University of Arizona. I was fast! Mia said, "Oh, I need that girl on my team!". I didn't even speak English. I didn't know basketball, it was hard. So, we had a translator to play. The team was tough. They said, "You're African? Show me you're a strong woman".

#### I HAD TO CHANGE MY LIFE

Now I am studying for the GED. In the future I would love to study social work and go back to my home to help women. Be a counselor or something.

I think American has a lot of opportunity. And you can change. Whatever you want to be. You have a lot of freedom; you use your force. Women like me, strong women, you learn, you get an education and go back to your country and share with people like you. Like, women there do not have an education. It's very difficult. And they marry young and if you're handicapped, your life is very difficult. But if you're like me and say no marriage, I had to change my life. It depends on your situation. A lot of people stay in Somalia, it's their country, it doesn't matter if we have a civil war. It's their country. I hope that one day it will be a safe place. I miss the people, culture, the food in Somalia.

I take the bus everywhere. I think refugee people like me, people left home, they don't have parents. Like my friend Halimo was four years old when she left her country. She was a refugee in Ethiopia a long time with her family. Now they all came and are happy. We very much appreciate the second chance. So now we change, now we learn another culture. The funny thing is every month is a holiday in America. December, we have a holiday. November it's a holiday. In Africa we only have on holiday the whole year, Ramadan, one holiday. Yeah, so we have to learn the culture. We have to thank everyone. All women deserve respect and better life. Before I never shared my story. Mia, we became like daughter and mom. People ask me who is she? That is my White mom. I think most American people are very good. Every country has problems. In my country, the people who killed, they're just Muslims., using their power to control women.

### REFUGEE PEOPLE ARE JUST HUMAN BEINGS

What I want people to know about refugees, I think when you see the country explosions and they say, "Who did it?" and they say the Muslim group - those people are not representative of our religion, you know. Some media is bad, like when you talk about the Middle East everything have problem, yes, we have problem, but I think those people use their own power. If you are Muslim or not Muslim you know, you are not killing. We don't agree. I think if my country is safe, I will stay in my country. Even if I didn't have opportunity, why am I refugee? Because it's not safe, my family died, I need to change my life. Refugee people are just human beings. You should look at them and what the situation is. But if you compare it to media and the refugee people, it's a big difference.