

Stories of Displacement and Disablement
Experiences of Syrian Refugees and their Families: A Qualitative Narrative
Research Study

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Abstract

The Palestinian poet Mourid Barghouti writes, *"If you want to dispossess a people, the simplest way to do it is to tell their story and start with, 'secondly'"* (Adichie, 2009). First-person accounts can inform and educate, clarify misconceptions, and challenge existing policies and practices (Atkinson, 1998; Greenhalg, 2016). Narrative research allows participants to take back their own stories by starting with 'firstly'. Dominant groups have often appropriated the telling of stories, particularly of those who are vulnerable and marginalized (Dossa, 2013). I interviewed ten Syrian families to provide a glimpse into the narratives of disabled Syrian refugees and the material and social conditions that shape their experiences. The stories of these ten families led to fourteen themes of disablement and displacement. Through this dissertation, I examine the critical relationship of disablement and displacement through stories of hope, pain, resilience, fear, oppression, and resistance. I explore disablement and displacement through concepts of citizenship, otherness, and intersectionality. This research contributes a unique and vital perspective to academic literature by challenging and disrupting the dominant narrative around disabled refugees,

a narrative which overshadows spaces in academia and popular culture, and that strategically segregates disablement from displacement.

Dedication

This work is dedicated to my family for whom I am truly blessed

To Imraan,
My best friend and confidant,
Your support is unwavering.
Thank you for being you.

To Hamzah and Aayah,
Mama loves you and is so proud of you.
Thank you for letting me work (sometimes).

To Fatema, Akila, Hawa, Faisal and Fahad,
You are my rocks.
Thank you for putting up with me throughout the PhD process.

To Mom and Dad,
Your encouragement, love, and support made me who I am today.
Thank you for all your sacrifices.

To My Beautiful Baby Aasiyah Haleema,
May we be reunited one day.
May Allah Almighty shower His Infinite mercy on you.
Now and forever.
Ameen.

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I hope and pray this work is used to highlight systemic barriers to inclusion and that it provides a platform for advocacy.

To the participants,
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“Home”

no one leaves home unless home is the mouth of a shark
you only run for the border when you see the whole city running as well
your neighbors running faster than you, breath bloody in their throats
the boy you went to school with who kissed you dizzy behind the old
tin factory
is holding a gun bigger than his body
you only leave home when home won't let you stay.
no one leaves home unless home chases you, fire under feet
hot blood in your belly, it's not something you ever thought of doing
until the blade burnt threats into your neck
and even then you carried the anthem under your breath
only tearing up your passport in an airport toilet
sobbing as each mouthful of paper made it clear that you wouldn't be going
back.
you have to understand, that no one puts their children in a boat
unless the water is safer than the land
no one burns their palms under trains beneath carriages
no one spends days and nights in the stomach of a truck
feeding on newspaper unless the miles travelled
means something more than journey.
no one crawls under fences
no one wants to be beaten pitied
no one chooses refugee camps
or strip searches where your
body is left aching or prison,
because prison is safer than a city of fire
and one prison guard in the night
is better than a truckload of men who look like your father
no one could take it, no one could stomach it
no one skin would be tough enough
the go home blacks, refugees, dirty immigrants, asylum seekers
sucking our country dry niggers with their hands out, they smell strange,
savage, messed up their country and now they want to mess ours up

*how do the words, the dirty looks roll off your backs
maybe because the blow is softer, than a limb torn off
or the words are more tender than fourteen men between your legs
or the insults are easier to swallow than rubble, than bone
than your child body in pieces.*

*i want to go home, but home is the mouth of a shark
home is the barrel of the gun and no one would leave home
unless home chased you to the shore, unless home told you
to quicken your legs, leave your clothes behind
crawl through the desert, wade through the oceans
drown, save, be hunger, beg, forget pride
your survival is more important
no one leaves home until home is a sweaty voice in your ear saying -
leave, run away from me now
i dont know what i've become
but i know that anywhere
is safer than here*

- Warsan Shire, 2015

Chapter 1: Introduction

Embarking on this dissertation project is my attempt to uncover and record some of the unexamined stories of disabled Syrian refugees and their families, and to build on the disruption in disability studies grounded in colonial whiteness, already shaken by the likes of Gorman (2005, 2007, 2016, 2018), Ervelles (2000, 2002, 2011, 2014), Razack (1998, 2013), Puar (2017), and Dossa (2009, 2013) amongst others. Research around disabled refugees, while slim, has primarily been quantitative, highlighting the numbers of people disabled and displaced, not their experiences (Elder, 2015). Behind the statistics of the number of disabled refugees are real stories of persons forced to evacuate their homes due to poverty, persecution, or extreme hardship, and once settled in their host country, their narratives continue to be ignored (Bäärnhielm et al., 2017). Through qualitative narrative inquiry, this research provides space to share these authentic and unexamined stories that will challenge policies and programs that reinforce the ongoing marginalization of disabled refugees.

Stories and their connectedness to human beings can only be understood by paying attention to social, political, and economic contexts (Dossa, 2009). According to Dossa (2018), “To grasp the meaning of the storied content and the multiple ways in which it is expressed, we must pay attention to the larger sociopolitical contexts that suggest the complex ways in which individuals are connected to the world” (p. 25). I write this dissertation during a time where disregarding the current sociopolitical and economic climate would not be just an omission, but a blatant disregard for reality. We are in an active global pandemic, where the health disparities of racialized and disabled persons have increased significantly yet continue to be ignored (Abe et al., 2021). I write in a time in Canada when the bodies of hundreds of Indigenous children were found in the fields of residential schools across Canada (Norris, 2021), yet the public outcry is faint. I write in a time when Black Lives Matter protests have erupted on North American streets due to the systemic ongoing anti-black racism that permeates our institutions (Mullings et al., 2016). I write in a time where a Muslim family was ploughed down by a white supremacist in London, Ontario in broad daylight because of their culture and faith (AlJazeera,

2021). I write in a time when wearing a hijab prevents one from becoming a public-school teacher or police officer in Quebec due to a discriminatory practice enacted in law (Quebec Official Publisher, 2019). I write in a time when using the words ‘Free Palestine’ makes you a political target and censured by a university institution that prides itself on academic freedom (Censure U of T, 2021). I write in a time where the world is witnessing the Syrian refugee crisis as one of the most catastrophic humanitarian disasters in modern times (UNHRC, 2018). Ignoring the local and global context of systemic discrimination would be a disservice to my dissertation and the families that trusted me with their stories.

Given the local and global context and the need to explore personal, national, and transnational narratives, I approach the stories entrusted to me within a backdrop of critical theoretical underpinnings. I interviewed Syrian families and several community organizers and settlement volunteers to examine the critical relationship of disablement and displacement through stories. My research has led me to ask the following questions: What does disablement mean to a refugee population? Conversely, what does displacement mean to disabled persons? How has the segregation of

disablement and displacement hurt disabled Syrian refugees and their families? How is such a powerful intersection of disablement and displacement left out of critical conversations on human rights, social justice, and social determinants of health and disability? How is it that stories of authentic intersectional experiences and oppressions are erased? I explore these questions in chapter two within the context of citizenship, otherness, and intersectionality. In 1993, Judith Butler asks, “Which bodies matter, and which bodies are yet to emerge as critical matters of concern?” (Butler, 1993, p. 4). While Butler poses this question in the context of gender equality, it is correspondingly salient as a concern for disabled refugees; do they matter? Are they yet to emerge as critical matters of concern? In chapter three, I discuss the methods used in my research, and how these methods lead to storied content. In chapters four and five, I share the themes that emerged from the research and conclude those findings in chapter six.

My Story

Throughout this dissertation I bring in parts of my own story. My narrative is a result of experiences that shape who I am. As Downey and Clandinin

(2019) suggest, “Narrative inquirers tell stories about the stories they and others live and tell, keeping in mind how their own stories shape how they understand and tell the stories of others” (p. 134). I grew up on stories. Stories of my dad dropping out of school at the age of six and working to support his family. Stories of my mom and her family escaping dangerous conditions during the Zanzibar revolution. Stories of my great-grandmother, who lost ten of her eleven children before she passed away through poverty, violence, and medical institutionalization. I heard stories of migration, conflict, and community. They were stories of pain and hardship and stories of strength and resilience. My parents' and grandparents' stories wove into transnational narratives of colonialism and settler colonialism. These stories taught me about my identity, family, culture, and faith, and helped shape my own story. As a Muslim woman of colour who grew up in Kitchener, Ontario, my central story became one of assimilation and gratitude. Even when I grew up, it became apparent to me that the hero in dominant stories is white, able-bodied, and non-Muslim.

After high school, this dominant narrative became more evident when my younger cousin Muhammad migrated to Canada from Tanzania. I

was fond of Muhammad; he was kind, and his laughter contagious.

Muhammad was diagnosed with Cerebral Palsy shortly after he arrived; the doctors said he could not see or hear, walk, or talk. But we knew he could communicate, move, learn, and love. I witnessed the numerous barriers Muhammad was presented with, it was not only his disability, but the colour of his skin, his Muslim name, his mother's hijab, his immigration status, and the list goes on. Time and time again, I witnessed service providers and educators ignore his story.

Upon graduating from university, I discussed the exclusion of personal and transnational narratives with other families of racialized children with disabilities, particularly refugees. I met many families who reported isolation and marginalization from community spaces, explicit and implicit incidents of xenophobia, Islamophobia, racism, and ableism, and difficulty accessing resources and navigating through social and healthcare services. The collective narratives of oppression experienced by these families led me to form SMILE Canada – Support Services (SMILE)¹. My

¹ SMILE Canada – Support Services (SMILE) is a registered Canadian charity that supports over 500 racialized disabled children and youth and their families through

work with SMILE has provided me the opportunity of working with hundreds of families in Canada who identify as racialized and disabled.

After forming SMILE, I went on to become an occupational therapist. I practiced in community clinics and school-based rehabilitation settings, working with children with ‘complex’ disabilities. In my places of work, stories of displacement and disablement were rarely acknowledged. I found this both ironic and harmful as the profession of occupational therapy seeks to identify one’s meaningful occupation, considering their whole story (Sakellariou & Pollard, 2016).

Then a few years ago, I received a phone call that made me question the dominant narrative that surrounded Canada’s response to the Syrian refugee crisis. The narrative that plastered local and international headlines, reiterating Canada as a hero welcoming Syrian refugees while neighbouring countries rejected them. A principal of a Toronto public school called me regarding a ‘disruptive’ and ‘noncompliant’ disabled student who could not remain in his current classroom for the following reasons: a) the child did

culturally responsive service navigation, social and community supports, and financial assistance (www.smilecan.org).

not know how to use basic classroom tools b) he had difficulty interacting with other children and c) every time the bell rang, he hid under the desk with his head between his legs, screaming and rocking back and forth. Before I had a chance to respond with what I thought would be a logical explanation for why a child who recently migrated to Canada from a refugee camp was having difficulty in school, the principal responded, “I know what you are going to say. He came from a war-torn country, but how long will we use that as an excuse?” The principal’s comments, while shocking, reflect the narrative that Syrian refugees now in Canada must forget their stories formed through their experiences and oppressions. They must quickly get over their trauma and be grateful for their chance at a new life.

My First Interview Story

My first interview was on January 6, 2021. It was the day white supremacists stormed the United States capitol hill during an active global pandemic (Willingham, 2021). I felt as though I was watching systemic oppression and white supremacy unfold for public viewing. I could not help

but ask if everyone saw what I saw on television - one of the most chaotic moments in North American history played out most civilly. The 45th president of the United States defended the actions of what he deemed as lawful protestors and rioters, not terrorists (Willingham, 2021). Perhaps it was a coincidence or maybe it was the universe telling me something about the world's current situation, but during that interview, I found out that Hassan (the first participant I interviewed) was being evicted from his home. Hassan (whom I will introduce more formally in chapter three) shared how his white neighbours frequently called the police because his disabled Syrian children made too much noise. His neighbours harassed his family, telling them to “go back where they came from”, a statement I have heard one too many times during my lifetime. Hassan sobbed while sharing how he was afraid of the police and did not know why people would be so cruel to his children. He pleaded to his landlord that he could not prevent his children from making noise as that was their form of communication, yet he was frequently interrogated about their condition. Hassan and I never discussed the irony of that day, but I spent hours reflecting on his story after

I hung up, wondering whether he felt the same way as I did while watching the news.

Going into that interview and throughout the whole data collection process, I assessed my assumptions and biases while acknowledging that I have a personal history, opinions, values, and experiences to reflect on (Taylor & White, 2001). These experiences form my stories (Clandinin & Connelly, 2000). I have experience as a visible Muslim woman of colour, a pediatric occupational therapist, a daughter of immigrant parents, a mother to racialized children, and a community organizer and advocate. I have worked with disabled Syrian refugees and their families for years and have heard countless times the difficulties experienced when accessing healthcare, educational, and social services, and when advocating for basic human needs.

A Global Pandemic

In January 2020, the World Health Organization (WHO) reported the first novel COVID-19 case, a fatal virus that swept across the globe within weeks (WHO, 2021). Since then, there have been approximately 335

million COVID-19 cases and over five million deaths worldwide (Worldometer, 2021). The virus has disrupted every aspect of human life and brutally worsened the challenges for displaced persons and refugees (UNHCR, 2020). Before the pandemic, over 80% of Syria's population lived in extreme poverty. The pandemic significantly impacted the situation in Syria, which had only grown worse since 2020; the number of forcibly displaced persons surpassed 80 million, with 29.6 million refugees (UNHCR, 2021b). On March 23, 2020, Antonio Guterres, the U.N. Secretary-General, made an international plea appealing for a global ceasefire:

Our world faces a common enemy: COVID-19. The virus does not care about nationality or ethnicity, faction, or faith. It attacks all, relentlessly. Meanwhile, armed conflict rages around the world. The most vulnerable — women and children, people with disabilities, the marginalized and the displaced — pay the highest price. (Unicef, 2020, para 6)

Government policies and processes implemented to slow the spread of the COVID-19 virus made it even more difficult for displaced persons to reach a host country. In April 2020, over 160 countries partially or entirely closed their borders (UNHCR, 2021b). Some countries have turned back refugees and forced them to return to the dangerous places from which they escaped.

Even many search and rescue operations in the Mediterranean were ceased due to the pandemic. Tedros Adhanom Ghebreyesus, the World Health Organization's Director-General, pleaded for public health protocols that do not reject refugees (Kashyap et al., 2021). Instead of banning refugees from entering, countries should have effective screening measures. In March 2020, the Canadian international borders were closed to non-Canadians (Armenski et al., 2021). However, as Alex Neve (2020), then secretary-general of Amnesty International argued, the Canadian borders must always remain open:

Canada's decision is out of step with public health measures designed to curb the spread of COVID-19 and runs counter to our international legal obligations. From moral, public health and legal perspectives, closing the border to refugee claimants is wrong. Turning refugee claimants away—including as a result of the decision to shut down the Canada/US border—exposes refugees, who face increased hardship, danger and ostracization worldwide related to this pandemic, to serious human rights violations, including inhumane immigration detention conditions and the risk of refoulement to torture and other human rights abuses. (CCR, 2020, Para 5)

Refugees are at a greater risk of contracting the COVID-19 virus and suffering poorer health due to poor living conditions, including living in overcrowded spaces (Fouad et al., 2021). Nagi et al. (2021) discuss the

risk factors directly impacting the transmission rates of a virus. These transmission rates are affected by a refugee's physical environment, which is often overcrowded in spaces with limited access to clean water and soap to maintain hygiene and personal protective equipment such as masks and gloves. One's awareness about the virus also impacts the risk of contracting it. Syria's already brittle healthcare system was profoundly impacted by COVID-19 as preventative measures to spread the virus were challenging to adhere to (Fouad et al., 2021; UNHCR, 2020). As of January 18, 2022, the Canadian government reported 2,801,451 active COVID-19 cases resulting in 31,679 deaths (Government of Canada, 2021a). Here in Canada, the response to the pandemic is disorganized and inconsistent. Bryant, Raphael and Aquanno (2020) argue that the impact of COVID-19 on the Canadian population is racialized, gendered, and affected by class, and impacted by Canada's liberal-welfare state model. In a press conference about the provincial restrictions, Ontario's premier Doug Ford stated, "This virus could hit any one of you or your loved ones because this virus doesn't discriminate. It doesn't care about your race, religion, or creed. It doesn't care about your age. Anyone and everyone is at risk" (Maclean's, 2020,

para 4). While the phrase “the virus does not discriminate” was echoed through media channels and political platforms, recent statistics suggest that society discriminates who the virus impacts and to what extent. Data indicates that COVID-19 disproportionately impacts communities of colour, persons with disabilities, and those who reside in confined spaces such as shelters and prisons. Public Health Ontario’s enhanced epidemiological summary (January 2020 – May 2020) revealed that the virus most significantly impacted Ontario’s most ethnically and culturally diverse neighbourhoods (Public Health Ontario, 2021). This impact includes the rate at which the virus spreads and the most severe outcomes, including hospitalizations and death. Refugees in Canada were met explicitly with barriers to financial and social support and access to healthcare, educational, and social services during the pandemic (Edmonds & Flahalt, 2021).

Syrian Refugee Crisis

The Syrian Refugee Crisis is an umbrella term highlighting the displacement of millions of people due to the 2011 war in Syria and ongoing proxy wars fought in surrounding areas (UNHCR, 2021a).

Displaced persons include refugees and internally displaced persons who remain in their home countries. The number of forcibly displaced persons in 2020 was approximately 70 million people worldwide, over 50% more than what it was ten years prior (UNHCR, 2020). The Syrian refugee crisis has led to more than half of the Syrian population becoming displaced, of whom approximately 25% are disabled (Humanity and Inclusion, 2015; UNHRC, 2018). By March 2021, approximately 6.6 million Syrians were externally displaced and 6.7 million were internally displaced (UNHCR, 2021a). Of those displaced externally, over 75% sought refuge in neighbouring countries such as Turkey and Iraq. The forced displacement of millions of Syrians is due to many domestic and international factors such as the destabilization of the area during the 2003 U.S. invasion of Iraq, the Arab Spring uprising, and the Syrian civil war (Bakke & Kuypers 2016; Bose 2020). The ongoing violence in Syria continues to drive more people to displacement (UNHCR, 2020). Syria itself is no stranger to welcoming refugees. In 2011, thousands of Palestinians registered with the United Nations Relief and Work Agency (UNRWA) were refugees in Syria (Erakat, 2014).

The enormity of the Syrian refugee crisis led to the Canadian government's initiative “Operation Syrian Refugees” in November 2015 to settle 25,000 Syrian refugees across Canada over 12 months (Houle, 2019; UNHCR, 2018). Since 2015, the number of refugees resettled has steadily increased (Houle, 2019). Canada has prioritized the resettlement of vulnerable families (Hyndman et al., 2017) which includes disabled persons, and half of those settled are under the age of 15 (Houle, 2019; UNHCR, 2016; Bose, 2020). In 2020, over 30,000 refugees were resettled in Canada, of which 60 percent were privately sponsored (UNHCR, 2020), a critical statistic that feeds into the dominant narrative around Syrian refugees in Canada. I will elaborate further on this point in the coming sections.

Dominant Cultural Narratives

Dominant cultural narratives are stories that influence policies and practices by reiterating a single story (Dossa, 2013). Stories are powerful.

Chimamanda Adichie, novelist and storyteller, shares what she calls the “danger of a single story” and how it leads to critical misunderstanding (Adichie, 2009). Adichie grew up only reading American and British

books. When she wrote or drew pictures, she illustrated characters who did not resemble her. They had white skin, blonde hair, and blue eyes. Adichie (2009) describes how vulnerable humans are in the face of a single story that is created by showing “a people as one thing, as only one thing, over and over again, and that is what they become” (np).

Dominant stories are recorded in our daily newspapers and history books and convey one side of complex and multifaceted accounts. They influence classroom lessons and ideas perpetuated in literature, music, film, art (Razack, 1998), and social media. Dominant cultural narratives are “systems of representation” (Hasford, 2016, p. 159). They have specific heroes and villains and are void of critical reflection and discourse. Last year, my five-year-old came home with a Thanksgiving colouring page that depicted white pilgrims giving gifts to Indigenous peoples, a narrative that I recall from elementary school. It is a narrative that reinforces settler-colonialism in Canada. The pilgrims are the hero in the story of Thanksgiving, a holiday that continues to be celebrated nationally. According to Friedman (2014), "Thanksgiving is a reminder of the onset of societal trauma by a foreign group's effort at dismantling their vision of the

world" (p. 135). Dominant colonial narratives like the Thanksgiving narrative have been regurgitated through the retelling of a single story and the erasure of real-life histories and narratives.

Like the colonial narrative of Thanksgiving, our real-life stories can be erased by shifting the narrative and re-writing a false narrative or not providing space for non-dominant stories to exist (Mothoagae, 2018). Saleh (2017), in describing her decision to wear hijab in a predominantly white environment, says, "Although the stories shift depending upon the beholder, I often feel the weight of each beholder's single story of who/what I am and who/what I should be like in their stories ..." (p. 41). For example, the image released by mainstream media of the 2021 London terrorist attacker who murdered a Muslim family in broad daylight was showcased smiling in a track-and-field picture (Taccone, 2021), re-writing the story of a domestic terrorist who believed in and acted upon a white supremacy ideology, into that of an average young athletic Londoner, incapable of such a heinous attack. Dominant narratives oppress non-dominant stories by taking them over while obscuring the very means that produced them (Ryu & Tuvilla, 2018). Dominant stories tell us what and who is important, who has power

(Dossa, 2008), and who can be cast aside. Dominant stories are not mere narratives that we can either listen to or ignore. Instead, these stories influence the world's economic, social, and political movements, and ultimately reveal how society confronts its problems.

The dominant narratives around disabled Syrian refugees exist within a realm of ableist, xenophobic, and Islamophobic thinking and remain largely unchallenged by migration and disability scholars alike. These narratives reiterate problematic images of refugees as terrorists, victims, criminals, and invaders (Baker & McEnery, 2005). These narratives influence who comes to Canada as refugees and how they are viewed and treated. Razack (1998) argues that the stories of refugees found in dominant cultural narratives ignore the colonial legacy imposed on the global south by the global north.

While refugee advocates and international humanitarian organizations suggest that Canada brings in refugees to protect them, historically, refugee protection in Canada has revolved around Canada's economic investment (Heibert, 2016) that systemically discriminates against undesirable immigrants. The process of becoming a refugee is often

gendered and racialized (Dossa, 2013). In a critical analysis of the ‘incident’ of Komagata Maru, the 376-passenger ship of immigrants that were prevented from seeking refuge in Vancouver, Kazimi (2012) sheds light on Canada’s historically racist immigration system that traditionally refuses those who do not fit the mould of the desirable immigrant; the middleclass, white, able-bodied immigrant. In 2001, the Immigration and Refugee Protection Act (IRPA) made it feasible for more resettlement of refugees with lower literacy rates and education levels, resulting in an increasing number of refugees from countries in the global south (Hyndman, 2011). While Canada has accepted more refugees in the 21st century, the demand for refuge for displaced persons has increased dramatically in the last two decades and the readiness of states to provide protection, particularly in the global north, has decreased (Bose, 2020).

The political reactions to the Syrian refugee crisis highlight ongoing debates on asylum seeking in the global north (Bose, 2020). The national narrative that Canada welcomes refugees with open arms stemmed primarily from the 2015 and 2016 political debates in Canada and the U.S. As Bose (2020) suggests:

In Canada, the momentum to resettle a large number of Syrian refugees became enmeshed in the 2015 Canadian general election, with the victorious Liberal Party headed by Justin Trudeau making the acceptance of Syrians a central part of its election platform. In the US, the opposite was true, with Donald Trump making the rejection of Syrians an important part of his winning presidential campaign in 2016. The outcomes of these national elections – Syrian refugees were part of the political campaigns but in contradicting or opposing ways. (p.3)

Canada has developed a global image as a saviour of Syrian refugees, whereas the United States portrays a global image of white nationalism that rejects them. A 2017 CNN report sums up the opposing reactions to the Syrian refugee crisis with the headline, *Trump halts refugee program; Trudeau tweets they are welcome in Canada* (Ahmed, 2017). The U.S. media portrayal of Syrian refugees was immediately placed within the context of 9-11 and the 'war on terror' (Rettberg & Gajjala, 2015). On January 27, 2017, Donald Trump issued an executive order titled *Protecting the Nation from Foreign Terrorist Entry into the United States* (White House Press Secretary, 2017). The direct 2017 federal register order tied the September 11, 2001, attacks to incoming 'potential' terrorists. Terms within the order included 'foreign-born' and 'would-be terrorists.' The order reads:

... deteriorating conditions in certain countries due to war, strife, disaster, and civil unrest increase the likelihood that terrorists will use any means possible to enter the United States. (p. 2)

The order limited travel and settlement of those from Muslim-majority countries, including Syria (Liptak & Shear 2018; Tanfani 2016). U.S. media outlets displayed images of bearded, muscular men explicitly linked with terms such as rapists, terrorists, and invaders. Such images perpetuate the narratives of Syrian men as cowards who could not tough it out in their own country, or as freeloaders, exploiting the resources of their host country (Rettberg & Gajjala, 2015). Furthermore, the absence of women and children in media depictions fuels the perception that only men are entering North America and reaffirms the idea that Muslim women are abandoned in their home country and require rescuing (Rettberg & Gajjala, 2015).

The 2016 election of Donald Trump shifted the political conversation from the traditional speaking podium to a transnational social media platform. Trump's use of *Twitter* and *Facebook* was unprecedented for a president (Stolee & Caton, 2018). Trump targeted many marginalized populations over social media, including Arabs and particularly Syrian refugees (Rettberg & Gajjala 2015; Scribner, 2017). His comments reduced

Syrian refugees to dangerous and worthless. In one tweet, he wrote, "Refugees from Syria are now pouring into our great country. Who knows who they are – some could be ISIS?" (Kruglanski, et al., 2019). American politicians, academics and professionals echoed the social media hashtag #RefugeesNOTWelcome. Some U.S. governors even opposed the resettlement of Syrian refugees in their states (Zong & Batalova, 2017), including then-governor Mike Pence who banned Syrian refugees from settling in Indiana due to his own peoples' safety and security (Gowayed, 2020). Such Islamophobic and xenophobic rhetoric also seeped into government policies. A 2016 submission by the Center for Migration Studies titled *How Robust Refugee Protection Policies Can Strengthen Human and National Security* states:

Refugees and other forcibly displaced persons have fled violence, persecution and other untenable situations. The overwhelming majority seeks a level of protection and security to which they are legally entitled. At the same time, large-scale refugee and migrant streams include persons with a mix of motives (some dangerous) and aspirations (some illiberal). (Kerwin, 2016, p. 84)

The rhetoric used north of the Canadian border had a different tone. In January of 2017, Prime Minister Justin Trudeau tweeted: "To those fleeing persecution, terror and war, Canadians will welcome you, regardless of

your faith. Diversity is our strength #WelcomeToCanada” (Hughes, 2019, np). This announcement of welcome framed Canada as a country willing to accept displaced persons fleeing persecution regardless of social or religious affiliation. While the difference between Canadian and American media portrayal of Syrian refugees was stark, Canadian media outlets have also shaped a precarious narrative of Syrian refugees. The February 2016 CBC article titled, *How Syrian refugees arriving in Canada became ‘extras’ in their own stories* sums up the homogenous narrative Canadians have embraced regarding Syrian refugees. This narrative depicts Canada as a global leader on human rights but focuses on the welcome of refugees, not the quality of their lives, once they have been accepted (Denette, 2016).

Kamal Al-Solaylee, a Canadian journalist and professor at Ryerson University, shared his hesitations of the portrayal of this welcome:

Al-Solaylee says he understands why stories about acts of kindness and refugees’ first visits to Tim Hortons resonate with journalists and their audiences. However, he worries feel-good stories are “suck[ing] the oxygen” out of important stories about what life in Canada is really like for immigrants and refugees after the welcome is over. (Para 6)

Those accepted into Canada are considered ‘lucky’ and must ultimately be grateful for Canada’s protection. Being ‘accepted’ is framed as a privilege

and not as a human right (Denette, 2016). This framing of acceptance means the mistreatment of refugees as Canadian newcomers can go without notice. Political leaders and media outlets highlight stories of resilient refugees who have succeeded economically, such as Tareq Hadhad, a Syrian refugee who founded the company, *Peace by Chocolate*. Prime Minister Justin Trudeau highlighted Hadhad's work at the United Nations Leaders' Summit on Refugees (Bisset, 2016). Hadhad, in an interview on *This Hour has 22 Minutes* expressed his love and admiration for Canadians and the favourable treatment he received upon arrival. However, the rags-to-riches story for Syrian refugees in Canada is rare. There is no doubt that real stories of entrepreneurial and financial success exist, but this is not the case for many Syrian refugees who come to Canada.

Not all Canadians support refugees coming to Canada, and not all Syrian refugees feel welcome. The welcome narrative is often followed up by a narrative of gratitude, a theme that emerged from the participants' stories in chapter five. Migrants and refugees have increasingly been described as financial burdens to taxpayers and provincial and federal governments. Media headlines such as: 'No space in Windsor's temporary

shelters for Toronto refugees' (CBC News, 2018) portray an idea that refugees are taking advantage of social welfare and taking up space reserved for 'real' Canadians. The Toronto Sun, amongst other news outlets, frequently highlighted how Canadians will have to pay for the lives of refugees with their tax dollars (Levy, 2019). This dominant narrative trickles down into policies that impact the real lives of Syrian refugees. While Canada maintains an image of appreciating the diversity and cultural richness refugees bring into the country (The Canadian Press, 2016), changes in policy and practice suggest otherwise (Olsen et al., 2016). For example, the Interim Federal Health Program (IFHP) changes in 2012 that reduced primary healthcare for refugees and that disproportionately impacted disabled refugees in Canada is a prime example of the dominant cultural narrative influencing federal policies (Olsen et al., 2016). While the IFHP was restored in 2016 (Chen et al., 2018), it is a case example of how the rights of refugees in Canada are fragile (Bose, 2020) and dictated by political actors. Bose (2020) echoes this fragility in a study that examined reactions from government officials working with refugees in Canada and the United States. One officer in the study referenced a proposed federal

‘Barbaric Cultural Practices’ hotline designed to call out unusual or violent behaviours of immigrants and refugees (Gravelle, 2018). Critics of the hotline called out the Islamophobic and racist assumptions embedded in such an initiative (Bose, 2020; Boudjikianian, 2020). The study (Bose, 2020) concluded that domestic policies and national identity, not humanitarian efforts, play a significant role in shaping refugee policies in both countries.

Private Sponsorship

Syrian refugees come to Canada through various ways: the Government-Assisted Refugee Program (GAR), the Blended Visa Office-Referred (BVOR), or the Private Sponsorship Program (PSR) (Haugen, 2019; Government of Canada, 2021). Government-assisted refugees arrive through the United Nations High Commissioner for Refugees (UNHCR), or another referral agency supported by the Immigration, Refugees and Citizenship Canada (IRCC) funded agencies. The Government of Canada covers expenses for the initial resettlement of refugees entering through the GAR program, including housing, clothing, and food. The Blended Visa Office-Referred (BVOR) program is a government-assisted program that

diminishes the financial costs of private sponsors and connects private sponsors with refugees already vetted (Government of Canada, 2019).

In the late 1970s, the Canadian government initiated a unique private sponsorship program to respond to the humanitarian crisis in China (Lanphier, 2003; Labman, 2016). Canada's private refugee sponsorship has gained international attention over the years. It has played a critical role in the response to the Syrian refugee crisis (Kaida et al., 2020). The Canadian government's revised private sponsorship program allows community groups, groups of five individuals, and sponsorship agreement holders to support refugees collectively for approximately one year. These groups must demonstrate the willingness and financial ability to sponsor refugees (RSTP, 2021). Sponsors pay the entire cost of resettlement. The sponsorship group may raise funds to support refugees financially for essential expenses, including housing, furniture, clothing, and transportation (RSTP, 2021).

While initially, private sponsorship was secondary to government-sponsored refugees, by 2016, nearly half of all Syrian refugees were brought to Canada through private sponsorship (Government of Canada,

2016; UNHCR, 2022). A sponsorship cost table prepared by the IRCC estimates sponsoring a family of five is \$35,500 per year (RSTP, 2021). Canadian citizens have privately sponsored over 327,000 refugees since 1979 (UNHCR, 2022). The program's voluntary nature can be problematic as private sponsors have increased responsibility with far fewer resources than the government. Chris Alexander, Minister of Immigration, Refugees and Citizenship of Canada (2013-2015), responded to questions from the media around the responsibilities of private sponsors with the following statement: "Hundreds of private sponsorship opportunities remain. We encourage sponsorship agreement holders to do their part to help displaced Syrians" – A strong message of private sponsors "doing their part" was echoed in government messages (Labman, 2016, p.8). What is missed from this messaging is that Canadian citizens have been actively sponsoring refugees for many years. However, this responsibility is given to individuals who may not have the capacity, willingness, or ability to follow through with sponsorship duties. While the private sponsorship model has no doubt allowed private citizens to support displaced persons seeking refuge in Canada, it is concerning how it has become the dominant method

of coming to Canada as Syrian refugees (CCR, 2017). The federal government has increasingly downloaded its responsibility to sponsor refugees to private citizens. With fewer funds and more commitment, but less guidance and oversight, private sponsors may not be suitable to provide culturally appropriate and responsive support (Lenard, 2016).

Recounting Research on Disablement and Displacement

Disability and migration scholars alike have overlooked the exposed and ostracized positions of disabled refugees (Mirza, 2011b; Crock et al., 2012; Pisani & Grech, 2015). Dawson (2019) suggests that despite the statistics released by the United Nations Department of Economic and Social Affairs (UNDESA), there are minimal reliable statistics on disabled migrants or refugees (Crock et al., 2012), including no reliable statistics on the social, environmental, or economic barriers, or the trauma, abuse, or persecution disabled refugees face. Recent qualitative studies on Syrian refugees in Canada have focused primarily on healthcare needs (Pottie et al., 2016), integration in schools (Massfeller and Hamm 2019), and the private sponsorship program (Hyndman et al., 2017; Hynie, 2018). For example,

while Oudshoorn et al. (2020) discussed accessibility housing needs of refugees with disabilities, the study did not examine narratives of disablement and displacement.

Like Meekosha and Soldatic (2011), several disability scholars including Pisani and Grech (2015), and Puar (2017) have critiqued northern disability studies for failing to include the experiences and oppressions of disabled persons in the global south. These scholars insist that the disability studies field consider the millions of disabled people living in the global south and those who have migrated from the south to the north. Over 80 percent of disabled persons reside in global south countries, the majority of whom live in poverty (WHO, 2021). Many disabled persons in the global south remain institutionalized or incarcerated and punished for their disability (Meekosha & Soldatic, 2011), paralleling the locked wards and group homes in the global north (Gorman, 2005). In both global south and global north countries, the lives of disabled persons are highly controlled (Tilley et al., 2012), including whether they can receive an adequate education, secure employment, have meaningful relationships, and even bear children (Saxton, 2006).

The discourse of disabled persons has been largely written by white, male, heterosexual, and able-bodied persons, leaving out perspectives and narratives of persons of colour, women, refugees, and disabled persons (Bell, 2006). While there has been ground-breaking work done in disability studies that highlight intersectional identities, experiences, and oppressions (Ben-Moshe & Magaña, 2014; Annamma et al., 2018; Bailey & Mobley, 2019), the unique influence and impact of racism, ableism, xenophobia, and Islamophobia on disabled refugees in Canada have been largely disregarded in both migration and disability studies (Pisani & Grech, 2015; Meekosha & Soldatic, 2011). Tuitt (2013) argues that while a refugee is defined as one who is escaping persecution, the selection of who seeks refuge and who migrates as an immigrant is based on a racial profiling system. While the United Nations has urged a specific focus on disabled refugees (UNHCR, 2021a), the response, particularly from leaders in the global north, is underwhelming.

Disabled persons continue to be among the most exposed and excluded groups in any displaced society (Women's Refugee Committee, 2013). Disabled refugees are ignored within humanitarian spheres,

including programs designed to support displaced persons (Crock et al., 2017). Disabled refugees are often overlooked in the planning of emergency healthcare services (Kett & Van Ommeren, 2009; Mirza, 2011a; Mirza, 2011b) and are at a higher risk of physical and sexual abuse, exploitation, abandonment, and death during conflicts and national emergencies (Crock et al., 2017). Many disabled refugees have experienced war, torture, and trauma (Mercy Corps, 2014) and poverty and malnutrition (Taleb et al., 2015). Many refugees do not report disabilities for fear of being left behind or enduring human rights abuses (Bradley & Tawfiq, 2006).

In Canada, the rallying cry of the Disability Rights Movement, "nothing about us without us", remains as urgent today as it did historically (Charlton, 2000). Ableist policies that promote the segregation of disabled persons negatively impact all areas of social life including education and employment (Rioux & Prince, 2002). Today, disabled people's exclusion can be seen in all areas of social life, from a segregated specialized education system to vocational training programs and day centres for disabled adults. Not only do disabled persons continue to have every aspect

of their personal, social, and professional lives controlled by state-sanctioned services and dominant cultural practices, but they are also excluded from decision-making processes at local, national, and international levels. Disabled persons are largely left out of the design and implementation of disability-related policies (Kayess & French, 2008) which often exclude the input and perspectives of disabled persons and contribute to the shaping and reshaping of harmful and oppressive ableist practices (Dossa, 2009; Ingstad & Whyte, 2007). Disabled persons in Canada continue to be marginalized by society even though they represent a significant portion of the total Canadian population. In 2017, 6.2 million Canadians identified as having at least one disability, representing 22% of the total Canadian population (Morris et al., 2018).

Elder (2015) describes how meaningful narratives and experiences of disabled refugees are frequently clouded by clinical protocols and quantitative checklists. These checklists overlook multiple and intersecting identities, daily experiences, and real-life oppressions and make it easier for policymakers, service providers, and educators to ignore the intersectional needs of disabled refugees.

Chapter 2: Theoretical Framework

My research engages in a narrative study of disablement and displacement situated within a critical paradigm of transnational disablement and informed by concepts of citizenship, otherness, and intersectionality. Social research and literature on disability and immigration describe the disabled-other and refugee or immigrant-other similarly, as a misfit archetype, both vulnerable and socially inferior (Fernando & Rinaldi, 2017). While frameworks found in critical migration studies and critical disability studies have largely ignored the disabled refugee (Reilly, 2010; Pisani, 2012), the combination of theoretical frameworks presented in this chapter will provide a critical perspective to examine the issues that impact disabled Syrian refugees within a local and transnational context. This chapter outlines the theoretical perspectives that have shaped my understanding of disablement and displacement and which I used to interpret and analyze the data.

Although my research does not explicitly explore a historically rooted materialist perspective, the tenets of the theory that underlie exclusionary immigration and disability policy can be expressed in terms of

economic undesirability. Going back to the question posed in chapter one by Butler (1993) —Why do only some bodies matter? Erevelles (2011) urges us to question the historical material conditions that make certain bodies more worthy than others. Bodies located at the intersections of race, disability, and gender are economically and socially determined as inferior by the very establishments devised to safeguard them. Fundamental rights are linked with:

economic conditions that sustain the unequal social relations of class. These unjust economic arrangements are obscured by the development of discourses of morality that justify those who are denied this right by categorizing them as “the undeserving”. (Erevelles, 2002, p. 15)

A capitalist hegemony continues to shape human belief and carries the biases, stereotypes, and prejudices that result in present-day inequities for several disadvantaged groups. In 2000, the Department of Citizenship and Immigration exempted refugees and their dependents from the excessive demand clause², which stated, “It is inconsistent for Canada to

² Subsection R1(1) of the Immigration and Refugee Protection Regulations (IRPR) defines “excessive demand” as either of the following:

accept that a convention refugee overseas is in need of protection but treat them as inadmissible because they would cause excessive demands on health services” (p. 5). These excessive demands would include strains on the healthcare system supposedly over-utilized and over-burdened by disabled refugees (CCD, 2012).

Further to a capitalist-hegemonic perspective, the ongoing effects of colonialism and settler colonialism, both historical and present-day, are critical in examining disabled refugees’ experiences (Grech & Soldatic, 2015; Erevelles, 2011). The objective of colonization is to invade a space, exploit resources, cause chaos and disruption, and then return home more powerful than before colonization. The colonized are left powerless and rely on the colonizers for economic and social support. When the colonized must come into the colonizer's now-territory, they must only be a few in

-
- a demand on health services or social services for which the anticipated costs would likely exceed average Canadian per capita health services and social services costs over a period of 5 consecutive years...
 - a demand on health services or social services that would add to existing waiting lists and would increase the rate of mortality and morbidity in Canada as a result of an inability to provide timely services to Canadian citizens or permanent residents (Government of Canada, 2022).

number, and they must be able to contribute in a way deemed fit by the newly formed society (Grech, 2015).

Disablement

While the terms “disability”, “disabled”, and “disablement” have been used interchangeably in academia and by disability persons' organizations, I am interested in the concept of disablement as a means "by which people become categorized as disabled" (Jampel, 2018). It involves both the social construction and social production of disability (Jampel, 2018). Gorman (2018), in a discussion on the dialectics of race and disability, examines disablement as a process rather than as an identity in her work on anti-colonial approaches to disability arts. Disablement is not linear or stagnant; it crosses borders, changes through time, and ebbs and flows within social, political, and economic contexts. Disablement in this regard is not the same as disability as identity. Disability as part of human identity is defined within a specific social and political context described by those in power through policies and legislation. The binary between disabled and able-bodied has been used to segregate and isolate those with disabilities and

ignores concepts of capacity, debility, and disablement (Puar, 2017). Ignoring these concepts isolate disabled persons in the global south and refugees and immigrants in the global north. Within my research, I examine the multifaceted relationship between disablement and displacement by exploring traditional and contemporary models of disability. While distinctive, the biomedical, social, and human rights models of disability all require a specific definition of what disability is.

Biomedical Model

The global north hegemonic discourse on disability (rooted in colonialism and settler-colonialism) stems primarily from the biomedical model of disability that perpetuates the idea that there is a good, beautiful, and correct way to look. Being able-bodied is considered natural (Oliver, 2004), whereas differences in appearance and behaviour that result from disability are considered unnatural and unattractive. The biomedical model frames disability in an individual's pathology (Smart, 2005) and focuses on the impairment of the body and treatments and cures of ailments that tarnish the body (Schur et al., 2013). The biomedical model equates disability to a problem that requires fixing or changing (Oliver, 2004). A key feature of

rhetoric in the biomedical model of disability is the assertion that being able-bodied is normal and being disabled is abnormal. Such classification is catastrophic because every aspect of disabled persons' lives becomes regulated to fit into the 'typical' or 'normal' archetype. The biomedical model largely ignores one's culture, physical and social environment, and personal history (Oliver & Barnes, 2012).

Social Model

The social model of disability moves away from a focus on cures, prevention of disability and illness, and rehabilitation of disabled persons, and instead examines policies and practices that make and keep people disabled (Oliver & Barnes, 2012). By challenging social barriers to access and inclusion, the social model has been instrumental in removing those barriers (Oliver, 2004). The social model allows for a critical reflection on the discriminatory and prejudicial treatment of disabled persons because it does not view disability as an individual's problem. Instead, the theory places a collective responsibility on society (Morris, 2001). Amongst the criticisms of the model are that it fails to identify and examine systemic

barriers that target specific populations that make and keep people disabled (Frank, 2000).

Human Rights Model

The human rights model of disability is a social justice approach that urges actors in positions of authority to assume a moral position (Farmer, 2003), a seeming improvement to the social model of disability. The human rights model emphasizes human diversity and embraces disability as one of several layers of identity (Rioux et al., 2011). Within this framework, one cannot perceive one life as inferior to another based on any physical, mental, cognitive, or sensory issue, illness, or impairment. To do so would be to disregard the principles of equality and social justice (Rioux & Carbert, 2003). Over several decades, the rights-based disability movement has resulted in legally enshrined rights as an ideological framework. The human rights approach highlights the importance of having legislation and policies that support the full involvement of all persons (Bickenbach, 2009), regardless of socio-political affiliation, economic status, or socio-cultural factors (Kayess & French, 2008). Although the language of human rights may generally be framed around all persons' inherent moral or ethical

rights (Blau et al., 2009), those rights cannot be realized in a disabling system that privileges the rights and freedoms of some persons over others. Having rights protections under the law does not ensure realized opportunities for disabled persons and economic and social rights. This long held and continued critique noting differences between rights promotion and achieving equality for disabled persons has been highlighted by several scholars, including Vanhala (2010), Jaeger and Bowman (2005), Jones and Marks (1999), and disability scholar and activist, Dr. Lynne Davis. She argues that while the idea that disabled persons' rights are human rights provides a framework for advancing the freedoms and interests of disabled persons, economic and political changes are required to secure them (Basser & Jones, 1999).

Rights and freedoms are primarily identified by people in power who decree which freedoms are deserving and which can be ignored (Kazemi, 2019). Human rights discourse has named who is worthy of rights, and subsequently, who is unworthy. Amongst the undeserving or under-deserving are disabled refugees. Clement (2016) suggests that we must question whether human rights are for all humans. The claim that all

humans have human rights by way of being human is an ideological stance that does not account for the social, economic and political means by which we obtain our rights. Farmer (2005) discusses these violations of rights as “symptoms of deeper pathologies of power” (p. 7) which are connected to social conditions that define who will be protected, whose rights will be upheld, and who will be ignored and harmed. We cannot ignore the relationship between power and human rights and that human rights abuses do not occur accidentally (Farmer, 2003). Instead, human rights violations are part of a deeper societal problem and are ultimately connected to social conditions that regulate who suffers and how much they suffer (Farmer, 2003). Power and authority are not restricted to governments alone (Farmer, 2003). More and more, those in power who have widespread decision-making abilities span across nations, as our geographical borders are becoming more obsolete. Consequently, we are witnessing a time when the culprits of human rights violations are largely unrecognizable. For example, corporations that engage in child labour often have the means to hide their crimes by having factories in places that do not regulate and have laws around child labour (Farmer, 2003). Transnational capitalist material

conditions produce circumstances that make and keep people disabled such as the ongoing illegal occupations in the global south (Erevelles, 2011) which have debilitating practices that prevent residents from moving, speaking, and living freely.

Convention on the Rights of Persons with Disabilities

In 2006, the United Nations General Assembly adopted the Convention on the Rights of Persons with Disabilities (CRPD) and the accompanying optional protocol (Kayess & French, 2009). The CRPD was formed in response to international human rights instruments' exclusion of disability rights (Degener, 2016). The CRPD was a pivotal milestone in upholding the rights of persons with disabilities by formalizing fundamental and practical concerns from the disability community (Kayess & French, 2008), including a call to end the institutionalization practices of disabled persons (Karsay & Lewis, 2012). The CRPD was the first human rights instrument that identified disabled persons as rights holders and recognized that illness, impairment, or disability could not be used to deny human rights (Crock et al., 2017; Degener, 2016). The CRPD was not designed to create or implement new rights but to realize and apply existing rights to persons

with disabilities (WHO, 2011), bumping disabled persons into the deserving-of-rights category. Disabled persons included both those who were citizens of a state and non-citizens, such as displaced persons (Crock et al., 2017). The CRPD had a tremendous global impact on how societies view disabled persons and the need to improve their overall social and economic situations (Kayess & French, 2008). It clarified the right of disabled persons to have and exercise legal capacity and significantly influenced human rights law and disability studies (Degener, 2016). Article 11 of the CRPD highlights that disabled persons must be treated equitably, including displaced disabled persons.

However, critics of Article 11 argue that the CRPD should apply only to citizens of a given state, especially since some countries increasingly have refugees crossing their borders (Crock et al., 2017). In 2013, with the outcry of leaders in the global north about the social and economic strain Syrian refugees were placing onto global north countries, the CRPD reiterated its obligation to apply the convention to all human beings:

Syria is a State Party to the Convention on the Rights of Persons with Disabilities. Article 11 of the Convention says that a State Party is

obliged under international humanitarian and human rights law to take all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including armed conflict. (p. 24)

The CRPD is a product of decades of rights organizing for disabled persons through an inclusion and exclusion framework that is not critical of historical and material contexts (Gorman, 2010).

Universal human rights instruments such as the CRPD that are developed in the global north have heavily influenced international human rights discourse (Meekosha & Soldatic, 2011). Like the biomedical and social models, the human rights model was developed in the global north within a Eurocentric colonial-settler context where Indigenous populations have been replaced with settler populations (Veracini, 2015), a point ignored in many disability discourses. Furthermore, the CRPD involves a concept of universalism that reiterates disabled persons as a homogenized population (Bickenbach, 2009; WHO, 2015). Countries worldwide may agree to universal human rights principles, but those principles are defined by wealthy and powerful players (Meekosha & Soldatic, 2011; Sen, 2009). Kazemi (2019) argues,

... the "universal" idea of disablement has abysmally failed, because transnational, local, and international advocacy groups do not fight for equality for disabled people in the "third world." Instead, they just fight for their "survival". (p. 201)

Human rights discourse has been used to further colonial-settler and imperialist ideologies (Meekosha & Saldatic, 2011). For example, the human rights rhetoric around protecting one's country, specifically post 9/11, which has prioritized human security of persons living in the global north (Grech & Psiani, 2015) has increasingly reduced the global south–north migration flow (Kofman, 2000). When migration is depicted as a privilege instead of a right, the rhetoric surrounding national security can transform the view of the refugee as one needing protection to one who is provided with an exceptional circumstance (Grech & Pisani, 2015).

Human rights have also become the basis for controversial discussions about sacrificing some rights to protect other rights. Examples of such discussions are killing civilians to promote democracy or allowing hate speech as free speech (Ishay, 2004). Furthermore, human rights rhetoric has justified ongoing human rights abuses and violations worldwide. For example, the formation of the United States detention camp

in Guantanamo Bay, the inhumane treatment of detention camp prisoners, and the torment of Afghan prisoners in particular was done to protect the human rights of U.S. citizens from so-called terrorist threats (Clement, 2016). The U.S. military invasion of Iraq, among several wars, was fought in the guise of obtaining human rights for Iraqi civilians. The U.S. invasion of Iraq was justified to save the perceived marginalized and vulnerable Iraqis by enforcing democratic values (Meekosha & Saldatic, 2011). It was also justified to protect those in the global north from threats to their national security. The Iraq war was catastrophic and resulted in gross human rights violations and abuses of the Iraqi people. The Iraqi Ministry of Health estimates that over 40,000 Iraqis became disabled because of the unjust war (Sarhan, 2011).

In Canada, human rights rhetoric has been used to justify racist, Islamophobic, and xenophobic practices, including Bill-21 in Quebec, a law that disproportionately impacts racialized communities including new immigrant and refugee communities. Bill-21 bans Canadians who wear religious symbols or garments such as hijabs or turbans from working in public spaces such as police stations, courtrooms, and public schools

(CCLA, 2021). Bill-21 limits the participation of Canadians who adhere to certain faith-traditions and choose to dress a certain way.

While international human rights documents are founded in the fold of the nation-state, human rights discourse undermines the nation-state's authority by granting all human beings rights regardless of citizenship (Sassen, 1998). However, this point has not applied to refugees and asylum seekers, who have limited or no means of claiming their rights (Grech, 2015). Disability rights activists have relied heavily on the CRPD to ensure rights for disabled displaced persons, but it does not adequately address transnational claims to justice around impairment because it continues to adopt a nation-state perspective (Soldatic, 2013). This perspective ignores who becomes disabled, how, when, and why, and it significantly harms those who have transitioned from one nation-state to another, who may have a different status in the various countries they are forced to reside in.

Article 18 of the CRPD reads:

States Parties shall recognize the rights of persons with disabilities to liberty of movement, to freedom to choose their residence and to a nationality, on an equal basis with others, including by ensuring that persons with disabilities:

- a) Have the right to acquire and change a nationality and are not deprived of their nationality arbitrarily or on the basis of disability;
- b) Are not deprived, on the basis of disability, of their ability to obtain, possess and utilize documentation of their nationality or other documentation of identification, or to utilize relevant processes such as immigration proceedings, that may be needed to facilitate exercise of the right to liberty of movement;
- c) Are free to leave any country, including their own;
- d) Are not deprived, arbitrarily or on the basis of disability, of the right to enter their own country. (para 1)

While the above article seems to allow the necessary rights for disabled displaced persons, states have the option to ratify the CRPD. Canada ratified the CRPD in 2010 (Government of Canada, 2020). However, other nation-states such as Australia have ratified the CRPD with an interpretative clause granting exemption from Article 18: Liberty of Movement and Nationality (Meekosha & Soldatic, 2011). Such exemptions spare countries from removing discriminatory migration laws, policies, and instruments that actively exclude disabled displaced persons (El-Lahib & Wehbi, 2012; Soldatic & Fiske, 2009). Given the centrality of the modern territorial state within the CRPD, there is no room within the CRPD for

pursuing disability justice rights with transnational or international corporations or institutions (Soldatic & Biyanwila, 2006). Pisani (2012) describes the paradox of international human rights instruments protecting all humans, yet nation-states protect their citizens against perceived threats, controlling their borders and essentially patrolling who is allowed membership. It is no surprise that refugees and asylum seekers are the perceived threat (Scott & Safdar, 2017).

Transnational Disability Framework

Figure 1: Syrian Father and Child



Photo credit: The 2021 photo of the year by the Sienna International Photo Award

The prevailing disability studies models, including the social model of disability and the human rights model of disability, celebrate disability as something that everyone will acquire at some point in their lives (Kazemi & Sarikaya, 2018). This idea ignores and represses the idea that disablement occurs largely through oppressive social and political situations (Meekosha & Soldatic, 2011). The above image by Turkish photographer Mehmet Aslan sums up the transnational disability approach that allows us to challenge and understand how disablement occurs. Our bodies tell stories (Caine, 2010). The photo displays a father who lost one of his lower limbs when he was hit by a bomb walking in the streets of Syria. He holds his young son who lives with a condition called Tetra-Amelia which results in the child being born without his upper and lower limbs (Baa & Behera, 2018). The child's condition directly resulted from the child's mother taking specific medication to relieve her of symptoms caused by nerve gas (Sienna International Photo Awards, 2021). A biomedical, social, or human rights model of disability cannot adequately capture disablement in the context of this young Syrian man and his family.

In her book *The Right to Maim*, Puar (2017) provides examples of Palestinian people targeted for disability. She explains how the debilitating effects of the occupation in Palestine are neither of ill fate nor accidental. They are intentionally designed to disable an entire population (Puar, 2017). Puar urges readers to think about disabled bodies through concepts of white privilege, economic freedom, and citizenship status (Puar, 2017). While Puar acknowledges that the comparisons are not ‘perfectly aligned’, she draws on the parallels of targeted disability, the process of disablement and intersectional oppressions within the social, economic, and political contexts of settler colonialism:

Ferguson-to-Gaza forums sought to correlate the production of settler space, the vulnerability and degradation of black and brown bodies, the demands for justice through transnational solidarities, and the entangled workings of settler colonialism in the United States and Israel. (preface)

In her discussion on disablement in Iraq, Kazemi (2018) suggests that disablement within the context of war involves attaining and living with a disability under unbearable conditions, including extreme poverty and lack of primary medical care. Whether disablement occurs through injury, birth, violence, or poverty, the transnational disability approach does

not ignore the impacts of colonialism and settler-colonialism and global issues such as international conflict and climate change. A transnational approach, as described by Kazemi (2019):

...locates the problem in the violence of global class-relations (capitalism, imperialism, and neo-colonialism), the dialectics of global politics, historical infliction of pain upon the poor and racialized body (e.g., colonialism, slavery, Indigenous genocide, indentured labour, war on terror), exploitative social relations (gendered, raced, and classes), and destruction of the planet by the ruling bourgeois class causing health issues for every species. (p.34)

I will highlight in chapter four how disabled refugees brought to Canada are thrown into a system where their transnational stories of displacement and disablement are discounted. The disability rights movement, a predominantly white, male-dominated movement, has ignored the focus of disablement caused by international conflict and imperialism (Gorman, 2005). Gorman (2018) asks:

What critical representations of disablement have been promoted or sidelined? When does disability emerge as identity, and what assemblages do these identities reference? What happens when we let go of disability identity in representations of war, migration, and sovereignty? (p.457)

These questions posed by Gorman are a shift away from those questions of identity that led to the formation of the traditional models of disability that

are taught and retaught in spaces deemed progressive and critical within global north disability discourse.

Citizenship

To critically examine transnational experiences of disability, we must rethink the way citizenship discourse is approached as a theoretical and analytical tool in disability studies (Erevelles, 2011). In the famous publication *Citizenship and Social Class*, T. H. Marshall defines citizenship as “full membership of a community” (Marshall, 1963, p. 72). Marshall (1950) breaks citizenship into civil, social, and political categories. Civil citizenship includes individual freedoms and liberties (Morris, 2005), such as the “rights necessary for individual freedom, liberty of the person, freedom of speech, thought and faith, the right to own property ... and the right to justice” (Marshall, 1963, p. 74). He argued that a free-market economy is necessary to uphold civil citizenship (Marshall, 1950). The social aspect of citizenship revolves around the belief that citizens need the required resources to live in a society. Those resources should be available to persons who require them (Morris, 2005). This

aspect is often understood as social welfare—how a state steps in and provides for those in need. The political element of citizenship involves participating in political decision-making processes, such as voting (Marshall, 1950). It is essential to note that Marshall’s work is based on the experiences of white, middle-class, and able-bodied men (Yuval-Davis, 1997). Nonetheless, Marshall changed how we think of citizenship by addressing belonging to a community rather than a nation-state (Yuval-Davis, 1997).

Analyzing disability within the context of citizenship forces one to challenge the biomedical approach to disability and the stereotypes the biomedical model perpetuates (Prince, 2009). Disabled citizens, regardless of their citizenship status in a country, have been subjected to the biomedical model’s otherness ideals, resulting in exclusion and discrimination (Hughes, 2014) based upon physiological characteristics. Instead, disability activists and scholars have used the idea of citizenship to explain the social exclusion of disabled persons (Barton, 1993; Hughes, 2014; Prince, 2004; Van Houten & Jacobs, 2005). The framing of disability within citizenship has been a powerful tool for disability movements

because citizenship emphasizes certain political, social, and economic rights (Prince, 2004). Oliver (1992) famously asserted that citizenship rejects disability because citizenship entails belonging and inclusion, whereas disabled persons are treated at best as ‘second class citizens’ (Barton, 1993; Oliver, 1992). In this regard, even when granted citizenship, disabled citizens continue to face social exclusion, as though they are non-citizens or partial citizens.

Pisani and Grech (2015) argue that when the social model frames disability rights under the banner of citizenship, it assumes that citizenship is a given right. Citizenship has historically been an integral pillar of the concept of a nation-state that delineates the rights of citizens within geographical borders (Janoski & Gran, 2002). Citizenship literature has failed to examine why disabled persons are not considered actual citizens (Rioux & Valentine, 2006). Devlin and Pothier (2006) describe disabled persons as “de-citizens” (p. 2) who are refused full citizenship rights (Rioux & Valentine, 2006). This exclusion may involve exclusive social and legal policies and abusive practices, such as forced genetic testing to determine if a child has a disability.

Ervelles (2002) argues that citizenship has become one of the most critical purposes of the liberal state. However, as the lines of nation-states have become increasingly blurred because of several socio-economic and political factors, such as globalization (Janoski & Gran, 2002), citizenship has become more aligned with the idea of being a member of a community. Framing citizenship in terms of membership in a community allows one to analyze citizenship within the context of the dominant national culture (Yuval-Davis, 1997). The difficulty with membership is that persons are excluded from membership based on several socially constructed factors. For example, many countries' citizenship policies, laws, and practices discriminate based on ethnicity, religion, class, and gender. In Jordan, non-Jordanian women who marry Jordanian men can obtain citizenship status, but if Jordanian women marry non-Jordanian men, their spouses cannot acquire citizenship rights (Crock et al., 2017).

Morris (2005) maintains that citizenship comprises three areas—self-determination, participation, and contribution. Perhaps the most controversial point is the latter. Disability scholars have critiqued the assumption that citizenship rests on an individual's capacity to contribute to

a country's economy. Social welfare systems have been designed to exclude disabled persons from the workforce and limit their social and economic potential. Disabled persons are chronically excluded from a workforce that values certain skills and perceives specific abilities above others (Prince, 2009). They are often forced into unemployment and poverty, making them dependent on social assistance and tainting their citizenship status (Arnold, 2004). Disabled persons are perpetually stereotyped as unproductive, economic burdens (Hahn, 1985), and unworthy of citizenship (Thobani, 2007). In this regard, disabled persons are viewed as obstructions to neoliberalist and capitalist structures designed to maximize profits (Russell, 2002). Even John Rawls, known for his book *Justice as Fairness* (1998), excludes disabled persons in his definition of a citizen through humanist logic (Erevelles, 2011). Humanist ideology emphasizes an individual's capability regarding competence, rationality, and independence (Garland-Thompson, 1997). Rawls's (1998) description suggests that a citizen must be a fully "cooperating member of society" (p. 5). The assumption that citizens will contribute in a particular valorized manner is founded on ableist and exclusionary ideals that equate typical

work with specific physical and cognitive abilities and traits. Evaluating citizenship based on whether one ‘gives back’ to the nation-state contradicts the idea that citizens have rights simply by virtue of their citizenship status (Goodley & Lawthom, 2019).

Citizenship for a refugee is further measured by one’s competence of ‘Canadian-ness’, or adopting Canadian values and practices, such as proficiency in Canada’s national language(s) and celebrating Canadian holidays (Beiser, 2009). Assimilation is required to demonstrate one’s commitment to the country they reside in (Rajaram & Grundy-Warr, 2007). In this way, belonging is determined through dominant cultural practices—the way people are expected to behave, dress, speak, move, learn, work, and socialize is coded within society. One must be capable, competent, rational, and independent to conform to neoliberal economic principles. Membership is only given to those who fit the normative mould based on white, heterosexual, middleclass, and able-bodied men. Those who do not fit into this category are not full citizens (Prince, 2004).

Othering the Other

Otherness entails being different and inferior (Murdick et al., 2004). It creates social categories as binary opposites (Bauman, 1991) such as citizen and refugee, able-bodied and disabled. Otherness has demonized refugees (Stone, 2017) and has limited disabled persons (Barton, 1993). The theoretical framework of Orientalism put forth by Edward Said (1978) triggered a critical debate over the unequal relationship between the so-called east and west (Skenderovic & Späti, 2019). Orientalism seeks to explain how colonizers identified those living in the Middle East and Asia, the 'orient', as backwards and barbaric, the supposed opposite of Europeans who were modern and civilized. In his analysis of Orientalism, Said (2000) discusses the concept of othering as:

A conceptual framework around the notion of us-versus-them [that] is in effect to pretend that the principal consideration is epistemological and natural—our civilization is known and accepted, theirs is different and strange—whereas the framework separating us from them is belligerent, constructed and situational. (p. 529)

Kyriakides et al. (2018) propose that orientalism frames refugees in the global north as inhumane and uncivilized, leading to discrimination and exclusion. Similarly, the othering of disabled persons is followed by marginalization and segregation (Campbell, 2009). Disabled persons have

been objectified and belittled because of their otherness concerning able-bodied persons (Barton, 1993) and do not meet the "criteria of normalcy" (Dossa, 2009, p. 31). In this regard, otherness is defined by social norms and a dominant culture that devalues and erases the stories of refugees and disabled persons.

Erasure of Identities:

The erasure of identities may be an issue of whether disabled refugees are deemed worthy of national and international concern. A 2018 research paper by the World Refugee Council titled "Xenophobia Toward Refugees and Other Forced Migrants" describes xenophobia as beliefs and behaviours that reject refugees based on the idea that they are alien to a particular community or national identity (Miller, 2018). Xenophobia thrives in countries that propagate the notion that refugees are dangerous and will infiltrate a nation's cultural identity. An exclusive perception of national identity plays a critical role in how xenophobia impacts newcomers (Hjern, 1998). Yakushko (2009) notes that the term xenophobia has historically been used to refer to a fear of outsiders. More recently, it has been connected to the claim that global north culture is superior to the cultures of

the global south. Even those who reside in a particular state for years can be subject to xenophobia because they appear foreign. This idea was echoed in Donald Trump's 'Make America Great Again' campaign, gesturing toward an all-white America. Xenophobia is not just a belief; it manifests in policies, legislation, and institutional practices that isolate and ostracize refugees. For example, the American Muslim ban barred immigrants and refugees from Muslim-majority countries from entering the United States due to perceived security threats (Elkassem et al., 2018).

Islamophobia is a term that includes discrimination and hostility toward Arabs, Muslims, and Islam (Beydoun, 2016). Rahman (2017) connects the concept of Islamophobia to Said's notion of Orientalism and describes Islamophobia as a process of othering Muslims (Rahman, 2017). Brown (2000) suggests, Islamophobia focuses on a religiously defined "other" rather than any specific racial or ethnic group. This categorization frames Muslims as foreign and dangerous (Mirza, 2013). While Islamophobia is not synonymous with Orientalism, Beck et al. (2017) argue that understanding Orientalism is essential to disrupt Islamophobia. Bullock and Zhou (2017) further argue that Islamophobia is a "neo-Orientalist

discourse of Islam/Muslims" (p. 446). Islamophobic othering impacts the everyday lives of Muslims in North America and correlates to adverse health and social outcomes (Samari et al., 2018).

Muslims in Canada are not a monolithic group (Jamil, 2012); they comprise people from different ethnic, social, and racial backgrounds (Bullock & Jafri, 2000). They belong to different sects or schools of thought, including Shia, Sunni, Ahmadiyya, and Ismaili Muslims. Between 2017 and 2019, a national survey noted that close to 3.7 percent of the overall Canadian population identified as Muslim (Cornelissen, 2021), partially due to the significant increase in immigration from Muslim majority countries. Canadians are increasingly reporting incidents of Islamophobia (Gravelle, 2018). A survey by the Angus Reid Institute found that Canadians most feared and had negative feelings towards Muslims compared to other faith groups (Reid, 2015). A 2016 survey of Muslims in Canada conducted by the Environics Institute concluded that 33 percent of Canadian Muslims experienced discrimination based on their religious and ethnic identities (Neuman, 2016). These experiences took place in various settings, including at schools, places of work, and included

daily microaggressions in public spaces (Badaloo, 2022). The rise of Islamophobia has resulted both from historical oppression towards Muslims and Arabs and white supremacists' political and economic interests (Bukar, 2020). Since 2016, alt-right media outlets are increasingly popular, and anti-Muslim and anti-immigrant and anti-refugee messaging has become more visible to Canadian audiences (Wilkins-Laflamme, 2018). A 2019 survey by Leger Marketing suggests that 60% of Canadians report viewing Islamophobic speech on social media (NCCM, 2021). Islamophobic sentiment does not only come from white supremacists or far-right-wing groups or platforms. In a case study of media coverage of Muslims by *Maclean's* magazine, Awan et al. (2007) detail the Islamophobic content published by the magazine between 2005 and 2007. The analysis reveals how the mainstream magazine promotes Islamophobia by representing Muslims as violent threats to western democracy and human rights values.

Intersectional Oppressions

The invisibility and otherness experienced by disabled refugees (Chandler, 2013; Dawson, 2019) are intensified by their intersectional identities and

oppressions. Kimberlé Crenshaw, a civil rights advocate who coined the term intersectionality in the 1980s, suggests that intersectionality begins by analyzing the intersection of one axis of oppression concerning another axis of oppression (Crenshaw, 1991). Crenshaw illustrates the term's relevance with an example of the multidimensionality of Black women's experiences in the United States, specifically within the context of gun violence (Crenshaw, 2016). She describes how Black men who have been killed by police officers have received some media attention, and names such as Trevon Martin, Jimmy Atchison and Willie McCoy have been published and shared in the media (Crenshaw, 2016). Conversely, Black women who are also victims of gun violence are mainly unknown to the public (Crenshaw, 2016). While their stories may seem similar, the intersection of race and gender plays a role in who hears their stories.

Central to intersectionality is an understanding that a single axis of social division such as race or gender does not shape people's lives. They are shaped by many factors that influence each other at different times and in different ways, creating individualized experiences (Hill Collins & Bilge, 2016). Contrary to understanding gender, race, and class as separate and

distinct social categories, the concept of intersectionality assumes that intersectional identities are mutually constitutive (Crenshaw, 1995). However, intersectionality is not about identifying sameness and difference or stacking identities and oppressions (Crenshaw, 1998; 2016; Dhamoon, 2011). Instead, distinctive identities emerge from experiences of intersectionality and result in individuals experiencing complex and unique oppressions. In this way, an intersectional framework can identify and confront social and political structures that reinforce marginalization (Spagnuolo, 2016).

Intersectionality functions as both a critical conceptual framework and an analytical tool for practical application (Hankivsky et al., 2014). Intersectionality helps us examine lived experiences of marginalized groups, recognize, and confront harmful policies and practices, and challenge the ongoing marginalization and subordination of persons repeatedly rejected from society (Morrow & Malcoe, 2017). It identifies the impact of social structures or how these groups experience the social, political, and economic circumstances surrounding them (Spagnuolo, 2016). The primary objective of intersectional policy analysis is to

acknowledge the multitudes of intersecting social factors—including gender, race, and class—that affect individuals differently and result in other inequities (Morrow & Malcoe, 2017). For example, disabled, Indigenous children must traverse barriers when accessing support in schools that “reflect colonial legacies” (Steinstra, 2018, p. 8).

The term intersectionality has gained immense popularity in the last decade and has become part of a national narrative around equity and diversity (Hester, 2020). Companies and organizations advertise using an “intersectional approach” to meet client needs. For example, Addepar, a wealth management group, highlights the “intersectional lens” the organization uses when conducting business (Hester, 2020). Canadian school boards have also used the term in policies in response to numerous incidents of anti-Black racism affecting students and their families (TDSB, 2017). A 2017 report on enhancing equity stated, “Students experience racism and oppression in different ways depending on their multiple identities (or intersections) (TDSB, p. 13).

An intersectional approach considers the historical, social, and political contexts and recognizes the individual’s unique experience based

on the intersection of all relevant grounds. This approach allows the experience of discrimination, based on the confluence of the grounds involved, to be recognized and remedied (Ontario Human Rights Commission, 2001). For example, in its policy on ableism, the Ontario Human Rights Commission (2016) acknowledges:

The concept of intersectional discrimination recognizes that people's lives involve multiple interrelated identities and that marginalization and exclusion based on Human Code grounds may exist because of how these identities intersect. (p. 19)

In this way, disabled refugees may experience marginalization not only based on ableism or xenophobia but on the intersection of racism, ableism, and xenophobia amongst other interrelated oppressions.

Berne et al. (2018) highlight ten principles of the disability justice framework proposed as a conceptual framework that recognizes the diversity, uniqueness, and beauty of our bodies. Of these principles the first is intersectionality. Berne (2015) explains how the framework is necessary to capture the intersectional oppressions of all disabled persons not just white, middleclass, and heterosexual disabled persons:

While a concrete and radical move forward toward justice, the disability rights movement simultaneously invisibilized the lives of peoples who lived at intersecting junctures of oppression – disabled

people of color, immigrants with disabilities, queers with disabilities, trans and gender non-conforming people with disabilities, people with disabilities who are houseless, people with disabilities who are incarcerated, people with disabilities who have had their ancestral lands stolen, amongst others. (Berne, 2015, np)

Berne (2015) highlights how the disability movement was actively involved in the othering and erasure of marginalized disabled persons. Disability scholars attempting to move away from a biomedical definition have ignored (and are complicit in) the colonial and capitalist order promoting and perpetuating white supremacy within disability discourse by ignoring intersectional experiences and oppressions. Refugees, in particular, may occupy multiple and sometimes contradictory social locations within a host country as well as outside of it (Anthias, 2012). Their social locations may be different in the various stages of their premigration, migration journey, and postmigration. Gangamma and Shipman (2018) propose the term “transnational intersectionality”, which “...alerts us to the possible ways in which processes of power and marginalization overlap, evolve, complicate, and sometimes contradict across national contexts in the lives of refugees” (p. 216). They present transnational intersectionality as a theory that addresses the complex intersectional identities and experiences

of oppression within transnational spaces and one that examines the processes of power and privilege.

Chapter 3: Introducing the Stories

Methodology

Narrative inquiry is the study of stories (Andrews et al., 2008). This type of qualitative research design is used to elicit authentic stories (Lawlor & Mattingly, 2000) and address and understand the complexities of human experience (Clandinin, 2006; Clandinin & Connelly, 2000; Hays & Singh, 2012; Webster & Mertova, 2007) while “communicating them to others in the form of contextualized stories” (Issari et al., 2021). Using narrative inquiry, I aim to go beyond telling or sharing a story and instead listen carefully to the participant or storyteller tell their own stories and share them through meaningful and honest interpretation (Clandinin & Connelly, 2000; Ntinda, 2020). While I draw on the works of Clandinin (2006, 2013) and Connelly (2000), I use the term narrative inquiry synonymous to a narrative study or examination and also draw on the works of Dossa (2009, 2013) and Butina (2015) amongst others. In their rawness and vulnerability, stories share a powerful message, and they have the power to create connections between people and provide universal truths about ourselves and the world we live in (Mahmoud, 2021; Lawler, 2002). Through

storytelling, we aim to highlight how our individual world relates to the outside world (Dossa, 2009). Narrative inquiry reveals lived experiences through complex and interconnected layers of stories. As Connelly and Clandinin (2006) suggest, “narrative inquiry, the study of experience as story, then, is first and foremost a way of thinking about experience” (p. 477). Our stories are shaped by personal, social, and institutional narratives (Clandinin et al., 2011; Clandinin & Rosiek, 2007). Narratives of experiences are developed by living one’s story, telling one’s story, retelling one’s story, and reliving one’s story (Clandinin & Connelly, 2000; Lawlor & Mattingly, 2000). I could hear, see, and feel the participants’ stories were relived repeatedly during our conversations. Part of sharing their stories meant revisiting them and reliving them (Clandinin, 2013; Clandinin & Caine, 2012; Clandinin & Connelly, 2000).

Narrative research seemed the most appropriate approach to describe the storied lives (Dossa, 2009) of participants I interviewed as I navigated through personal, national, and transnational narratives about displacement and disablement. While the stories were often difficult to share, storytelling can be a “social act” and lead to social change (Dossa,

2013, p.103). Those who find themselves pushed to the margins of society often rely on stories to advocate for themselves, their families, and their communities. In relation to dominant stories told for them or about them, refugee stories can become alternative stories (White & Epston, 1990), overlooked and unrealized (McMahon, 2007). Refugees are in the middle of telling and living their life stories (Greenhalgh, 2016). While they may have left turmoil and arrived in Canada, their stories have not ended (Eastmond, 2007). By listening carefully to the participants, I explored how privilege and power dynamics function in society to uncover intersectional experiences and challenges, an appropriate approach when examining the patterns of oppression experienced by disabled refugees (Harris & Roberts, 2003).

Methods

After receiving ethics approval from the Office of Research Ethics at York University, I interviewed ten Syrian refugee families with children with disabilities. Participants were recruited through advertisements at local Muslim and Arab centres and participants' word of mouth. Of the ten families, nine resided in Ontario and one family had recently moved to

another province. In addition to interviewing the ten families, I spoke with two settlement workers, three private sponsorship volunteers who worked with disabled Syrian refugees, and my sister Fatema who volunteered at a refugee camp in Leros, Greece several years ago. These supplemental discussions were a means to better understand the national and transnational narratives around displacement and disablement.

Recruitment advertisements for participants were shared in written English and Arabic, and participants were told that interviews would be held in English with the support of an Arabic language interpreter who spoke a Syrian dialect of Arabic. All research instruments, including advertisements (Appendix a) and consent forms (Appendix b) were translated into Arabic. The advertisement read: Are you a Syrian refugee now living in Canada? Do you have a child with a disability? Would you like to share your story? Interviews were scheduled by telephone with the support of the Arabic language interpreter. The same interpreter was used for all of the discussions to ensure consistency in how the study was presented and how the questions were posed. At times, some participants spoke in English, and the interpreter remained silent. Most of the time,

participants spoke in Arabic, and the interpreter translated verbatim. The participants were encouraged to ask questions about the study before the interview and on the day of. Participants were reminded during the interview to interrupt me at any time with questions, comments, or concerns.

Prior to the interview, the purpose of the study and the research questions were discussed with the potential participants. The narrative research method does not impose strict guidelines on which questions to pose during the interviews and which questions must be answered, but instead allows the stories to ebb and flow as the participant narrates. I used a semi-structured interview guide (Appendix e) which allowed me to dive into personal stories (DeJonckheere & Vaughn, 2019) in the participants' own words (Walliman, 2006). Open-ended questions captured real-life experiences that could not be reduced to a single digit or sentence (Pope & Mays, 2006; Dossa, 2009). I began by saying, "we all have a story or stories, and today I would like to know about your story". All the participants consented to use pseudonyms and to the removal of identifying information. The pseudonyms selected were Arabic and familiar within

Syria and surrounding areas. In addition to using pseudonyms for participants, I used pseudonyms for the individuals who supported and worked with Syrian refugees to ensure that no connections would be made between the volunteer sponsors, settlement workers, and participants. Each interview lasted approximately 45–60 minutes and took place at the participants' convenience.

All the interviews and follow-ups took place virtually due to the COVID-19 health protocols in Ontario at the time. While I identify ten participants below who actively participated in the interviews, it was made clear during the initial conversations with potential participants that other family members could be an active part of the interview. In some cases, both parents and children were in the home. The children ran around the room in two cases, while the parents shared their experiences. In three interviews, both parents were present but only one parent communicated with me and that is the parent I included as the participant. During one conversation, a youth listened to the entire conversation while logged onto another device.

While I interviewed parents, I carefully chose to frame the interviews as families' experiences of disablement and displacement. Participants decided who to include or exclude in the conversations. They shared their stories as individuals, parents, spouses, caregivers, and advocates. While some participants did not directly identify as disabled, the entire family was involved in the child's narratives of disability (Lawlor & Mattingly, 2000). I did not ask specific questions about a child's diagnosis or specific treatment, nor did I ask how children felt or for parents to describe their children's experiences. Instead, I asked about the family's experiences and left that to the participant's interpretation. In the book *Children in Canada Today*, Albanese (2016) discusses the exclusion of children in research about children. She suggests that researchers increasingly recognize children's agency in their storytelling and conclude that children's reflections are not inferior to adults. While I hold firm to this belief, I am interested in the collective experiences of disablement and displacement as a family. For example, the migration journey that led to the family coming to Canada and their experiences navigating healthcare services and supports. I understand that children may have different

experiences than their parents and reflect on their experiences differently. I also understand that the collective experience is different from individual experiences, and one parent may speak inadequately on behalf of the family.

Analysis

Interpreting and presenting the data of a story can be challenging (Bochner et al., 2000). With written and verbal consent, each interview was audio-recorded, translated verbatim, and transcribed from the audio recording to text using Microsoft Office transcription software. The verbatim notes were read and re-read as I carefully combed each story. I created a secure digital folder for each participant for field notes and included my observations and reflections on each interview. I read and re-read my notes, organized, and labelled them by colour-coding the transcripts as I removed real names from the quotes. I left the colour-coding until the last minute to ensure I knew each participant, even though I used pseudonyms. I noted facial expressions and vocalizations such as sighs or laughs and recorded the date and time of each interview. After familiarizing myself with the data by reading and re-reading the transcripts, I organized the data identifying

meaningful chunks (Belotto, 2018). While reviewing the data, I highlighted sections in the transcripts, and used colour-coding, tracked changes, and the comments function to note the smaller themes on the transcripts (Tracy, 2013). Upon identifying the significant chunks of data, I merged the subthemes into several themes. The stories were analyzed carefully using thematic analysis (Braun & Clarke, 2012). Thematic analysis required identifying patterns in the emerging themes and looking at how the participants expressed those themes (Presser, 2005).

I then returned to my field notes and reflections (Butina, 2015) and placed those notes under the different themes. The headings changed several times as I carefully read and re-read the stories. After manually organizing the data, I used the qualitative data analysis software NVivo to support the organization process and reaffirm the themes. I reviewed all the themes again using the software and made minor adjustments to the original themes. I then returned to the participants who all provided consent to verify their stories, check for data accuracy, and make any necessary additions or revisions. I welcomed verbal and written feedback and comments from the participants on how they felt about the interviews and

the accuracy of the data. Data verification was necessary to capture the actual and intended meanings of the narratives (Polkinghorne, 2007) and not reiterate a dominant narrative. In chapters four and five, I intentionally leave many quotes for the readers of this dissertation as I felt these quotes illuminate the experiences of the participants in their own words. As one participant told me, "Now you are a witness to what we have shared".

Participant Profiles

Participant stories speak back to the dominant national and transnational narratives around disablement and displacement. I share a brief profile of each participant and their family that highlights their unique story. While the participants all identify as Syrian refugees with children with disabilities, their stories are very different. For example, some of the participants described living in big cities and going to university, while others described living in small towns and not having access to post-secondary education. The initial prompts to the conversation led to different types of answers. The first was to tell me a bit about who they are, and the second was to share their story. For the former question, participants described where they were born, when they married, and how many

children they had. The latter was a deep dive into personal and family narratives about disablement and displacement. The profiles below include information from the first prompt, but is not at all sufficient to describe the individuals whom I spoke with. I included points in the profiles that struck me in their individual stories. As I combed through the transcripts of the stories, themes stuck out in a way that highlighted how the participants' stories were interwoven. I never discussed the participants' stories or profiles with each other. I never disclosed who else I interviewed and never shared any participant information, but it was as though participants shared their stories with one another ahead of time. Their stories were distinct yet similar. They were individual yet collective (Dossa, 2013).

Marwa

Marwa and her siblings were born and raised in a small village in Syria. She got married and had her first child during her teenage years. She shared that in her village, the girls would marry at 15 or 16, have children at a young age, and very few girls would continue their education or get a job. Marwa expressed how much education meant to her. She said she always wanted to go to school and get a diploma, and she desired for her children

to be formally educated so that they would have more opportunities to succeed socially and economically. Marwa was privately sponsored through a community organization while living in Lebanon. She resides in Ontario, Canada with her husband and five children, some of whom live with a disability. Marwa is currently pursuing adult education classes along with her husband while maintaining full-time employment.

Amal

Amal and her husband Yusuf were born and raised in Syria. They both grew up with disabilities and identified as disabled for most of their lives. Amal described many daily challenges growing up, including being excluded from her community, barriers to educational opportunities, and facing ongoing discriminatory practices. Their two children were born in Syria. Shortly after their second child was born, Amal and her family learned that he had a disability. Amal escaped Syria to a refugee camp in Turkey after her home and family business were demolished. After a few years, she was connected to the BVOR program and re-settled in Ontario, Canada.

Halima

Halima was born and raised in a major city in Syria. She met Ahmed while in college and shortly afterwards got married and had her first child. She described her life to be one full of hope. She had a bright future. She and her husband dreamed of pursuing further education and growing their family business. When the war broke out, Halima and Ahmed fled Syria to Egypt with their three children. All three children displayed delays in gross motor, fine motor, and communication skills. She arrived in Canada with her family through the United Nations refugee application process.

Muhammad

Muhammad described himself as growing up in a small town in Syria where everyone was like one big family. He was well-connected with his family and community and was focused on his career and his family. Muhammad got married at a young age and had four children, one of whom lives with a disability. When the war broke out, his family fled to Jordan where they stayed for a few years. Muhammad shared that he had a relative in Canada who encouraged him to apply through the United Nations

refugee process. Muhammad and his family were approved for asylum and arrived within a few years.

Hajra

Hajra was born in a small city in Syria. She got married after highschool and had her first child shortly afterwards. When she fled Syria, she moved to Lebanon, and from there learned about the private sponsorship program for refugees. Some of Hajra's children had difficulties communicating verbally and learning in school. Hajra wanted them to get the medical and educational support they required. Her husband could not come to Canada with her and their children as he supported his immediate relatives who were denied legal rights to come to Canada as refugees. Living in Canada, Hajra is a single mother. She is the only one who can provide financially for her family. She reported not having any relatives to assist her and not having enough social and emotional support.

Hassan

Hassan described his life in Syria before the war as a life that made him proud. He had his own business and depicted himself as being one of the

most talented workers in his field. Hassan shared how he was able to fulfill his family's financial needs. Once the war broke out, he experienced losing many friends and relatives to the war. From Syria, he travelled to Egypt and applied to come to Canada through the United Nations refugee process. Hassan cares for his wife who lives with a chronic health condition and their disabled children. Here in Canada, he does not have any relatives or close friends and cannot maintain employment due to his caretaking responsibilities.

Muna

Muna described her life in Syria as one full of challenges. She struggled financially and caring for a disabled child was difficult. When the war broke out, Muna feared losing one of her children as she witnessed the death of family members and friends including many children. Muna fled Syria with her family and sought refuge in Jordan. Muna applied to come to Canada with her children through the United Nations refugee process. Here in Canada, Muna is a stay-at-home mom. She wants her children to receive

a quality education so that they will have career opportunities and not struggle financially like she did.

Sarah

Sarah began her story by describing a forced marriage with her relative. She expressed how complicated her pregnancies were and described how she struggled to get adequate healthcare in Syria. Sarah shared how her family did not accept or understand her children's disabilities. The war made her marriage more complicated as she could not care for her own needs and the needs of her children. Sarah escaped Syria with her children and then-partner to Lebanon. From there, she applied through the United Nations refugee process and made it to Canada a few years later.

Omar

Omar and his family fled Syria to Jordan once the war broke out. From Jordan, Omar advocated tirelessly to get his child medical attention and educational support. Omar applied to come to Canada citing exceptional circumstances due to his son's medical condition through the United Nations refugee process. A few years later, Omar arrived with his wife and

kids. Now in Canada, Omar struggles with his personal health needs. He desires to maintain full-time meaningful employment but struggles to juggle work and his family responsibilities.

Dalia

Dalia was the eldest participant in the study. When the war broke out, she escaped Syria to Egypt with her partner Mahmoud and their adult children. While in Egypt, Dalia was split up from her adult children, one of whom lives with a disability. Dalia's children were eligible to migrate to Europe for their professional careers, but Dalia and Mahmoud were ineligible due to their age, lack of education and professional careers, and their disabilities. After some time, Dalia applied to seek refuge in Canada and was granted asylum. Since that time, she has not seen her children and is alone in Canada with her partner.

In addition to the in-depth interviews with the above participants, I wanted to learn about the experiences of settlement workers and volunteer private sponsors working with and advocating for disabled Syrian refugees. Within this paper, I share some insight from three private sponsors Naima,

Najma, and Jahan, and two settlement workers Salma and Yasmine. I also share some testimony from my sister Fatema who volunteered at a Syrian refugee camp in Leros, Greece several years ago.

Reflexivity

I heard my story echoed in the stories of the participants. I found myself in the participants' stories. I resemble some of them in appearance and sound - with my hijab, brown skin, and Arabic name. I connected with them. Some participants referred to me as their daughter and greeted me with the traditional Islamic greeting of peace and blessings, *Assalamu Alaikum*³. As demonstrated in chapter two, I can resonate with the stories shared with me and reflect on them even while they are not my own. I can try to understand them to challenge the dominant narrative in academia, policymaking, and practice.

However, a narrative approach to research, like other methodologies, can be dominated by those in power (Dossa, 2009). We must be critical of who is telling the story, who is sharing the story, and the

³ Means "Peace be upon you" and is responded with *Walaikum Salaam*, "Peace be with you too".

motive behind sharing the story (Bochner et al., 2000; Clandinin & Connelly, 2000), identifying whose interests are being served by the research (Guruge & Khanlou, 2004). Stories of disabled Syrian refugees and their families must come from disabled Syrian refugees and their families. In chapter one I state my position as a Muslim woman of colour, healthcare professional, and community organizer who has worked with numerous disabled Syrian refugees and their families. However, I am not Syrian, nor do I identify as disabled. I have only experienced disablement and displacement intergenerationally. I acknowledge the many privileges I hold, including being born in Canada and educated within the Canadian school system. I am familiar with the education and healthcare systems in Canada and many social and community services. I must ensure I am not misappropriating the stories entrusted to me. When collecting and presenting research, stories must be handled with great care (Greenhalgh, 2016). I must reflect honestly on why my research on disablement and displacement should be considered and the means by which I obtained the stories. Storytelling requires the storyteller to share in the most dignified ways, involving the listener's active participation (Dossa, 2009). Dossa

(2009) states, “When readers engage with stories and their various interpretations, new meanings are created that will reverberate in the readers’ own local culture and sometimes the dominant culture as well” (p. 25).

I shared my story at the beginning of this dissertation, and that story is not something I can remove myself from (Tracy, 2013). It is essential I am aware of my own influence on the research process (Patnaik, 2013) and examine my own positionality (Hickson, 2016). My story is a result of years of experiences that have shaped who I am. As a Muslim woman living in the Greater Toronto Area and a community organizer, I acknowledge that the participants may have come across my name or recognized my face and may have felt obligated to participate. Several participants commented on my level of education and commented on being proud that a Muslim woman has achieved so much. One participant told me how proud he was of me and that I am representing Muslims in academia. Two participants referred to “how young I look” but not in the derogatory way that I have received in the past. These comments were accompanied with a gentle smile and followed up with statements around how much I

have achieved professionally. One participant stated I am like their daughter and that my accomplishments are for “them.” I told one participant that I was not becoming a medical doctor after he referred to me healing sick people. He smiled and said, “knowledge is everything.” A few participants had not met me personally through SMILE but had heard of my name as the founder and executive director.

Generalizations, stereotypes, and assumptions must be considered when sharing a story and continuously challenged to unpack dominant ideas and practices (Shaw & Bailey, 2009). One way to avoid generalizations is to engage in the practice of reflexivity and reflect on the privilege of the researcher (Dossa, 2009). According to Frank (2000), reflexivity is a critical piece of storytelling. To make sure I critically reflected on the stories, individually and collectively, I kept an ongoing journal of reflections. Pon (2009) suggests that reflexivity goes beyond cultural competency. Cultural competency repeats whiteness as the norm and urges people to be competent – a minimum and demeaning standard. Instead, researchers should challenge power and privilege through reflexivity (Hankivsky, 2012). Influences of interpretation, including any biases, must

be documented and disclosed to participants. Reflexivity helps researchers identify their privilege (Frank, 2000), but acknowledging this privilege does not ignore the researcher's power in their position. Reflexivity may be uncomfortable and unfamiliar (Pillow, 2003), I explored uncomfortable and unfamiliar ground when writing down my own reflections.

Greenhalgh (2016) suggests that rigour in narrative research is not about technical procedures. Instead, it is about being honest and critical. Throughout the study, I questioned these two aspects at every opportunity. I would ask myself if I was honest about who I was and how I presented myself to the participants, my intentions behind the research, and how I was situated in this research. I would also ask myself what limitations impacted the research. I identified the following: Firstly, the platforms used to communicate with participants were at times inaccessible. While the COVID-19 restrictions prohibited me from interacting with participants in person, virtual participation was challenging. Some participants communicated via the teleconference software, zoom. Others requested a phone call. It was clear that some participants struggled to maintain a strong internet connection, and the disruption in the internet connection obstructed

the conversation. For example, my discussion with one participant was cut off several times due to poor internet connection. When she reconnected, she began the sentence with, “I don’t remember where I was, that’s ok”. While I reminded her where she was in her narrative, it felt that she had moved on to the following sequence of her story. For one participant, their child was using the computer for their online learning, so the parent used the phone to complete the interview while supporting their child’s online learning. The participant stopped several times to address their child’s concerns. When they returned, it also seemed as though they had moved on in their story.

Communicating with participants via an interpreter was also a challenge. At times, the interpreter paused the participant to convey the information to me in English, but it was possible that the participant was in the middle of a critical moment in their story. The interpreter may have wanted to capture the entire sentence; however, this disrupted the conversation and discouraged participants from continuing with their thoughts. Furthermore, the participant could have felt frustrated waiting for

me to get information from the interpreter, which could have changed the course of the conversation.

Chapter 4: Transnational Disablement

A transnational framework is necessary to understand and appreciate the participants' narratives. Each shared story was complex, multifaceted, and layered. Without a transnational framework, the stories within the following sections are indecipherable. While I have placed certain stories and storied experiences under themes I derived through data analysis, the stories collectively fall under the banners of transnational disablement and xenophobic ableism. Transnational disablement includes stories of disablement, a disabling Syria, complex migration journeys, and arrival in Canada. Xenophobic ableism includes stories of surviving a pandemic, obtaining human rights, intersectional oppressions, forced gratitude, navigating an oppressive system, and advocacy.

Stories of Disablement

Disability as identity, social construction, physical impairment, and medical condition were ideas embedded within the conversations. When referring to the participants in this study, I intentionally use the term disabled based on the idea that disablement occurs through systemic oppressive practices that

make and keep people disabled (Shakespeare, 2010). However, it must be noted that only a few participants used this term during our conversations. Some participants referred to their children as having ‘special needs’; others referred to their medical condition as their disability. I actively made sure that I did not correct anyone or suggest terminology that I thought was politically correct. I have observed academics and disability activists correct the terminology families use when describing their children's behaviours or conditions and believe that this can remove control of the story from the person telling it. For example, I witnessed a disability rights activist correct a parent who referred to their child's condition as ‘a special gift’ by saying, “There is nothing special about having a disability”. The parent responded, “But my child is a gift from God, and his condition is a test for us as parents”. The parent's belief that the child was exceptional in the eyes of God was a personal belief, and correcting the parent involved placing the activist’s perspective as the authoritative one. In this regard the activist is retelling the story of the parent and their family, a typical behaviour in a settler-colonial context.

Furthermore, words are translated differently in different languages and have different connotations. The Arabic words for disability mostly used during the interviews was ذوي الاحتياجات الخاصة (*Zawi alihteyajat al khassa*), which translates to people with special needs, and الإعاقة (*al Aaqah*) which translates to impairment or obstruction. Some participants reported they never identified as disabled nor did their child ever identify as disabled before coming to Canada. Yet, they experienced exclusion from community spaces in their home country and local host country because they were 'different'. When they came to Canada, they heard terms such as "autism" and "global developmental delay" for the first time, and these terms became a marker of their children's identity. For other participants, their disabled identity and their child's disabled identity gave them leverage to come to Canada on humanitarian and exceptional grounds as vulnerable refugees.

Amal's story centered around her disability. She shared how identifying with a disability has always been difficult for her family, even though she and her partner have had visible disabilities since they were young. Before getting married, she was always told that no one would want to marry her, that she could not bear children, go to school, or get a job.

Despite the systemic ableist barriers and stigma that surrounded her, Amal went to school, found a job, fell in love, and had children. When her child was born, and people found out he was also disabled, they told her she was cursed. Wiping away her tears, she shared a time when a man came to her house and said, “there was one, then there were two, and now there are three”, referring to disabled persons in her family. Amal spoke about the stigma of caring for a child as a disabled parent. While she mostly discussed this topic in the context of Syria, the conversation is ever relevant in the global north. Parenting with a disability is challenged by an argument that revolves around the idea that parents must be physically and emotionally independent to care for a child who depends on them (Olsen & Clarke, 2003; Parchomiuk, 2014). Amal spoke about the ongoing discrimination her family faced when her child was born. She shared that it was not her child’s disability that made it difficult for her family; rather, it was the stigma and judgement her family faced.

Hassan described his children as being born with disabilities. He learned about the genetic nature of his children's medical conditions in Canada. Before coming to Canada, doctors did not know of his children’s

conditions, and he often got contradictory advice on what the disease was and how to treat it:

I went to a lot of doctors; nobody knew what was wrong with them in Syria. Okay the second child came and then third child came along. We went to another doctor to deliver, a good doctor to deliver the third child and they said that it has nothing to do with the way he was born. Then we got pregnant with the fourth child as the doctor said it's not that she [wife] will have the same problem and the fourth child did have the same condition.

While Hassan's children were born with a genetic condition, his first child did not receive adequate medical attention at the time of his birth due to the difficult economic and political circumstance in Syria. Upon learning of their diagnosis, I did some research on the identification of the disease. In Canada babies are screened after birth for approximately 25 genetic conditions (Newborn Screening Ontario, 2021). Hassan's children's condition is amongst those that are identifiable and treatable if caught early. Hassan shared how a lack of medical care in Syria and in their host country hurt their development.

Marwa discussed how in Syria, doctors told her that her children had a curable disease. When she arrived in Canada, she hoped that the doctors would provide medication that would cure their condition. After

being assessed at the local children's hospital, she realized there was no medication or cure:

I started to see doctors around. I met the neurology doctor after six months after my arrival and they referred me to the children's hospital for my two daughters. Well, they started to do some tests and they did genetic tests, and it took six months for it to come. I got the results and they said it's not what we thought, it's something close to it. Its malformation in the genes. Unfortunately, they told us this disease doesn't have a treatment and that there might be some tests or treatment in the future.

While Marwa, Hassan, and Amal described their children as having been born with a disability, they all shared how they did not receive adequate medical attention or information regarding their children's conditions. This significantly impacted their children's early development and their childhood experiences.

Other participants shared how their child's disability was acquired directly because of the impacts of the war. Omar, for example, reported that his son could not get access to oxygen he required since the sanctions on Syria meant medical supplies were restricted from coming into Syria. Furthermore, he described how curfews prevented the movement of people in the city, including healthcare workers. Omar described his son's condition as a direct result of the lack of humanitarian aid:

My son, he had lack of oxygen when he was born and then due to the war, they couldn't get his medication and the care he needs. So now he developed a damage to his brain.

Hajra discussed the impact of chemical weapons and subsequent chemical poison and toxicity on her children. She reported fleeing the affected area with her family, but she believed residual effects of the chemical attacks impacted her child:

When he was three, we took him to a doctor in Lebanon, and the doctor said the child has a high metal and high toxicity. It could be a result of chemical poison they said.

Hajra shared how the doctors in Lebanon were aware of the environmental conditions of war and violence that lead to chemical poison. While in Canada, doctors did not seem to believe her story. The doctors ignored her family's experiences and oppressions by relying on standardized protocols for developmental disabilities. Upon reflecting on her story, I read up on chemical attacks in Syria and the impact on Syrian families. I found the entire discussion around chemical attacks and weapons in Syria complex. The chemical attacks in Syria led to more civilian strife with international responses through missile attacks, further disabling the population. A 2021 submission of the Syria Justice and Accountability Centre urges further

research in the area of disablement and chemical weapons. Hakeem and Jabri (2015) suggest the long-term effects of chemical weapons in Syria are largely unknown and require further investigation. For example, pregnant women and their children who have been exposed to chemical weapons have lifelong disabling effects.

Stories of a Disabling Syria

Several of the participants shared how beautiful and full of life Syria was. They talked about the rich history, magnificent scenery, close-knit communities, and vibrant culture. They shared how much they were at peace and enjoyed their lives prior to the onset of the war. They began their stories by talking about their experiences at school and at work, and spending time with family and friends. They spoke about their cultural and faith communities and described their hopes and dreams for the future. They all talked about their lives before the war and discussed the war as a point in time that changed everything when they were not displaced or refugees. They all spoke about leaving Syria because of the conflict. Muhammad said, “After the war broke out, things spiraled out of control.

Jobs were gone, homes destroyed, infrastructure broken, and lives lost”.

The participants spoke about how the war forced them into new circumstances and identities. They were not born as refugees. They became refugees.

Jahan, one of the private sponsors I spoke with shared her thoughts on the dominant narrative around refugees being “lucky to be in Canada”:

Refugees are forced to seek refuge. They don’t have too many options; coming to Canada was the last resort. People don’t realize it’s a choice of life and death; it’s not a preference.

This choice to live was shared through powerful statements by the participants:

I left Syria because of the way it was difficult with the war, there was no work and no security. I was afraid for my family. We did not feel safe, everything was so difficult. – Sarah

I was afraid that I was going to lose one of my kids in the war. I could not lose any more and I could not lose my children. – Muna

My kids wanted to go out of Syria because of the traumatizing things they saw under explosions. They wanted to live. I wanted them to live. – Halima

In addition to fear of losing their lives and losing loved ones, the conflict also meant unemployment, financial insecurity, hunger, demolition of homes and businesses, and inadequate access to healthcare and social

support. The war changed every aspect of their lives. Muhammad and Amal spoke about job insecurity and financial distress in Syria, their neighbouring host country, and in Canada. Amal shared how she and her husband lost their jobs and could not make ends meet. Her financial situation meant that she could not care for herself or her children:

The war destroyed my family home and my husband's business and with my son having a disability there was no support for him. One day, my child got really sick. We did not even have money to take him even to the hospital. Our neighbor came and he took the child from us. He ran to the hospital with him, and he paid for everything. And that was ... ugh that hurt. And we were very embarrassed that we weren't able to provide our son with whatever he needed. That's when we decided to get out of Syria, and we would try to find a place where they could provide for his needs.

Omar was one participant that did not describe his time in Syria during the war, instead he said, "I need not tell you a lot about the difficulties in the war, because mostly we all know about it. For us it was real". While I did not think we did all know about real stories of the Syrian war, I did not push Omar to expand on what he meant. Upon reflecting on Omar's words, I was drawn to Clandinin's (2013) retelling and reliving of the story. I reflected on how pain is relived through imagery and rhetoric that surrounds us and how often we ignore the trauma of telling one's story and

sharing one's experiences (Saleh, 2019). As Omar highlighted, the stories of the participants were not fictional, they were real.

Stories of Difficult Journeys

Stories of refugees are often portrayed as leaving one place and arriving at another (Issari et al., 2021), and the experiences of refugees often do not account for the actual journey or migration, which includes the means and conditions of transportation and the impact of an arduous journey (Ilcan et al., 2018). I spoke to my sister Fatema about her experience in 2015 as a volunteer assisting at a refugee camp in Leros, Greece. She shared how the journey out of Syria was like a survival-of-the-fittest test, one that many would not endure. I pulled up one of her emails from her time in Leros where she wrote:

They were on the boat, cold and wet for days without food. We gave them three biscuits and water when they arrived. Only three biscuits! The two girls were soaking wet because no one would get them a pad, so I asked one of the officers if I could take them to the bathroom, helped get her a change of clothes. She spoke a bit, of English so I was able to understand that her brother was also not well - looked at his fingers that had gone all blue and purple - so the medics were allowed to take him to the makeshift tent to get some assistance.

The conditions Fatema described in her emails was a glimpse into the actual narratives of displacement journeys. As I searched through her emails, I read about the policing of refugees, the rationing of food and medical supplies, and the ableist selection of who gets to survive.

All the participants in the study sought refuge in neighbouring countries before coming to Canada. The families I interviewed reported seeking asylum in Egypt, Lebanon, Turkey, and Jordan. They all reported that the neighbouring host countries' economic, political, and social situation was extremely challenging. According to Bose (2020), the situation in neighbouring host countries was equally hostile as the situation in Syria for many Syrian refugees. Muhammad shared that this was the case for his family. He felt the situation in Jordan was as bad as the situation he left in Syria. Like Muhammad, several participants experienced food and housing insecurity in their host country, while others shared how they were afraid of the political turmoil and being persecuted. Being a refugee made them a target because there was no citizen's protection. They did not have relatives to assist them, nor did they have the financial security to move out of the refugee camps and into safer spaces. Muna shared how her family's

journey was challenging because they were forced to leave without any income or belongings:

It was one of the most difficult part of my life. Uh, we didn't have any money to fulfill any needs we have in Jordan.

Marwa thought the host country would provide more support since refugees could not travel with their possessions. “We only had the clothes on our back,” she said. She explained how her family could not afford to send her children to school and consequently they did not go to school:

When the war started, we went to Lebanon. I was hoping that the medical care is better in Lebanon than Syria. I tried to send them [kids with disabilities] to school but they didn't accept them. The private schools were very expensive, so I kept them home and they didn't go to school there. I started my journey and I had depression and it was really hard for me.

Not having an education made it difficult for Marwa to find work in the host country. She spent her days caring for her children and looking for ways to make ends meet. She also tried to educate her children at home to the best of her ability.

Making another journey to Canada was highly taxing and traumatizing for the participants. While the media narrative made it sound like Syrian refugees were all rejoicing when they landed, overcome with

feelings of relief and gratitude (CBC, 2016), the participants shared that this was far from how they felt. Sarah expressed how difficult her migration to Canada was:

Coming to Canada was a horrible, horrible experience. I tried to get him [child with a disability] in the airplane and he was crying and screaming and hitting us all and hitting people even around him. And in the first airplane, it was a disaster. And the people around us were really irritated that we couldn't do anything about it.

Halima also spoke about feeling overwhelmed in the airplane and the lack of empathy with other passengers and airport personnel. As a mother of two young children, I could not help but reflect on my own experiences travelling alone with my two kids, getting dirty looks from passengers when my children cried, and finding it difficult to ask for help. But what Halima shared was not like my unpleasant experience, it left her traumatized:

The journey was difficult. The trip it was super difficult. It was like we suffered more than other people. The kids weren't able also to carry their bags or do anything. So, it was so super super difficult for us. And it was a long, long trip. Every one of them [children] needs to go to the washroom. They need me to go with them and it was really difficult. No one was helping us, even when we asked for help.

Halima shared how the experience in the plane was her first glimpse of meeting people of other cultures and backgrounds. She could not leave her

other children while taking one child to use the airplane toilet. Her children were afraid and confused. She thought it would be a pleasant experience, one that mimicked what she had seen on T.V. Instead, people gawked at her and her children as though they had done something wrong. I could hear the pain in her voice as she shared her story of being on an airplane for the first time.

Like Halima, Marwa also shared her fears about travelling in an airplane for the first time. She disclosed how at no point in time when filling out her paperwork or when preparing for the journey was the process of travelling of travelling to Canada explained to her family. She did not know what to expect, how long the journey would be, who would be there to greet her family when they arrived, and who would support them:

I was so scared, I was terrified, I was coming to the unknown.
My first time travelling in an airplane, I was so scared.

Having a disabled child who required additional support was a common theme amongst the participants as they described their migration journeys. Participants shared how their children needed to be carried or pushed in a stroller or wheelchair. They described how they required specific help with feeding and toileting. Participants spoke about the difficulties with

supporting their children during the long car rides, dangerous boat trips, and exhausting flights.

Stories of Trauma

All of the participants in the study shared stories of trauma - while in Syria, through their displacement journey, and in Canada. Trauma includes the experience of, and responses to negative and violent experiences that can have short and long-term effects (Government of Canada, 2018). “Do they know what we went through? I wonder if they know about what we went through?” Omar asked. The question seemed rhetorical as he went on to answer:

We had no electricity, no water, no food, nothing there, and no hospitals, and for me, so I couldn't look after my leg. I couldn't walk properly and get help for my family.

I kept quiet thinking to myself that his narrative was probably not one that people knew. I do not think people know what they went through. I do not think authentic stories of disablement and displacement are well known. Not because we don't hear about it on the news, nor because we cannot read the history of the Syrian war, and the impact of the war and violence

on communities. Rather, we choose not to listen, and we regurgitate the dominant narrative around Syrian refugees having to come to Canada for a new fresh start, assuming people leave behind their stories and traumas. I reflected on my own profession; specifically, the education and training I went through to become an occupational therapist. During my undergraduate studies, I took courses in health policy, equity studies, bioethics, and health sciences and never learned about the impacts of individual and collective trauma and did not learn about material or economic conditions that impact refugees in Canada. In graduate school I learned about occupational performance, and client and family-centered care, but never learned about the systemic impacts of social determinants of health and disability on a refugee population. I did not learn about intersectional experiences or oppressions, nor did I learn about the effects of intergenerational trauma. In fact, I went to elementary and high school in Kitchener-Waterloo, Ontario, and was never told about a residential school that existed less than 50 kilometers away. At no point in my education was I ever taught about the need to look at the local and transnational histories or narratives to understand real experiences, real oppressions, and real systemic problems

to identify real solutions. “Our treatment is supposed to be trauma informed” Salma, one of the settlement workers said loudly, “But nobody is talking about trauma, and in fact, in most of the cases we hear, not only are they not talking about trauma, but when people bring up trauma, whether in schools or at doctors’ appointments, they’re told they are in a different place now!” Halima explained how the pain and trauma she experienced in Syria gets relived in Canada in different ways:

It is traumatizing. I feel like I am often back in the same pain, the same trauma and because we stayed there in this terrible situation for two years. So, I sometimes feel like I am back in the same pain that I had before. But my oldest one is giving me a really hard time. He's not accepting anything, even his dentist appointment. I took the appointment and then when the appointment came, he doesn't want to go and he doesn't want to do it. I cannot force him, so I cannot do anything for him. He is afraid.

Yasmine, another settlement worker explained how trauma is perceived inconsistently by healthcare and educational professionals and refugee experience is highly misunderstood. She said most people treat refugees like immigrants, but they are not immigrants; they are refugees, seeking protection. For Sarah, she relives the trauma every day. She expressed how her trauma has manifested into a medical condition. She has anxiety and high blood pressure, and it has impacted her everyday life:

I'm hoping that nothing would happen to me. My heart condition is not good. I need to be able to take care of my kids and do everything. Because this happened all because of the stress and the fear, feeling, and everything that I have been through.

After my conversation with Yasmine, I contemplated a video I saw about Yusra Mardini, a Syrian refugee Olympian who made international headlines with her story of crossing deep waters from Syria to Germany. Mardini was in a boat that capsized, and she had to swim a dangerous lengthy stretch to reach Germany (UNHCR, 2018). Mardini shared her personal narrative with other refugee women who had to make dangerous and difficult journeys across waters to get to their host countries. She described in a 2018 UNHCR video that many of them had suffered great loss. In the same interview, Mardini advocates for the power of personal narratives, "when they ask you, don't say I want to forget my story. No, this story made you who you are. This story made you as strong as you are," she pleads. The power of narratives was echoed by Sarah who shared how she was just scratching the surface with her story. At the very end of our conversation, she wiped her tears, smiled, and said:

One day I may be able to do something like write something and express what I did in my life, someone might want to read it. People don't know what we have been through.

Stories of Asylum in Canada

As discussed in chapter one, there are a few means by which Syrian refugees can seek asylum in Canada. Participants arrived through the government refugee program, the blended program and the private sponsorship program. Of the three participants I interviewed who had support from private sponsors and volunteers, two reported having significant support upon arrival to Canada and getting the appropriate resources as they transitioned into a new lifestyle. One participant shared that their private sponsor had gone "above and beyond" to help them during the challenging process of resettlement. The second participant reported wanting to continue the same level of support they received when they arrived and shared how the year was extremely challenging and went by too quickly. The third participant reported feeling abandoned by the people who cared for her and her family:

I didn't know any resources, and I lived in a small community, I came to the unknown and I think it wasn't fair that I came through private sponsorship – not like other people who came. And were given information on where to go or what to do.

Naima, one of the private sponsorship volunteers I spoke with shared how private sponsorship was initially framed as providing support with the direction of the Canadian government through the BVOR program. The reality for Naima and her colleagues was that very little assistance was provided. “What we did not know is that there would not be much guidance”, she said. “We did it because we came to Canada as refugees. We wanted to help, and it felt good to know we can support others in their journey”. She went on to explain that private sponsorship was not what she thought it would be, “It was up to us, the sponsors to give funds received to families or help them out by purchasing items and showing them the way”. When the funding ran out, she and her colleagues felt overwhelmed and exhausted and used many personal funds and resources to support the families. Private sponsors have had to do more with less funding in recent years (Labman, 2016).

All the participants reported feeling overwhelmed, scared, lonely, and confused when they arrived in Canada. Hajra summed up her experiences in one statement, “Here [in Canada], we saw other struggles than we saw in Syria. We are having other struggles. All my years here [in Canada] are full

of struggles”. Sarah spoke of how everyone around her was rejoicing when they first arrived at the hotel, but she and her family could not leave the hotel room due to her child's behavioural needs. The time spent at the hotel was supposed to be full of relief, but instead, she was anxious and questioned the choice she had made for her family by coming to Canada. Sarah expressed how the staff were not sensitive to her family’s needs:

Okay, well everybody in the hotel were having fun. They were going to the swimming pool and eating in the restaurant. But we had to go through a lot of trouble because we couldn't go to the restaurant because my son was giving them a hard time. He used to hit them there so we were only allowed to eat in the room and even the elevator, we wouldn't get in there. The staff did not help us.

Marwa spoke of wanting to go back to Syria shortly after landing in Canada. While her private sponsors encouraged her to take advantage of the situation, she did not feel welcome, and missed her community culture, a culture where neighbours were like family:

After a month, I was so depressed, I was talking to my husband, I wanted to go back. The sponsor told me the advantages of being in Canada. But I was depressed. I didn't speak the language and secondly the Arabic culture – we always have neighbours, and we are so close together and I came here, and I was disconnected from everybody. There is no culture like that here, neighbours aren't talking to each other.

Dalia sought asylum in Canada through the United Nations refugee process. When she arrived, she received support for food, shelter, and clothing through a local settlement agency. Once the agency weaned off their support, there was no one to help her and her husband. She could only rely on her elderly husband and wished her children were there to provide emotional, social, and financial support. Dalia's adult children were rejected Canadian visas. In addition to sharing how much she missed her children and how worried she is about them, she expressed concerns about something happening to her husband who already had some major medical issues:

I need my son to help me. What if something happened to my husband? I am going to be left alone. I cannot do anything by myself.

Dalia went on to talk about how lonely she felt in Canada. She was taken back by the many stark differences in Canada and Syria that she shared were challenging. For example, Dalia and several of the other participants spoke of the cold weather and how they were not prepared for the extreme temperatures. Aldiabat et al. (2021) found that extreme cold temperatures impacted the everyday health of Syrian refugees. For Halima, wearing extra

clothing and winter accessories to keep safe and warm was a huge challenge for her disabled children:

And well, being here in November it was winter, and here gets anyway like it's so hard for them to adjust to new temperature so they were refusing the change and specifically in winter they had to wear gloves and hats and they are not used to it. So, it was an extra. The winter was difficult until now my son, he does not wear gloves or a hat in the winter. Yeah, we found it really difficult to adjust and it took them a long time to adjust it specifically that they cannot leave their children alone in the house. They cannot go anywhere.

Some participants spoke about the complicated public transportation system that is confusing and difficult to navigate. Others felt overwhelmed by the long distances of driving and traffic in the city. For Marwa, the cold weather made travelling using an unfamiliar public transportation system extremely difficult:

It was really cold; I didn't have a car and it was -15 when I got here. We used to take a stroller with my husband and carry big bags on my shoulders and in the cold. Every time we did this I was crying; I couldn't take it anymore. A lot of time we got lost, we didn't know where the station was. People didn't understand us and would not help us.

Naima reported that the volunteers themselves did not know a lot about the public transportation system because they did not rely on it. Instead, many of them had their own vehicles. She also discussed how the most difficult

challenge with transportation was knowing how to book and plan for wheelchair accessible services. “We did not know how to do it. We were figuring it out as we were helping them [Syrian refugees] and they could probably tell”, she sighed.

Stories of Economic and Social Conditions

Financial security, employment, financial responsibilities, and expenses of caring for a disabled child were all topics connected in the participants’ stories. Marwa shared while she had the so-called right to work, obtaining employment in Canada was very difficult for newcomers. She shared how she and her husband had worked so hard to develop their skills in Syria and that the jobs they got in Canada were not what they hoped. Neither can utilize their previous skill set or excel in their respected profession. Instead, they both work in a bakery baking bread:

My husband, he is a mechanic. He is a good mechanic and well known in our city. And this agency finds jobs for people, so they signed for him to work in a bakery. He could not find any job opportunity in his field, so he had to work in a bakery where he makes bread. And he is so frustrated about that he thinks he should be doing something different and take more money other than just making bread.

When Marwa arrived in Canada, a refugee agency sent her to work for a company that's net worth is billions of dollars. Marwa has five children, some of whom have disabilities that require significant financial support. Marwa described how she felt exploited with the company she was working for because of the poor working conditions and minimal pay. To protect Marwa's privacy, I will not share the name of the company. However, she told me something that I reflected on for quite some time after our conversation. She said that as a worker who made so many of their products, she could never afford to even buy a single item with her salary.

Expenses for caring for a child with a disability are significantly higher than caring for a child without a disability (Burton and Phipps, 2009). Participants discussed the out-of-pocket expenditures of therapies and respite services, and the cost of adaptive equipment and assistive technology. They discussed how it was critical that they obtained and maintained meaningful employment. Hassan spoke of his thriving career back in Syria. Since coming to Canada, he has not maintained employment due to his responsibilities at home caring for his wife and children:

I was working in car mechanics and had my own shop in Syria. Like a place where I did not only work, I owned it. Well, I was working to

get my family their needs but here in Canada I cannot have a job because I cannot leave my kids or my wife as she is not well, and especially in COVID also there are no schools open so there's no support at all so I cannot go and get like work and find a job. Who will take care of my children? Support is good but we need more. I said earlier in our conversation that I might seem selfish, but I am not being selfish, I need more help and my children need more help.

Like Hassan, Muhammad reported he could not get a job because of his duties at home with his family. He shared how childcare was too expensive, especially when it comes to caring for children with disabilities. While Muhammad did not refer to systemic discrimination, I reflected on how unfair it was that services cost more for disabled children than children without disabilities. Anderson et al. (2007) share data that disabled children are often born to low-income households, and households with disabled children are more likely to end up in financial distress. Muhammad's child requires 24-hour supervision and care, and he cannot neglect his child's needs by leaving his family to work. Muhammad also described how it was not just childcare expenses that he could not afford. Other essential expenses are not covered by OHIP or other publicly available means such as a wheelchair ramp or dental care.

Omar spoke of the number of diapers his child uses due to incontinence and explained how they are less readily available at local pharmacies and more expensive because they are above the average range for children who generally use diapers. Omar shared that he did not have a budget for these diapers, and he could not ration them. Instead, he had to pull from other necessary aspects of his life, such as gas or food. I wondered if there was an organization that would help cover such costs. If I, as a healthcare worker (who has extensive experience working in the social services field) had no idea, how would these participants find out about additional services or funding? How would they know who to connect with or what their options are? It is unclear to me whose job it is – is it the role of a family physician? Most of the participants did not have a family physician or a social worker? Is it the teacher’s job? These questions remain unanswered. Sarah addressed how nobody directed her to the supports that are available:

Well then, nobody told me where to go or what steps to take. They [disability agency] told me that I am entitled for some things, but I don’t know how to fill the applications and they did not provide anyone to help me complete them. The country provides some funding, services but the thing is no one tells us that we are entitled for anything – it’s mostly the individuals that are at fault.

Halima also reiterated that funding may be available for her child, but she is unclear how to get funding for programs and services. She reported she did not know where to get the forms and what the requirements were for her child to get funding:

That's my problem. Yeah, nobody tells us all those about funding, about programs or services. We don't know how to find out. Yes, like that's my problem here in Canada.

Chapter 5: Unpacking Xenophobic Ableism

Stories of Survival

The interviews all took place between January 2021 through July 2021. During this time, participants faced school closures, numerous lockdowns, a vaccine shortage, vaccine mandates, and the many social and economic implications of the virus (Government of Canada, 2021). Participants were impacted by COVID-19 locally and globally. Some participants reported their family members not surviving the pandemic overseas, and the deadly virus's social and economic ramifications such as job loss. Others reported fear their families would not have access to personal protection equipment or vaccinations, and due to their circumstances, could not follow recommended protocol such as distancing themselves physically from others.

In chapter one I briefly mention my conversation with Hassan. Hassan shared a piece of paper during the interview that the building supervisor slid under his apartment door. Immediately after putting it up on the screen, the interpreter and I identified an eviction notice that cited noise complaints. We recognized that it was the final notice and it stated that

authorities would be called to evacuate Hassan and his family if they did not leave by the date listed on the paper. Hassan said, “they are always putting flyers under our door!” It was clear that he did not understand what the notice meant. Upon his request, we read it out to Hassan, and he proceeded to tell us about the ongoing harassment he has received at his home due to the noise his children make. When expressing their feelings, be it excitement, frustration, or pain, they often bang on the walls and make high-pitched sounds. Hassan shared how the complaints against his children increased during COVID-19 as his children were home during the day since schools were closed and like many children being home all day, they were increasingly frustrated. Hassan tried to prevent the noise by keeping the windows closed, even on hot days, and by driving his kids around for long periods to keep them away from their home. He even tried blocking the doors and windows and put down extra carpet. Hassan paid for these modifications out-of-pocket to reduce the noise:

My kids make a lot of noise. They cannot communicate so they make these sounds. During the summer all I did was open the window and my neighbor were sitting outside and they right away gave me a notice because the kids are being noisy. During the lockdown I am taking my kids for drives for three hours and now the mileage of the car is a lot like 55,000 miles and that’s all I can do

during the lockdown. That's because of the neighbors mainly, because of the neighbors so I just want to go so they [children] don't bother the neighbors and stuff like that.

Muhammad shared how the confinement to home brought about past traumatic experiences of curfews and social restrictions as a result of the conflict in Syria and nearby host country. He shared how his neighbours, his children's schoolteachers, and even the doctors did not consider the impact of COVID-19 on refugees. Hassan discussed how he understood it was necessary to have restrictions to keep his family safe, but he also expressed how difficult it was to be stuck at home and hoped others understood their trauma.

Several participants spoke about the difficult switch to online learning and not feeling well-informed or physically or technologically equipped to support their children virtually. Though the transition to virtual learning has no doubt been challenging for Canadian families, it has significant ramifications for resettled refugees in Canada (Edmonds & Flahault, 2021). For Sarah, the shift to virtual learning and the lockdowns impacted her son's mental health and his ability to cope with daily stressors. During the interview she shared how she cannot open the curtains

to let natural sunlight light into her home because her son becomes increasingly anxious:

In March COVID happens. We stayed at home since March. Until now my son doesn't even want me to open the curtain to look outside. He's having a severe depression. I cannot get him to go outside or even open the curtain, look through the window, or anything else. So now he's staying at home. He's not going to any school. He is in the house alone and he doesn't even want his own brother to be near him. He doesn't want anybody to be near him. He doesn't want his father. He doesn't want anybody to get near him. He is so depressed. It's so hard to communicate with others online and share the activities with other kids. It is too hard for him.

Hajra, Muhammad and Halima shared how their children regressed significantly in their physical and social skills since the beginning of the pandemic. The lockdowns and school closures specifically impacted their disabled children for many reasons, including the lack of a routine and the absence of educational and social support provided at school. Before the pandemic, their children received daily support for learning, and completing activities of daily living such as feeding and toileting. Once the lockdown happened, these services were suspended, and parents were not provided with tools to support these activities in the home. Furthermore, many of the services and supports their children received outside of school and that were once considered essential suddenly became non-essential

with the pandemic. As a result, the children did not go to in-person therapies or receive respite support. Hajra spoke of her son's regression during virtual learning and how frustrated he felt. She expressed how her son could not keep up with his peers and accordingly felt depressed:

So, the past 11 months is virtual because of COVID. He is not going good with computer, and it is difficult for him to focus on the screen and be with the other classmates. It's been almost one year. So, his habits and his way of doing his homework is completely different. He can't keep up with his peers. His problem-solving skills is very bad, he is always angry and frustrated. He's not organized, everything is everywhere, and he is always irritated and always screaming and angry.

Muhammad reported how difficult it was to maintain employment, support his child's virtual learning, and care for his children. Halima shared how challenging it was to explain to her children why they were not allowed to go to school or public spaces like the mall:

And now in COVID, I always telling him it's closed. It's closed, the mall is closed so he doesn't want to go anywhere. He asks to go to the Walmart. He likes that. When COVID hit it got so difficult and we were not like we were not a space for them or something like that. So, they did not go, and the older kid it's hard for him to do anything. He only wants to do something he likes or wants. When we couldn't go anywhere it was so hard. Before he used to go to his friend, his dad's friends like to go for a couple of hours but that stopped since COVID.

Hassan described sharing his only device, a small cell phone with his children to complete their online learning. The school had promised laptops to students who did not possess the technology. However, the laptop provided did not include a camera so his children would not be seen by the other children and subsequently excluded from virtual classroom activities. In addition to having a suitable device, virtual learning requires students to have access to high-speed internet (Edmonds & Flahault, 2021). Marwa shared how the internet connection at her home was not good enough for her children's virtual sessions and that the teachers required students to have a strong connection. Marwa felt it was unfair to assume all the students had highspeed internet. She shared how the teacher would play videos and her child's video would lag and they would miss the content. Even while conducting the interviews, several participants, including Sarah, could not use their own devices as their children required them for school. I thought about the unfair expectations teachers and school boards had for parents and caregivers. My daughter is in kindergarten and her public-school teacher uses an application or software that allows me to communicate with her directly using my smartphone. Using this application, parents can read

and respond to messages from the teacher including videos and pictures. While I have found the application to be convenient to view my child's progress, no one ever asked if I had a smartphone or the ability to navigate through the application. I was never offered technical support, or an alternative communication method, had I not had a smartphone. A certain degree of fluency in the English language of instruction is required for virtual learning as well (Edmonds & Flahault, 2021). The assumption that families are equipped for virtual learning is not only unfair, but it further isolates disabled refugee children from others and puts them at a disadvantage in the classroom environment.

Stories of Rights

Several participants discussed how disabled persons in Canada should have rights and freedoms and be free from discrimination and harmful practices. Omar referred to Canada as “a human rights country”. He said Canada has been able to provide his son with all of his acute medical care needs, but he believes too much of the funding goes into the esthetics and design of the buildings and not enough into the services. “Have you seen the Sick Kids lobby?” he asked, referring to the Hospital for Sick Children in downtown

Toronto. “It looks better than any mall or hotel we have where I am from, but... we don’t need that” he said. “We need services for children with special needs that protect them and help them”. Omar discussed how money should be used to address the long wait lists, the minimal time a patient spends with a physician or a therapist, and the amount of money it costs for rehabilitation services and adaptive equipment. He questioned why the funds are used on esthetics and marketing. Referring to another local community disability agency, he described the location:

Considering, like when you look at these buildings, all of them, the decor and the wood, everything is so perfect. But really when you go in there, the service is nothing so. So well, I think that if they like instead, they provided us with a stander that he can start to stand on. But like I think it's better to provide them with services like ... I need for my son like speech therapy, physical therapy and all of that.

Like Omar, Amal’s expectations of the treatment of disabled persons in Canada were far from reality:

Coming to Canada was not what I expected. I expected that here in this country specifically that has a top rank in taking care of people, that I would find what I need. But they do not even give the minimum for disabled people.

Amal expressed how she thought Canada would have rights that protected disabled persons' rights. Instead, disabled persons are caught in a disabling system that discriminates and isolates the most marginalized:

Don't we have human rights here? There is a discrimination in the system, but in a hidden way... in a hidden way that the person who discriminates is not, uh, like is not treated like he's not guilty for what he did, or you cannot see anything to prove that he discriminated.

It was made clear by other participants' statements that they too felt that Canada was a country that upheld the rights of people to the highest standards. These rights however, particularly of vulnerable populations, are not realized. Furthermore, while refugees may be granted certain rights, the experiences of the participants were of disabled refugees and their families, a population that cannot go unexamined. Conversations on human rights can ignore the economic and living conditions that ostracize and keep disabled refugees in vulnerable positions, dependent on discriminatory welfare institutions and social services.

Stories of Intersectional Oppressions

While none of the participants used terms such as ableism, racism, xenophobia, or Islamophobia, these were recurring themes in the data, both directly and indirectly. For example, all of the participants shared how ableist attitudes and practices impacted them in their home country, their local host country, and in Canada. Amal spoke about her experience with systemic ableism in Syria:

It started when I was a kid when I tried to go to school. The principal kicked me out of the school because I had a disability, and I was bullied at school and at home. What can you do? They were telling me, what can you do? You just you can do nothing in the future. Uh, so I reached when I was a teenager. I was thinking that it's better for me to die instead of staying in this like situation. People kept pushing me down. They said I could not be in school; I could not learn. Even if I finish my school they said, I am not going to get a job and I finished school and I got a job. Then they said, even if you finish school and get a job, you will not get married. And I got married. Then they said even if you get married you cannot bring children into this world. And then I got married to a person, my husband with disabilities also and they also started to say like he accepted to take me because maybe he doesn't, uh, bring children or something like that. And then I had a child.

Amal went on to discuss her experiences in Canada. She shared how when she arrived in Canada and was relocated from a temporary residence to a

permanent one, she and her husband, who are both wheelchair-users, received housing accommodations that had several stairs:

We got to our new home after such a long journey, and we could not even go to our rooms. We could not support each other because we both use wheelchairs. Of course, there are like people waiting and everything, but there should be priorities for people who need some accommodation, for a case like mine, they should not give me a house that has stairs.

Amal disclosed how she endured being in an inaccessible place for years. She reported feeling humiliated every single day. Then after much advocacy, writing letters to public officials, and calling different agencies, Amal got moved to an apartment above the 20th floor. Amal described a day when the fire alarm went off. It was not routine, and her family was not told of the alarm procedure. She was given a pamphlet on safety procedures but her English language skills were limited. She did not understand the instructions. The elevators automatically shut down when the alarm sounded. When she called for help, she was told to wait until someone could reach her but that it would take some time. “I thought to myself, I escaped a war, and I came here just to burn in a fire because they do not care about people like us”, she said.

Omar and Hassan described the ongoing explicit and implicit discrimination their families faced while in Canada. Omar uprooted his family to another home because he did not feel safe where he was. He shared how he could not change the way his child moves around or makes sounds:

I cannot know what the Canadians are thinking in their heads. But this woman she was. I felt that she was filled with hatred, and she was calling the security for even a little sound my child made. But I cannot fix that. I cannot see what she's thinking. So, I thought the best option for me is to move to another place where I could, so I went.

He described trying everything to please the neighbours including hiding his children. However, the situation escalated as the neighbours began calling the police. Unlike Omar, Hassan could not leave his current home. Hassan is currently fighting a legal battle with his landlord to remain in his home:

My home is good, I live in an apartment and they [his children] like it but the neighbors are giving us a hard time because of the noise of the children...I don't know if they are racist or if they don't like my disabled children. But it is a lot for me. I am afraid for my life. I am scared that they are going to change the locks. I am afraid that we will end up out alone. They say mean things and they leave notes on my door. They called the police. I am afraid of the police.

Hajra expressed facing discrimination but not because of her children's behaviour but because of her hijab and because she speaks limited English and with an Arabic accent. Immediately after Hajra shared incidents of discrimination, she smiled and said, "... but some people are helpful and pleasant, there are places where I meet people who are rude to me, and I do not know why". She quickly added, "They are individualized mistakes, not Canada as a whole". Muna shared how she thought all Canadians were "nice people". She said while no one has hurt her, they stare sometimes and say things that are not kind about her culture and her child with a disability.

As I listened to Halima's story below of Islamophobic and xenophobic encounters at school, I could not help but think about all the harmful questions and comments I received as a young racialized Muslim woman who wore hijab: "Are you hot in this"?, "Are you bald underneath that thing"?, "Do you shower with it on"?, "Do your parents force you to dress that way"?, "Are your parents related"? After my conversation with Halima, I reflected on how exhausted I always felt by such inappropriate and offensive questions. Defending my choices, my culture, and my faith,

was an extra exercise my peers did not have to do. Halima shared how her daughter's teacher reported that the jilbaab⁴ she wore over her clothes was inappropriate. The teacher said it must make her feel hot, and that it further isolates her from her peers since her disability already makes her stand out in the classroom.

She used to wear the jilbaab, a Syrian coat. Usually in Syria, they wear a short like light coat in the summer on top of their clothes, and so everyone was telling her why are you doing that way? Wearing that and they kept like saying bad things about it. So, she just took it off, she started to wear just the shirt and the pants like they [other children] do. But now she feels different. Before she didn't feel different.

Halima shared how removing the jilbaab made her daughter feel unwelcome and different because she could not be proud of her Syrian culture; "I am not from Syria. I am Syria" she whispered to her mom when she got home from school one day.

⁴ A Jilbaab is a full-length outer garment, traditionally covering the head and hands, worn in public by some Muslim women (Oxford Languages, 2021).

Halima then shared an incident with her other disabled child about his experience during the Islamic month of Ramadan⁵. Like the rest of her family, her son was fasting from sunrise to sunset by abstaining from food and water. Halima thought it was strange that the teachers did not know about Ramadan since so many Muslim students attended the school. She felt it was inappropriate that teachers equated fasting to abuse:

My son was fasting. His teachers give him a sandwich and he didn't eat it. He wants to fast but everyone in school were telling me and my husband like why are you forcing him to fast, he will starve, and we said we don't force him. He wants to fast. He wants to be part of our culture, our religion, you know our family.

A few participants reported feeling surprised to learn about systemic and institutionalized racism in Canada. One family reported moving from the province of Quebec to Ontario because of Bill 21 (Quebec Official Publisher (2019) and expressed how it would limit their children's future employment opportunities. Dalia talked about the June 2021 London terrorist attack, killing four members of a family including a child (AlJazeera, 2021), and shared how her and her husband could not believe

⁵ The ninth month of the Islamic year observed as sacred with fasting practiced daily from dawn to sunset (Merriam-Webster, 2022)

someone could kill a family because they were Muslim. “We look like them”, she said, shaking her head in disbelief.

I noted how many participants discussed incidents of racism and Islamophobia while sharing how great Canada was and how grateful they were for being in Canada. They used phrases like “there was one incident” and “there was that one time”. For example, Marwa began talking about discrimination with the words, “Everybody was so kind to me, and no one discriminated against having kids with special needs, everyone was helping me, but...” She then went on to discuss an incident where her daughter was physically abused at school by a teacher’s aide. Her daughter came home with a big bruise on her forearm. When asked about the incident, her daughter reported that her teacher held on to her too tight and hurt her even though she told her to stop. The police were notified, and child protective services did an investigation, but the report concluded that her daughter’s statement was inadmissible because she has a cognitive impairment. Marwa could not believe the authorities rejected her daughter’s testimony because she was disabled:

But my daughter does communicate with us. We know how she feels, what she wants, and what she dislikes. So, it was her word against the teacher. We had to move schools.

Amal spoke about explicit and implicit ableism within healthcare policies and practices that lead to partial health coverage for disabled persons. She explained how acute injuries take priority over long-term disabilities by allocating more resources and publicly funded services for acute injuries:

The government covers only for a person who has a broken arm or something minor. But when it comes to a person who needs physical therapy on a long run, someone with disabilities they consider it luxury. That is what is wrong with the system. We need to be able to use the funds they give us for the things we need them for.

Amal discussed her need for ongoing physical therapy and questioned why she had to pay for it even though it was critical to her health and well-being. Suppose she does not get physical therapy; her physical health deteriorates and then she requires some more expensive acute medical intervention. The pain and discomfort she endures on a daily basis impacts her quality of life but she cannot afford the therapy.

Stories of Gratitude

All the participants expressed their gratitude for entering Canada at one point or another. They expressed gratitude towards the Canadian government for allowing Syrian refugees to settle in Canada. They shared gratitude towards God for giving them a ‘second chance’ and gratitude towards the ‘Canadian people’. Several participants compared themselves to those back in Syria who did not or could not seek asylum. While I can only imagine how grateful one may feel to be safe, I could not help but wonder what expectations of gratitude formed through the dominant narrative. The grateful narrative seems to be the only one that is accepted. This narrative largely ignores transnational experiences. While participants are told about their rights in Canada and frequently lectured on how lucky they are, the ableist systems prevent access to services and supports, meaningful education, healthcare, and social engagement. In the same breath, Hajra expressed her love for Canada and her disappointment that disabled children were not being taken care of:

I do love Canada so much and Canada is like my mother, and I think Canada can do good things but I’m disappointed that kids with special needs are struggling, there has to be some support. All the doctors who aren’t helping, someone should talk to them and make them understand that there needs to be more services for special needs kids. They need help.

Similarly, Mohammed let out a big sigh during the interview and said, “I am very thankful for being in Canada, but...don’t get the support we need!”

Omar also expressed his gratitude for being in Canada:

I handle everything, I am thankful for everything, but I found it difficult, the expenses and the hate. Sometimes when we think of where we've come from and it's really difficult, and then we're trying to, you know, come to be thankful for where we are. But as Muslims we always say we will handle, and we want you know to be grateful for whatever we do, whatever we suffer in our lives.

As a Muslim, I am familiar with the concept of شكر (shukr) that Omar mentioned several times. The term shukr appears many times in the Quran. It is an Arabic term denoting thankfulness, gratitude, or acknowledgment by humans of what they have been given. Hassan reported that Allah⁶ gave him a situation so he can handle whatever comes his way, but he is worried about his children, and he wants them to be safe and have the means not only to survive, but live purposeful and meaningful lives. While this gratitude may be customary, and a critical part of one’s narrative, it is

⁶ According to Muslims / Islamic faith, Allah is “the one”, the Being worshipped as the creator and ruler of the universe

enforced through the dominant cultural narrative in a way that continuously shapes otherness.

Stories of Navigating a Biased System

Navigating a system not designed for disabled refugees surfaced throughout the conversations. Muna shared how thankful she was that primary healthcare services were covered financially in Canada. However, navigating through essential services was not what she expected:

We don't have to pay but there are a lot of difficulties I have been through. It's not like I expected before I came here. I was hoping to find answers. I went here to the children's hospital and was hoping that they do at least like a CT scan for his head because he had meningitis and they didn't follow up. They told me his head is not like other kids, but they didn't tell me what is wrong with him. They gave him medication to calm him down and to make him less hyperactive. So, they finally did a CT scan eight months ago for him after I kept asking but I don't know the results.

Like Muna, Amal described how navigating services for her disabled child was not easy. Not only did she have difficulty finding the services, but she also did not know what services her child required. She had not heard of many of the therapies prior to coming to Canada. For example, she did not know the purpose or benefit of services like applied behaviour analysis or

occupational therapy. As parents were discussing therapies and diagnostic assessments, I reflected on the photo essay by Church et al. (2020), that stated:

Disabled childhoods are constructed less around individuals' experiences of bodily difference than they are around encounters with professional assessment and diagnostic identification, often beginning at birth. (para. 5)

Muna and Hajra discussed how the doctors in Canada spent very little time with their children but quickly diagnosed them with life-long conditions. They both shared how it was impossible to share their story, and the stories of their children within a few minutes. Furthermore, they shared how the doctors took all their information from checklists and verbal assessments. They did not ask their children to perform certain activities, nor did they check to see if their children had certain skills, instead they were given standard forms in English that they were asked to complete:

This is not fair for my son and not fair for me as I don't know what to do with him or where to take him. The doctors who diagnose autism should be in the know of the services that we can seek or what funds we can apply to. Even the doctor took all the things he needs to know from me as a parent or caregiver, not from him [child with a disability].

Hajra did not know what support her child required to foster his academic and social skills. She said she could not be his mother, teacher, therapist, and doctor. She did not know how to do all of that and thought it was unfair to expect that of her. Hajra learned about Kumon, an academic tutoring service. Her friend reported that Kumon was successful in helping children with their math and reading skills. For Hajra, Kumon was expensive, but she wanted to help her child. She paid for Kumon privately and used up her funds on a tutor:

I am very sad that I couldn't find anybody to show us where to go to get resources or help for him. And the thing that didn't help, I used all my money for Kumon and for tutors. And they wouldn't help him. I didn't know he needs specialized people like occupational therapy and services like that.

Several participants reported language barriers when accessing services and supports. Language is one of the biggest barriers to resettlement in Canada (Danso, 2002). Muna described how critical it was for there to be interpretation services at all appointments and that she usually has an interpreter when attending doctor's appointments. However, recently, the interpreter was not available, and due to the COVID-19 protocols, she was given virtual appointments. She was forced to

communicate in English, and the doctor told her that he could not understand her and that if she explained the child's results, Muna would not comprehend them. Muna was offended and hurt by this. Marwa also shared how communication had been a barrier for her to express her family's needs with others. She shared the challenge in talking to her children's teachers and advocating for their needs. The classroom teachers did not translate materials and did not make any efforts to simplify materials.

For Sarah, the difficulties of communication were compounded. She had to learn English but also American Sign Language. She had been taking English classes to better advocate for her children but had to stop due to her responsibilities at home. Sarah's children were learning sign language to communicate with their teachers and peers, but Sarah had not been taught. The gestures that Sarah used at home with her kids she either made up or learned from Syria. Sarah was not involved in a deaf community in Syria and had communicated with her children in the only way she knew how:

I learned sign language by myself to communicate with my children with special needs. My English is not so bad, but I am trying to learn better English so I can talk to the doctors and lawyers and do everything on my own. I want to learn English, but I am stuck because I need also to take care of my children.

Stories of Inclusion

The theme of inclusion came up many times throughout the discussions.

Participants expressed the need for inclusion, the desire to be included, and the harmful impacts that result from exclusion in society. Several participants spoke about inclusion in Canadian public schools. For Muna, having a child with a disability being accepted into school was life-changing:

They go to school, and they are enjoying, and even my disabled son is going to school, and I am happy that I found a school that could accept him and do activities for him. In Arabic country, nobody will give me any of those services there. Instead, he be like home sleeping, you know, understand why I mean. But uh, but mostly here it's comfortable.

For other parents, their experience was not as positive. Sarah shared how her son was extremely lonely when he went to public school. He had aggressive behaviours and did not get the support he needed. Her child was often excluded from the classroom and school-wide events and activities. He had difficulty fostering friendships, and his behaviours caused negative attention from students and teachers alike. He was even removed from the bus:

I tried to send him to public school, and he was so lonely. He was so aggressive. He was so aggressive in the bus it didn't work well. Both of my children were accepted into the private schools for kids with special needs. There are private programs for deaf and blind children.

Sarah shared her experience with private schools as being “exceptional”. She said they understood her children’s needs. However, she went on to share that removing them from the school after two years was cruel as her children got accustomed to communicating with teachers who were experienced working with children with specific accessibility needs and accommodations. Sarah said that her children are likely to regress significantly, but she has no choice but to send them back to public school. Hajra also struggled with her children’s public-school setting. She was suspicious that her child was not participating in the classroom, so she became a school volunteer for several months. During that time, she noticed that her child was frequently ignored, but when she asked the teacher why, she replied, “Ford cut the funding,” referring to the funding cuts by the present premier of Toronto, Doug Ford. I reflected on this comment because I have heard it from the teachers at my child’s public school. The February 2021 memo issued by Deputy Minister Nancy Taylor discusses

the “more than the typical number of redundancy notices to its staff this winter/spring” (p.2) which means cuts to several staff roles, including mental health workers, early childhood educators, and paraprofessional staff, many of whom would provide support to disabled children (Press Progress, 2021).

Hajra removed her children from public school and placed them in a private Islamic school. However, the private school did not provide her children with an Individualized Education Plan (IEP)⁷ and could not meet their learning, behavioural and social needs. Hajra said not only is she paying out of pocket for her child to attend Islamic school, but she also must pay for a resource teacher and additional resources for him to learn. While she is happy her child is included and respected for his cultural and faith identities, she still must sacrifice the quality of his education:

I want my child to do well and reach his full potential. Kids are supposed to come first. On the other hand, my daughter [without a disability] has a good teacher, they believe in her, they push her, they

⁷ According to the Ontario Ministry of Education (2018), “An IEP identifies the student's specific learning expectations and outlines how the school will address these expectations through appropriate accommodations, program modifications and/or alternative programs as well as specific instructional and assessment strategies”.

believe in her. I came here because this country has rights for people. And kids come first.

Hajra compared the quality of education of her child with and without a disability. The child without a disability is motivated by teachers to excel academically, while the child with a disability was provided with a bare-minimum standard of education, an idea that surfaced throughout the conversations. Muna shared that while her child was accepted, teachers ignored disabled students and instead wanted to challenge able-bodied and neuro-typical children to do well. “What is so special about special education?” Halima asked rhetorically. We sat in silence for a few moments before she moved on to discuss how her child was also excluded from social activities within her own faith and cultural community.

Throughout the discussions, all of the participants described the importance of feeling accepted, welcomed, and respected and the need for social relationships. Two of the privately sponsored participants shared how instrumental their sponsors were in helping them meet individuals from their community and form critical social bonds. Dalia described how shortly after her arrival in Canada, she met a Palestinian woman who became her best friend and greatest advocate in Canada. Dalia conveyed

how the woman helped her book appointments, get groceries and other daily essentials. Most importantly, this woman helped Dalia connect with other women who had similar stories. Dalia described feeling comfortable disclosing her experiences to the Palestinian woman as she had also endured many obstacles fleeing Palestine, which she believed had shaped her compassion towards others. I heard about the need for trusting relationships and community connections throughout the narratives, whether concerning service navigation or relying on others for emotional support.

Stories of Advocacy

During my master's in occupational therapy, one of the first tenants we learned was that the client or patient is the expert. They know how they feel, if they are in pain, and if that pain is dull or sharp. They know their physical and emotional goals and desires and the impact their condition, illness or disability has on their life. Learning about client-centred practice and family-centred practice in school does not always translate to equitable practices. Client and family-centred care should involve culturally

responsive, relevant, and safe methods and practices. It should mean anti-oppressive practices, but it does not. As Whalley-Hammel (2015) describes, more research is required in this area to determine whether healthcare professionals, including occupational therapists, consider client narratives. My conversation with Hajra highlighted how healthcare workers often have a pre-set agenda working with patients or clients. When they see similar diagnoses and conditions, they react in a standard way, a way that ignores one's individual (authentic) story. For Hajra, she could not understand how a life-long diagnosis of ADHD and autism could be determined within fifteen minutes of meeting a doctor. How could the doctor listen to one's story?

Hajra's story was by far the most difficult for me to hear. She discussed the chemical attacks in the city of Douma. Hajra shared how the toxicity of chemical weapons was not addressed by the doctors or therapists in Canada, no matter how much she told them about it. Some doctors she met believed it was irrelevant, while others questioned whether she was telling the truth. The doctors instead only discussed ADHD and autism. One doctor prescribed her child a medication that was not a good fit; it

made him very sleepy, so Hajra stopped him from taking it and instead, she continued to advocate for her son by taking him to another doctor. That second doctor reported that her child missed many of his developmental milestones and that she had to take better care of him. Hajra shared how it was not her fault that she did not speak English fluently and could not advocate for him. She had just recently arrived in Canada, and she was being punished for her life circumstances:

I took him to another doctor, and the doctor blamed me a lot, and the doctor said you should have helped him in the other years. And me not knowing English is not my problem because if any of you moved to another country, it is not my fault, if you moved to another country, you won't be able to understand what they are saying.

Hajra then described how the doctor never once interacted with her child. He spoke about him in front of him and never examined him thoroughly. Instead, he asked her some questions about him and checked off certain boxes on a chart:

He asks a couple of questions and that is it. I was imagining that they would talk to him, ask him how' he's doing. He only did an assessment one time and then forgot about it.

When discussing advocacy for their children, some families reported they required therapeutic services, while others did not desire the therapies

offered. “Therapy. Therapy and More Therapy. Not everyone wants it or needs it”, Halima shared. I heard this statement from a few of the participants. As a therapist, I tried not to let that pinch because I pursued a PhD in critical disability studies to challenge the idea that therapy will ‘fix’ a problem resulting from a disabling system. Muna also reported that neither her child’s history during the war, nor her family history was ever considered during her initial conversation with her child’s doctor. The doctor seemed to ignore her account of her child’s medical history and instead assessed him at present. While the doctor used terms such as global developmental delay (GDD) and Attention-Deficit Hyperactivity Disorder (ADHD), she was more concerned about her child contracting meningitis and not getting treated for it:

I am having difficulty with his diagnosis. I am hoping that I find someone who knows more about his case about the history because everything they give my child is for GDD and I want to know about other things like meningitis. No one [doctors] talks to me about it. I always tried to say to the doctors that his ... my son’s story starts from the beginning, but they always do not focus on that area and they [doctors] don’t want to listen. They just look at his behaviors and tell me about GDD and ADHD and they take a picture of it at the moment we came here to Canada. Well, every agency here refers them to behavioural therapy, and I don’t see any progress.

“Does he need more behaviour therap”? she asked sarcastically. The behaviour therapy was not working. The strategies the therapists used with her child were not leading to any improvements or positive changes in her family’s life. Yet the therapies were continuously suggested. She reported her child plays at therapy instead of learning to effectively communicate with others:

The therapy doesn't suit his case like he wants to play on his iPad. They tried to tell him how to move to something else, but it doesn't work for him.

Hajra shared that not only was the therapy not suitable for her child, but it harmed him. He resisted attending therapy, but Hajra forced him because the therapists and caseworkers said it was necessary. Hajra expressed that she knew her child, what he had gone through, and how resistant he was to try new things. It was already hard enough in Canada getting accustomed to so many new social and environmental factors, trying a therapy that they had never heard about was scary:

But after treatment, he got much much worse. This is the worst thing they did to him.

Sarah described how support must go beyond therapies. She believed families should get help with finding employment to survive and be

financially independent, not dependent on social services. Sarah talked about her older son finding a job to support himself and fostering his skills, a nuanced conversation as her son is deaf and faces ableist barriers to employment (Canadian Hearing Services, 2016):

I need help with finding support for rent like the governmental support for a house like to help me in the rent and seriously for a job for my elder kid. My son, he is finding difficulties finding a job because he's deaf. Nobody accepts him for any job and it's affecting him, and it would be really helpful to find a job. For my other son I cannot go to work because he needs me all the time. I cannot even leave for five minutes.

While Sarah did not explicitly mention systemic ableism or discrimination while discussing employment opportunities available for persons with disabilities, I could not help but reflect on how disabled persons are chronically excluded from a workforce that values specific skills and abilities above others (Prince, 2009).

All participants reported self-advocating for their children – be it at school, with health care professionals, or finding resources. All the participants expressed their love and admiration for their children. They all addressed the hope they had for their children to live meaningful lives and

excel socially, academically, and professionally, and they all pointed to the material, economic, and social barriers that prevented their children from succeeding. Hajra shared how her son was so talented and creative, and he loved architecture and was skilled at building blocks. “I can send you pictures”, she beamed with pride but then immediately frowned. I waited for her to continue her story, “I told the doctor how good he was. How he loves architecture and how is so good at science. The doctor laughed when I said he is good at science”. While this part of Hajra’s story may seem minor compared to the other pieces of her displacement and disablement narrative, I found this point extremely difficult to hear. I could not imagine a healthcare professional laughing at a parent's belief that their child is talented. The strength-based approach is championed in Canada within healthcare and social services, always looking towards a child’s strengths, and their family’s unique needs (Swartz, 2017), yet many of the participants did not witness this approach. Several of the participants spoke about the lack of culturally responsive, culturally relevant, and culturally safe practices. While none of the above terms were used during the interviews, participants spoke of feeling excluded, judged, and discriminated against

from the services being offered and the need for healthcare workers and service providers to know about and respect other cultures. The narratives of the participants highlight how much work needs to be done for healthcare and educational services and supports in Canada to function in an anti-oppressive manner.

Listening to Our Stories

While each participant shared their story, I knew it was only a tiny piece of a much bigger puzzle of interwoven narratives. I could hear notes of hope, fear, pain, and joy in the stories shared with me. A common theme amongst participants was how Canadian medical and education professionals they interacted with ignored their family's Syrian identity and experiences as a refugee even while they knew the participants' children were newcomers to Canada. Many newcomers did not have access to formal education or adequate healthcare in their home country or host country. Hajra shared her desire to have her child treated like the other children in Canada while not erasing her child's identity. She wanted her child to learn in school and wanted their learning needs to be assessed thoroughly. She wanted their

teachers to provide strategies and solutions that met her child's learning needs, but they always blamed their weaknesses on the war:

I sent him to school and everyone (teacher and principal) they labelled that everything that was wrong with him was due to the war in Syria – due to the trauma and the war but he didn't witness the war. He was too small.

For other participants, their stories of the tribulations from the war and displacement journey were not validated. They were told they were overreacting or exaggerating their circumstance. Ignoring stories was mostly discussed in the context of schools and when seeking help from healthcare professionals. Participants reported that their stories of their children's medical conditions were not deemed reliable since they did not possess the 'appropriate' or 'valid' medical records. As a result, they could not get immediate support when they entered Canada and endured months of waiting for assessments to obtain services. Naima shared how a diagnosis from another country that is not aligned with the health processes in Canada is not even considered. She experienced this firsthand with the refugees she supported. However, for Naima, it was not about listening to their stories; it was more:

I think it's not so much listening to their parents. It's something even bigger. It's about the non-Canadian to Canadian process. Canadians feel the way or system here is superior to the so-called third world. We discount everything that is shared with us based on the idea that our knowledge is superior.

As a private sponsor, Najma witnessed several xenophobic encounters when taking Syrian refugees to doctors' appointments that alluded to the idea that Canadian healthcare was far superior to healthcare in Syria and the Middle East in general. The repercussions of such ideas were dangerous since it also meant that the participants lacked knowledge about their own health experiences and the health experiences of their children. Hassan expressed shock when the doctors in Canada diagnosed his children with a disease he had never heard of before. Doctors he previously encountered shared a different diagnosis and explanation for his children's conditions. The Canadian doctors presented the diagnosis in an approach that lacked empathy. They did not consider what previous doctors had told Hassan and why they may have relayed a different diagnosis. They did not provide space for Hassan to grieve; it was a matter-of-fact approach to the condition that overshadowed Hassan's previous encounters with physicians in Syria and Egypt.

Muna shared how the doctor would not provide her space to discuss her son's trauma and that he did not seem to want to know about her child before the time they entered Canada. She talked to the doctor about years of extreme poverty, food insecurity, and physical and emotional violence, but he quickly reminded her of his professional expertise. During these interviews, I kept thinking back to a book I read a few years ago titled *The Social Transformation of American Medicine* by Paul Starr. Starr provides a historical overview of the development of the American medical system, the rise of physicians as a social class, and explains why physicians hold such authority today (Starr, 1982). As I reflected on the conversation with Muna, I thought about how timely Starr's book was.

Amal shared how ignoring her story led to a personal tragedy. A few months before the interview, Amal became pregnant with her third child. In her third trimester, Amal miscarried. While Amal believed that the loss of her child was ultimately in the hands of Allah, she said the doctors ignored her symptoms and consequently did not provide her or her unborn child with adequate healthcare. Instead, they sent her away without examining her thoroughly. Holding back tears, she rhetorically asked if it

was because she was Muslim and wore hijab, because she was Arab and a refugee, or because she was disabled:

When I went to the to get medical care from the emergency, I was pregnant in the third trimester. I had bleeding and cramps and I asked the doctor to test me. But the doctor was asking why I came to the emergency, he kept saying to go to my family doctor, but I said I didn't have one. The doctor said its normal and I can go home. I was giving the doctor options; I asked them, why don't you do an ultrasound? I asked if they need to do any blood work or anything? He said no, nothing. I was so scared, then he told me to follow up with my family doctor, but I kept saying I don't have one. But he sent me home. I went home. After five or six hours, I lost my baby.

The emergency doctors insisted that Amal go to her family doctor, but she did not have one. The doctor and healthcare team ignored her narrative and her self-advocacy. Amal described how she had recently moved to that city, and she did not have any supports in place. It was especially difficult because she required wheelchair accessible services and language interpretation services.

Conclusion

Throughout this dissertation, I resort to the power of stories – storied content, storied experiences, and the "danger of a single story" (Adichie, 2009). In chapter one, I share my story, provide an overview of the Syrian refugee crisis within a national and transnational context, highlight the dominant cultural narratives surrounding disabled Syrian refugees, and review the gaps in research on disablement and displacement. Chapter two presents theoretical frameworks around disablement and displacement that guide this study, including transnational disability theory, the concepts of citizenship and intersectionality, and the theoretical framework of otherness that stem from xenophobia and Islamophobia. Chapter three introduces the study's qualitative narrative methodology, including the thematic analysis, reflexive process, and limitations. Through this perspective, I provide the themes that emerged from the stories in chapters four and five. Now in chapter six, I will conclude by summarizing the findings of this study and present implications for future research and practice.

Although the number of refugees has increased globally over the past decade (Donato & Ferris, 2020), the experiences of disabled Syrian

refugees and their families continue to be understudied (Mirza, 2011b) and ignored (Crock et al., 2012; Pisani & Grech, 2015). Refugees globally experience hostile attitudes, environmental barriers, poverty, and violence (Koç & Anderson, 2018). Still, little attention has been given to the collective patterns of oppression experienced by disabled refugees (Harris, 2010). My concern about the lack of information on disabled refugees, particularly disabled Syrian refugees, and their families, has led me to embark on a qualitative research journey exploring their authentic narratives. This concern led me to ask: What does disablement mean to a refugee population? What does displacement mean to disabled persons? How has the segregation of disablement and displacement impacted disabled Syrian refugees and their families in Canada? How is such a powerful intersection of disablement and displacement left out of critical conversations on human rights, social justice, and social determinants of health and disability? Why are their stories erased? While I used open-ended questions during the interviews and left the participants to share their stories as they deemed fit, the collective narratives responded in some way to the questions above. Their stories arrived at fourteen major themes that

spanned pre-migration, migration, and post-migration phases. These themes fell under two major headings: transnational disablement and unpacking xenophobic ableism. Participants shared experiences of disablement in Syria, during their migration journey, in their host countries, and now in Canada. They spoke about their child's diagnosis of disability, disability as identity and impairment, and their interactions with healthcare and educational professionals. They shared the many social, economic, and environmental conditions that impacted their daily lives, including the social and economic obstacles related to the COVID-19 pandemic. Participants discussed the challenges they encountered pursuing meaningful employment, navigating the healthcare and education systems, and seeking financial, social, and emotional support. They shared their experiences of belonging and not belonging in Canada and expressed the need to have their stories heard.

Throughout this paper, I bring up the issue of human rights in Canada and how championing international human rights is part of the dominant narrative around Canada's response to the Syrian crisis. Within this discourse, Canada is deemed heroic, a saviour to Syrian refugees. This

hero narrative (Razack, 2007) is accompanied by the gratitude narrative – disabled Syrian refugees should be grateful for the opportunity to be protected. Through this portrayal, refugees, and disabled refugees in particular, are deemed victims; helpless, dependent, and a charity case. The stories in this study highlight how this narrative reinforces an expected level of assimilation into Canadian culture (Scott & Safdar, 2017). This narrative bleeds into policies and practices tied into Islamophobic, xenophobic, racist, and ableist tropes that implicitly and explicitly make the concept of full citizenship impossible for disabled refugees. When Hajra's daughter was asked by her teacher to remove her jilbab to fit in with her classmates, she could not belong as she was. She became othered by her disability, her faith, and her culture. Removing her garment did not make her like the rest of her peers; it further isolated her. As a young child, she recognized the attitudinal barriers placed before her as a disabled Syrian refugee. She could not exist as is. Her story had to be re-written.

Similarly, when Amal rushed to the emergency room seeking medical attention for her unborn child, she was sent away without a full assessment, including fundamental basic medical tests. As a disabled,

pregnant Syrian refugee, Amal felt betrayed by the same healthcare system that vowed to protect her. Ignoring her story had the most detrimental consequences. Shortly after being sent away from the hospital, she lost her unborn child. Through the stories of disabled refugees, we recognize that their histories, experiences, and oppressions cannot be overlooked or ignored and that their stories must be heard and respected.

Contributions:

This research contributes to the existing body of research in the area of disablement and displacement in critical disability studies and enriches research contributions in other academic fields, including social sciences, healthcare, and humanities. The qualitative narrative methodology used in this dissertation is a means to share participants' stories as the principal narratives. Bhargouti reminds us of the danger of making human stories secondary (Adichie, 2009). The participants' stories and subsequent analysis highlight the need to listen to, reflect on, trust, and tell stories of those whose stories have become appropriated. While some studies have examined the experiences of disabled refugees living in the global north (Aldiabat et al., 2021; Oudshoorn et al., 2020), this study's qualitative

method of data collection positions the participants at the core of the research as the experts in their own stories (Issari et al., 2021). Their stories can inform others, clarify misconceptions, and question existing practices (Atkinson, 1998). As Dossa (2009) shares, stories "restore our humanity because they provide flesh to what we may otherwise remain abstract" (p.5). While it may have been challenging to retell and relive their stories (Clandinin, 2013), the participants in this study shared sincere accounts of their ongoing journeys of disablement and displacement. Participants described not being heard; their stories were over-ridden by a single story (Adichie, 2009) and often told through the beholder's perspective (Saleh et al., 2014). Like the doctor who laughed at Hajra's son for wanting to succeed, his words and actions reiterate the dominant narrative that disabled refugees have lesser value. By recognizing the participants as "producers of context-specific knowledge", I communicated "with them" versus "for them" (Dossa, 2009, p. 28).

Future qualitative studies that reveal real experiences of disabled refugees will work to combat the dominant narratives that ostracize and harm disabled refugees. This realness cannot be ignored or overshadowed

by theoretical perspectives, nor cast aside with quantitative data around the number of disabled refugees Canada accepted.

The need for a reflexive account is also emphasized in this paper. While I offer transparency in my position as a researcher, a healthcare worker, an advocate and community organizer, and a Muslim student of colour, reflexivity entailed a commitment to listen to the participants, intentionally and actively (Einagel, 2002). My positionalities do not exist independently of the research process. By allowing space to be honest and uncomfortable throughout the research process, reflexivity grants me the ability to challenge my assumptions of the research and my perspectives as a researcher (Berger, 2013). This study demonstrates how reflexivity can help critically unpack the dominant narrative that influences research, policymaking, and practices, an essential exercise when examining the experiences of a marginalized population.

This study highlights the need to examine further a transnational disability theoretical framework that addresses and seeks to understand the storied lives (Dossa, 2013; 2018) of disabled refugees. The combination of theoretical underpinnings presented in this study on disablement,

intersectional oppressions, citizenship, and otherness are all necessary to examine and to understand the excluded positions of disabled Syrian refugees in Canada. The participants' stories cannot ignore the transnational framework of disability. Disability is not simply a social construction, nor is it a result of a single biological factor. Hajra and Omar spoke about the direct impacts of international conflict on their children's conditions, including the impacts of chemical weapons and sanctions on medical equipment. For Muna and Sarah, the effects of the war led to a decrease in their family's health and wellness through poverty, trauma, lack of adequate education and meaningful employment, and the absence of safety and security.

By utilizing a transnational lens, this research contributes to a new way of understanding "racist ableism," a form of ableism that directly and systemically intersects with racism (Gorman, forthcoming). Campbell (2009) argues that Critical Race Theory can help us examine the systemic processes of ableism, explicitly drawing upon internalized racism and ableism. Campbell maintains that we must look to ableism as oppression of study rather than disability. Further to the idea proposed by Campbell

(2009), racist ableism, a term coined by Gorman (forthcoming), is a distinct form of ableism; it is layered, multifaceted and intersectional. While some scholars, including Annamma et al. (2018), Dematthews (2020), and Erevelles (2014) discuss the intersection between racism and ableism and the need to examine intersections critically. Gorman (forthcoming) explains that while ableism can impact all disabled persons:

'Racist ableism' directs us to think alongside anti-racist and transnational feminist scholars who describe differential forms of racialized gender oppression that only happens to specific groups (np).

Gorman (forthcoming) further describes:

racist ableism is part of a white supremacist settler logic that affords the possibility of reclaimed white privilege and belonging for some disabled subjects (subjects who are more proximate to white middle-class respectability) in part through the othering and/or erasure of BIPOC disabled subjects (np).

Addressing ableism or systemic ableism historically excludes experiences of racialized disabled persons, including refugees, asylum seekers and immigrants. Like concepts of gendered racism (Essed, 1991), gendered Islamophobia (Zine, 2004), and racist ableism (Gorman, forthcoming), the stories shared with me led me to reflect on this powerful intersection of oppressions that could not be torn apart. By separating the experiences and

impacts of disablement and displacement, the stories of disabled Syrian refugees are not only ignored, but they are also re-written. The proposed notion of xenophobic ableism highlights the critical impacts of xenophobia (one form of oppression) onto ableism (another form of oppression) to further isolate disabled refugees.

Notwithstanding the limitations described earlier in this study, this research critically identifies and examines systemic inequalities and discrimination patterns amongst disabled refugees and their families, including xenophobic ableism. Expanding on Gorman's (forthcoming) work on racist ableism, xenophobic ableism is necessary to examine the transnational context of disabled refugees and how xenophobia has explicitly led to the exclusion and discrimination of disabled refugees.

According to Goodley and Lawthom (2019):

Ableism, because of its isolationism, invites new iterations of homophobia, xenophobia, nationalism, racism, sexism alongside disablism as ideological positions of prejudice that fit the logics of ableism (p.237).

We must ask how refugees have experienced this ableism? The participants' stories intertwined the intersectional impacts of Islamophobia, xenophobia, racism, and ableism. As Crenshaw suggests, intersectionality examines how

systems make particular identities the "consequence for the vehicle of vulnerability" (Crenshaw, 2016). For disabled Syrian refugees, their faith, their disability, their displacement and migration experience, race, and ethnicity all tie into an intersecting identity. While the conceptual framework of intersectionality encourages us to examine the intersections of identities, experiences, and oppressions, conversations on intersectionality frequently leave out disability, migration status, and faith. Incorporating disability and ableism in conceptual frameworks of intersectionality is critical and will transform diversity, equity, and inclusion initiatives (Jampel, 2018). Identifying the impacts of xenophobic ableism allows us to shape our advocacy efforts to recognize and challenge xenophobic ableism within our society.

Understanding disabled refugees' narratives that highlight the intersectional needs and oppressions of this population will inform changes in policies and practices that contribute to the marginalization of disabled refugees. Real stories can expose policies and practices that discriminate against disabled refugees and their families and limit them from navigating healthcare and education systems and accessing resources and supports.

The narratives shared in this study highlight the urgent need to critically examine ableist policies and practices that impact racialized communities such as the Syrian newcomer community.

This research can inform those working with other racialized refugee and disabled populations, such as Sudanese or Afghan refugees who have recently sought asylum in Canada. While their histories and intersectional experiences are not synonymous, social workers, healthcare workers, educators, and other service providers can draw from the participants' stories of lived experiences to better understand unique and diverse needs. For example, while healthcare providers use the term 'trauma-informed', it is evident through the data analysis that childhood trauma, intergenerational trauma, and trauma that resurfaces through the perpetuation of a single story (Adichie, 2009) is overlooked. A trauma and violence-informed approach can help us recognize the impact of trauma on one's life, reduce harmful and oppressive practices, and develop responses that are safe, purposeful, and meaningful (Government of Canada, 2018).

The stories also highlight the need for critical change in healthcare and educational practices to ensure practices are culturally responsive, safe,

and relevant. In the theme ‘Stories of Advocacy’, participants spoke of how, when advocating for their children's needs, their voices were ignored and overpowered by the idea that they were less knowledgeable on their children's conditions and experiences than the healthcare providers. This theme highlights the need for service providers to ensure client and family-centered practice by listening to a patient or client's story carefully and thoroughly. Their story will only be partially received without acknowledging, recognizing, and listening to one's story of disablement and displacement. The consequence of which is detrimental. A recent cultural shift in Canada away from a diversity model to a diversity, equity, inclusion (DEI) model has spanned across institutions and businesses. The DEI model is encouraged in healthcare spaces, educational institutions, and corporate settings (Ramirez, 2021). However, DEI work continually excludes dis/ability, and ableism from conversations on inclusion and rarely involves intersectional experiences and oppression (Singleton et al., 2021), including refugees, or more specifically refugees with disabilities, a population caught between a national and transnational narrative. While conversations on diversity, equity and inclusion can be viewed as a step

forward in various disciplines, disabled refugees must be included within that fold. Anti-oppression training that includes anti-ableism, anti-racism, and anti-xenophobic teachings is necessary to explore our biases and privileges and tackle systemic discrimination within our institutions. By doing so, we will have more successful outcomes, such as families accessing services they need and desire, not services forced upon them. Such training can address multiple and intersectional forms of oppression and educate healthcare professionals, service providers, and educators on the significant forms of oppression that impact disabled refugees. Intentional awareness on transnational disablement and xenophobic ableism and the need to identify and listen to stories of disabled refugees will impact service provision in healthcare and education.

Future Research:

Further research is required to examine disability within a transnational context to enrich the findings of this study. Specifically, the unique needs of disabled Syrians in Canada must be discussed, along with the social and economic implications of xenophobic ableism on their experiences in educational settings and when accessing healthcare services. Furthermore,

specific research is required on the individual and collective trauma, structural violence, and institutionalized xenophobic ableism faced by this population and how the dominant narrative unfolds and harms disabled refugees. Many questions remain unanswered and areas that require further investigation are unexplored. For example, how has COVID-19 impacted disabled Syrian refugees in Canada? While some participants touched upon school closures, vaccine scarcity, and lack of PPE, further investigation in this area may reveal how participants may have disproportionately experienced the pandemic. How has the dominant narrative of disabled refugees played into the political and economic response to the pandemic? How will stories of disablement and displacement inform participants' future relationships with service providers, educators, and healthcare professionals? Can the stories of disabled refugees influence policymaking and subsequent practices? It is my sincere hope this dissertation draws attention to the honest stories of disablement and displacement shared by the participants in hopes that necessary changes to health and education policies and practices will occur.

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Appendices

Appendix A: English Recruitment Flyer

**Are you a Syrian refugee living in Canada?
Do you have a child with a disability?
Would you like to share your story?**

If you answered, “Yes” to the above questions, I invite you to participate in the following study: Disablement and Displacement: Experiences of Disabled Syrian Refugees and their Families – A Qualitative Narrative Research Inquiry.

The study involves one or two one-hour virtual interviews to learn about your story.

My name is Sukaina Dada. I am a fourth-year Ph.D. student at York University and am interested in learning more about the experiences of Syrian refugees who came to Canada, specifically, those who have a child(ren) with a disability. As part of the interview, I would like to ask you questions about your experiences of disablement and displacement (your experiences with disability and migration).

If you would like to participate in the study or if you would like more information about the study, please contact me directly by email at sdada@yorku.ca

A \$20 Tim Horton's gift card will be provided to anyone who participates in the above study.

Appendix B: Arabic Recruitment Flyer

هل لديكم طفل ذو إعاقة؟
هل تريدون أن تعرفوا الآخرين عن تجربتكم مع طفلكم؟

إن أجبتكم "نعم" رداً على هذه الأسئلة ، فندعوكم للمشاركة في الدراسة التالية بعنوان: الإعاقة والنزوح: تجارب اللاجئين السوريين ذوو الإعاقات وعائلاتهم - بحث استقصائي سردي نوعي.

تستغرق المشاركة في هذه الدراسة ساعة إلى ساعتين في مقابلة تقام عبر الانترنت للتعرف عن تجربتكم.

اسمي سكينه دادا. أنا طالبة في السنة الرابعة من دراسات الدكتوراه في جامعة يورك وأهتم بتجارب اللاجئين السوريين الذين أتوا إلى كندا وبالأخص أولئك الذين لديهم أطفال بذوي الإعاقات. أريد أن أطرح عليكم بعض الأسئلة عن تجاربكم حول النزوح والإعاقة (أي كيف جرت تجربتكم مع الإعاقة خلال الهجرة).

إذا أردتم المشاركة في هذه الدراسة، أو إن أردتم المزيد من المعلومات عن هذا البحث أرحب بكم بالإتصال بي مباشرة عبر الإيميل في عنواني: **sdada@yorku**

- ستعطى بطاقة مكافئة من قبل "تيم هورتن" بقيمة عشرين دولار لأي شخص يشارك في هذه الدراسة.

Informed Consent Form

Study Name: Disablement and Displacement: Experiences of Disabled Syrian Refugees and their Families – A Qualitative Narrative Research Inquiry.

Researcher name:

- Sukaina Dada, Principal Investigator, PhD Level 4, Critical Disability Studies, School of Health Policy and Management, York University
- Email: sdada@yorku.ca

Purpose of the Research:

- The purpose of the study is to explore how Syrian refugees living in Canada experience disablement and displacement by asking participants how they think Canada has responded to the Syrian refugee Crisis.
- A qualitative narrative inquiry that examines one’s personal story will provide valuable and detailed information that may uncover untold stories of challenges and oppressions. This methodology will reveal real stories from the participants as “real” people.
- This type of research will help take back the narrative about how refugees with disabilities and their families feel about their situations.
- I plan to share this valuable information through verbal presentations and written published articles in hopes that this information will have an impact on the future of health policy and practice in Canada as it pertains to disabled Syrian refugees and their families.

What You Will Be Asked to Do in the Research:

- As a participant, you will be asked to do the following:
 - Respond to the initial advertisement to participate in the research by contacting me as the principal researcher by phone or email.
 - Complete a consent form and agreement to participate in the study.
 - Collaborate with the researcher to determine an appropriate date and time to conduct the virtual interview.
 - Virtually meet with researcher for interview and participate in the interview process.
 - Review researcher's story of you as a participant to determine if your narrative was captured accurately.
- Each participant will require 1 hour for the initial interview (with breaks as needed) and additional time to review the data and engage in the fact checking process.
- Each participant will be offered a \$20 Tim Horton's gift card for their participation.

Risks and Discomforts:

- Participants in this study may experience some negative emotions such as feelings such as sadness or anxiety as a result of sharing their personal stories which may include traumatic events or experiences related to displacement and/or disability.
- If you feel these feelings are interfering with your every day activities or mindset, you are encouraged to seek advice from a family doctor, call your local telehealth or visit a local walk in clinic.

Benefits of the Research and Benefits to You:

- You may experience positive feelings as a result of sharing your story. You may have a sense of empowerment, as well as an increase in knowledge that came about as a result of the study.

- Your story and the stories of the other participants may potentially have an impact on the future of social policies that impact disabled refugees and/or the treatment of disabled refugees in Canada.

Voluntary Participation and Withdrawal:

- Your participation in the study is completely voluntary and you may choose to stop participating at any time. Your decision not to volunteer, to stop participating, or to refuse to answer particular questions will not influence the nature of the ongoing relationship you may have with me as the researcher, with my supervisor or the nature of your relationship with York University either now, or in the future.
- If you decide to stop participating, you may withdraw without penalty, financial or otherwise, and you will still receive the promised inducement of the \$20 Tim Hortons gift card per participant.
- In the event you withdraw from the study, all associated data collected will be immediately destroyed wherever possible. Should you wish to withdraw after the study, you will have the option to also withdraw your data up until the analysis is complete.

Confidentiality:

Due to the current Covid-19 restrictions, the interviews will take place virtually. Virtual interviews (via phone or video) will be audio and/or video recorded. The audio and video recordings are used to ensure that I have not missed any information (verbal or non-verbal). Prior to the recording, you will be asked for explicit consent for video and/or audio recording. I will transcribe the recordings verbatim into notes using a word processor. These notes will be safely secured in a password protected folder. Audio and/or video recordings will be kept in secure folders that are password protected

and will be destroyed once data is analyzed. Only me, as the principal researcher will have access to the folders.

This study will use Microsoft Office 365 to collect data, which is an externally hosted cloud-based service. When information is transmitted over the internet privacy cannot be guaranteed. There is always a risk your responses may be intercepted by a third party (e.g., government agencies, hackers). Further, while York University researchers will not collect or use IP address or other information which could link your participant to your computer or electronic devices without informing you, there is a small risk with any platform such as this of data that is collected on external servers falling outside the control of the research team. If you are concerned about this, we would be happy to make alternative arrangements (where possible) for you to participate, perhaps via telephone. Please contact sdada@yorku.ca for further information.

- Recordings (audio/video) will be saved in a password protected file to research team members' local computer, not the cloud-based service.
- Please note that it is the expectation that participants agree not to make any unauthorized recordings of the content of a meeting / data collection session.
- As a participant, your identifying information will not be shared with anyone. The data will be anonymized. All personal information such as your first and last name will be removed from the data and will be replaced with a number as a code. A list linking the number with your name will be kept in a secure database and when printed in a secure locked cabinet, separate from your file.
- Throughout the interview, I will also take research notes in a designated notebook and following the interview, I will record my own observations and reflections in a reflexive journal. All notes will have the identifying information of participants removed with

permanent black marker and replaced with the above-described codes. This reflexive journal will be kept in a locked cabinet for the duration of the study, whereby only I, as the principal investigator have the key.

- During the dissemination of the results, an anonymous name will be assigned to each participant that does not give away any identifying information. If the results of the study are published, your name will not be used and no information that discloses your identity will be released or published.
- Once the study is complete, I will destroy all the data. The hard and soft data will be stored until January 25, 2023. Before this date, all soft data will be deleted and permanently removed from my computer. All hard copy data will be destroyed using a cross-cutting shredder.
- Unless you choose otherwise, all information you supply during the study will be held in confidence and unless you specifically indicate your consent, your name will not appear in any report or publication of the research. Confidentiality will be provided to the fullest extent possible by law.

Questions About the Research? If you have questions about the research in general or about your role in the study, please feel free to contact me by email at sdada@yorku.ca or my supervisor, Dr. Rachel Gorman at gorman@yorku.ca. You may also contact Collette Murray, the Graduate Program Assistant (Critical Disability Studies and Health) at c_murray@yorku.ca.

This research has received ethics review and approval by the Delegated Ethics Review Committee, which is delegated authority to review research ethics protocols by the Human Participants Review Sub-Committee, York University's Ethics Review Board, and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the

study, please contact the Sr. Manager & Policy Advisor for the Office of Research Ethics, 5th Floor, Kaneff Tower, York University (telephone 416-736-5914 or e-mail ore@yorku.ca).

Legal Rights and Signatures:

I <<fill in participant name here>>, consent to participate in Disablement and Displacement: Experiences of Disabled Syrian Refugees and their Families – A Qualitative Narrative Research Inquiry conducted by Sukaina Dada (Principal Investigator). I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

Signature _____
Participant

Date _____

Signature _____
Principal Investigator

Date _____

Additional consent (where applicable)

[You must seek additional consent by including check boxes or requesting additional signatures for the following if applicable.]

- [For audio recording, please include the following:]
 - 1. Audio recording**
- I consent to the audio-recording of my interview(s).
- [For video recording/authorize use of photographs, please include the following:]
 - 2. Video recording or use of photographs**

I _____ <<insert participants name>> consent to the use of images of me (including photographs, video and other moving images), my environment and property in the following ways (please check all that apply):

In academic articles	<input type="checkbox"/> Yes	<input type="checkbox"/> No
In print, digital and slide form	<input type="checkbox"/> Yes	<input type="checkbox"/> No
In academic presentations	<input type="checkbox"/> Yes	<input type="checkbox"/> No
In media	<input type="checkbox"/> Yes	<input type="checkbox"/> No
In thesis materials	<input type="checkbox"/> Yes	<input type="checkbox"/> No

Signature:

Date:

Participant: (name)

- If you are offering the participants the option to waive anonymity, include the following:
3. Consent to waive anonymity

I, _____ <<insert participants name>>, consent to the use of my name in the publications arising from this research.

Signature:

Date:

Participant: (name)

استمارة موافقة على المشاركة في بحث دراسي

التاريخ: ١٨ كانون الأول ٢٠٢٠

عنوان الدراسة:
الإعاقة والنزوح: تجارب لاجئين سوريين معاقين وعائلاتهم – بحث دراسي سردي ونوعي

اسم الباحث\ة:
سكينة دادا، الباحثة الرئيسية، دكتوراه درجة ٤، دراسات حول الإعاقة، قسم سياسة
الصحة والإدارة، جامعة يورك
عنوان الإيميل: sdada@yorku.ca

الغرض من البحث:

بغية هذا البحث الدراسي استكشاف تجربة اللاجئين السوريين المقيمين في كندا فيما يخص الإعاقة والنزوح وسيتم ذلك بطرح بعض الأسئلة للمشاركين عن كيفية تعامل كندا مع أزمة اللاجئين السوريين.

هذا البحث نوعي سردي يحلل روايات شخصية ذات معلومات مفصلة تساعد على تسليط الضوء على روايات غير محكية حول الصعوبات والقهر الذي عاناه النازحين. منهجية هذه الدراسة ستكشف روايات حقيقية لما يشعر به النازحين المعاقين وعائلاتهم.

سيساعد هذا البحث على امتلاك الروايات التي تهتم بوضع اللاجئين أخطط إلى تقديم نتائج القيمة لهذا البحث عن طريق تقديمات شفوية ونشرها في مجلات علمية متمنية أن يكون لنتائج تأثير على مستقبل سياسة الصحة في كندا بما فيها ما يخص اللاجئين المعاقين وعائلاتهم.

المطلوب منكم في هذا البحث:

سيُطلب منكم كمشاركون القيام بالآتي:

الرد على الإعلان الأول للمشاركة في البحث وذلك باتصالكم بي (الباحثة الرئيسية) عبر الهاتف أو الإيميل

ملء استمارة موافقة للتعبير عن القبول بالمشاركة في البحث الدراسي

التعاون مع الباحثة في تحديد تاريخ ووقت مناسب لإجراء المقابلة عبر الإنترنت

الاجتماع مع الباحثة عبر الإنترنت للمقابلة والمشاركة في المقابلة

مراجعة رواية الباحثة عنك كمشارك لكي تتأكد من دقة روايتك كما ترويها الباحثة

سيُطلب من كل مشارك في البحث ساعة واحدة للمقابلة الأولية بما فيها من استراحات ثم المزيد من الوقت لمراجعة البيانات والقيام بعملية تحقيق المعلومات

كل من اشترك في البحث سيستلم بطاقة مكافئة لـ "تيم هورتنز" بثمان عشرين دولار

المخاطر والمشاق المتوقعة:

قد يشعر المشاركون ببعض الأحاسيس أو المشاعر السلبية كالحزن أو القلق كجزء من المشاركة في هذا البحث ونتيجة رواية تجارب شخصية بما فيها من تفاصيل مؤلمة تتعلق بالنزوح أو الإعاقة أو الإثنيين منهما.

إذا شعرت بأن هذه المشاعر أو الانفعالات تؤثر على حياتك اليومية أو أفكارك اليومية فنحنك على طلب النصائح من الطبيب، أو أن تتصل بالصحة الهاتفية المحلية أو أن تذهب لعيادة أو مصحة محلية تسمح بالدخول بدون موعد

فوائد البحث والمنفعة لك:

من الممكن أيضاً أن تشعر بأحاسيس إيجابية نتيجة التحدث عن تجربتك. قد تشعر بالقوة الذاتية وبمزيد من الوعي والمعرفة نتيجة المشاركة في هذا البحث.

قد تؤثر روايتك وروايات مشاركين آخرين في هذا البحث على مستقبل السياسات الاجتماعية التي تتعلق ب اللاجئين ذوي الإعاقات فضلاً عن المعاملة التي يتلقونها في كندا.

المشاركة الطوعية والانسحاب من البحث:

مشاركتم في هذا البحث تطوعية ويمكنكم الانسحاب متى ما شئتم. عدم المشاركة أو التوقف عنها أو رفض الإجابة عن أي سؤال لن يؤثر على علاقتكم بالباحثة، أو الأستاذة المشرفة على البحث أو على طبيعة علاقتك بجامعة "يورك" الآن أو في المستقبل.

الانسحاب من البحث لن يترتب عنه أي مخالفة وسوف تحصلون على بطاقة مكافئة ل "تيم هورتنز" بعشرين دولار كما وعدناكم.

في حال انسحابكم من البحث سنتخلص من جميع الاستبيانات التي ساهتمتم في إعطائها. إذا قررتم الانسحاب بعد نهاية البحث يمكنكم طلب إلغاء جميع استبياناتكم حتى وإن كان البحث في مرحلة التحليل.

السرية:

تفرض علينا جائحة كوفيد-19 إجراء المقابلات معكم إلكترونياً عبر الإنترنت وأسأجلها إما بالصوت أو الصورة أو الاثنين معاً. ستضمن لي التسجيلات عدم اتلاف أي من المعلومات أو البيانات لفظية كانت أم غير ذلك. وبالطبع سأستأذنكم قبل أن أبدأ التسجيل بإذن صريح وموافقة شفوية لتسجيل المقابلة معكم صوتاً وصورةً كما ذكرنا. سأنسخ التسجيلات حرفياً إلى ملاحظات باستخدام برنامج WORD

وأفيدكم بأنني سأحتفظ بكل ما أنسخه في ملف محمي بكلمة سر كما أنني سأحتفظ بالتسجيلات في ملف خاصة محمي بكلمة سر أيضاً وسأتخلص من التسجيلات بعد تحليل ما فيها من بيانات ولن يستطيع أحد من غيري (الباحثة الرئيسية) قراءة محتوى الملفات أو الوصول إليها.

ستعتمد هذه الدراسة على برنامج "ميكروسوفت أوفس 365" لجمع المعلومات وإن هذا البرنامج سحابي مستضاف خارجياً. وبطبيعة الحال عند إحالة المعلومات عبر الإنترنت تصبح الخصوصية غير مضمونة فهناك دائماً نسبة من الخطورة في تعرض أجوبتكم لالتقاط من طرف آخر (كالهيئات الحكومية، أو الهاكرز المتسللين الإلكترونيين). إن جامعة "يورك" لا تجمع أي عنوان "أي بي" أو أي معلومات أخرى تربط مشاركتك لحاسوبك الشخصي أو أجهزتك الإلكترونية الشخصية الأخرى دون إخباركم مسبقاً وننبهكم بأن هناك نسبة خطورة بسيطة في استخدام أي نوع من المنصات الإلكترونية كهذه فهناك عوامل خارجة عن سيطرة الباحثة التي قد تؤثر على حماية البيانات. إن

لكي نقوم بترتيبات sdada@yorku.ca أفلتكم أي شيء من هذه المعلومات فنرجو أن تخبرونا
بديلة قدر المستطاع كأن تشاركوا هاتفياً. الرجاء الاتصال ب
للسؤال عن التفاصيل أو للمزيد من المعرفة.

- سيتم حفظ التسجيلات (صوت/صورة) في ملف محمي بكلمة مرور في حاسوب فريق البحث وليس في الخدمات السحابية.
- نرجو الانتباه بأننا نتوقع من المشاركين عدم تسجيل محتوى المقابلات خلال الاجتماع لجمع البيانات بدون إذن
- لن نعطي معلوماتكم التعريفية لأحد. ستكون الاستبيانات مجهولة المصدر وأي معلومات عن هويتكم الشخصية كالاسم واللقب ستُحذف من البيانات ذاتها وسنستخدم رقماً رمزياً بدلاً منها. سنحتفظ بالقائمة التي تقرن الرقم الرمزي بأسمائكم في قاعدة بيانات آمنة في خزانة محكمة منفصلة عن ملفكم.
- سأكتب ملاحظات عن البحث أثناء إجراء المقابلات وستكون تلك الملاحظات في دفتر خاص بها، ثم بعد المقابلة سأدون بعض تأملاتي في دفتر لانعكاساتي الخاصة. سأحذف أي معلومات تعريفية بقلم غير قابل للمحي وسأستخدم الأرقام الرمزية التي ذكرتها مسبقاً. سأحتفظ بهذا الدفتر في خزانة محكمة أثناء إجراء البحث وسيكون المفتاح الوحيد لي، الباحثة الرئيسية.
- عند نشر نتائج البحث سيتم تعيين اسم مجهول لكل مشارك/ة كي لا تُكشف أي معلومات عن المشاركين. إذا نشرنا نتائج البحث فلن نستعمل أسمائكم أو أي معلومات تعرف هويتكم في أي شيء ننشره أو نسلمه عن البحث.
- عند انتهاء الدراسة سأتخلص من جميع الاستبيانات. سأحتفظ بالاستبيانات الملموسة والغير ملموسة إلى ٢٥ كانون الثاني ٢٠٢٣. سأحذف جميع الاستبيانات الغير ملموسة من حاسوبي الخاص
- قبل هذا التاريخ بالكامل. سأتخلص من الاستبيانات الملموسة باستخدام "شريد" أو ممزق الكتروني شامل.
- جميع المعلومات التي تقدموها لنا ستحفظ سرياً إلا إذا سمحتم لنا بالتصريح بشكل محدد. لن تظهر أسمائكم أو أي معلومات تعريفية عنكم في أي تقرير أو مطبوعات عن البحث. سنوفر السرية التامة إلى أقصى حد ممكن.

أي استفسار عن هذا البحث؟

إن كانت لديكم أي أسئلة أو استفسارات عن البحث عامة أو عن دوركم في هذا الدراسة على وجه
أخص فأنا أرحب باتصالكم بي عبر الإيميل sdada@yorku.ca

ويمكنكم أيضاً الاتصال بمشرفتي الدكتورة ريتشل غورمن Dr. Rachel Gorman at gorman@yorku.ca
كما أنه يمكنكم الاتصال ب المساعدة لبرنامج الدراسات العليا (قسم الصحة ودراسات الإعاقة الأساسية) كولينت موري Collette Murray c_murray@yorku.ca.

لقد حصل هذا البحث على مراجعة وموافقة لجنة استعراض أخلاقيات البحث وهي هيئة مفوضة بسلطة استعراض أخلاقيات البحث وبرتوكولاتها لدى اللجنة الفرعية لمراجعة المشاركين. ونفيدكم بأن هذه اللجنة ملتزمة بمعايير اللجنة الكندية للمبادئ التوجيهية للأخلاقيات في البحث. إن أردتم معرفة المزيد عن هذا الإجراء أو بحقوقكم كمشاركين في هذا البحث الدراسي نرجو الاتصال بكبار مدراء ومستشارين السياسة في مكتب أخلاقيات البحث، الدور الخامس، كانف تاور، جامعة يورك Sr. Manager & Policy Advisor for the Office of Research Ethics, 5th Floor, Kaneff Tower, York University (الفاكس 416-736-5914 \ الإيميل ore@yorku.ca).

Legal Rights and Signatures:

الحقوق القانونية والإمضاء

أنا _____ <<اكتب اسم المشارك>> أوافق على المشاركة في دراسة:
الإعاقة والنزوح: تجارب لاجئين سوريين معاقين وعائلاتهم – بحث دراسي سردي ونوعي
تجربه الباحثة الرئيسية سكينه دادا. فهتمت طبيعة هذا البحث وأريد المشاركة. أنا لا أتنازل عن
حقوقى القانونية بالإمضاء على هذه الاستمارة. توقيعى فى الأسفل يشير على موافقتى.

الإمضاء _____ التاريخ _____
المشارك\

الإمضاء _____ التاريخ _____
الباحة الرئيسية

موافقة إضافية (حيث ينطبق)

يجب طلب موافقة إضافية بما فيها من مربعات الاختيارات أو طلب إمضاءات إضافية في الحالات التالية (حيث ينطبق الأمر)

• للتسجيلات الصوتية، الرجاء إضافة التالي:

1. تسجيل صوتي

أوافق على تسجيل صوتي في المقابلة

• لتسجيل الفيديو أو لترخيص استخدام الصور الرجاء إضافة التالي :
2. تسجيل فيديو أو استعمال الصور

أنا _____ <<اكتب كلمة المشاركة هنا>> أوافق على استعمال صوري (بما فيها صور، فيديوهات، أو أي صور متحركة)، الإطار الذي أوجد فيه وممتلكاتي في كل من الآتي (الرجاء وضع علامة حيث ينبغي):

[] لا	[] نعم	في المقالات أكاديمية
[] لا	[] نعم	في أشكال مطبوعة أو رقمية
[] لا	[] نعم	في عروض أكاديمية
[] لا	[] نعم	في الإعلام
[] نعم		في مواد الأطروحة أو رسالة الدكتوراه
[] لا		

الإمضاء:

التاري

خ :

(المشاركة): الاسم

• إن كنت ستمنح الخيار للمشاركة أن يتجاوز السرية، فينبغي إضافة التالي:

4. الموافقة بالتجاوز عن السرية:

أنا _____ <<اكتب اسم المشارك>> أوافق على استخدام اسمي في أي مؤلفات تتبع من هذا البحث.

الإمضاء:

التاريخ

:

اسم المشارك

Appendix E: Interview Guide

[Narrative / Intersectional Identities, experiences & oppressions]

- Please tell me about yourself and your family?
- We all have a story. I would like to hear about your story. Please share whatever you feel comfortable sharing?

[Displacement]

- What were the circumstances like where you were living prior to coming to Canada?
- Please tell me about your migration to Canada / Can you describe your journey?
- What were the challenges in coming to Canada / what obstacles did you face?
- How did you feel about coming to Canada?

[Disability & Displacement]

- How does disability and/or disablement impact your experiences as a Syrian refugee, and your life here in Canada?
 - a. Rephrase: How did disability/disablement affect or impact your family's journey to Canada and now – life in Canada?
- How do you feel about life in Canada? How has it been for your family?

[Other]

- Is there anything else you would like to share with me?
- [Rephrase] Do you want to share anything else about your story with me?