Nothing About Us, Without Us:
The Pursuit of Inclusive and Accessible Positive Peace

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A thesis
submitted to the University of Otago
in the fulfilment of the requirements for the degree of
Doctor of Philosophy

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Abstract

People with disabilities are the largest minority in the world; a minority that continues to face high instances of direct, structural and cultural violence during times of peace, as well as during times of conflict and displacement. Exacerbating their marginalisation has been the absence of the disability community from Peace and Conflict Studies (PACS) research, literature and practice, which has perpetuated ableist ideologies and hindered the pursuit of "positive peace". This research responds to this absence by investigating the intersectionality of disability, conflict and displacement from a PACS perspective. Its purpose is two-fold. The first aim is to conduct pure research that challenges the on-going marginalisation of people affected by disability, conflict and displacement, by intentionally de-subjugating and valuing their knowledge and experiences. The second aim is to use applied research to conceptualise and demonstrate ways in which PACS might actively advance inclusive and accessible positive peace. The design of this research was strongly influenced by critical theories, the transformative paradigm, appreciative inquiry, narrative inquiry and partial-insider research. Over a period of five weeks, twenty interviews were conducted in Ecuador with refugees and asylum seekers with disabilities from Colombia and Venezuela, and their family members. A further five interviews were conducted with service providers. The key findings were simple. Participants confirmed that the intersectional experience of disability, conflict and displacement can be dangerous and harrowing. As participants shared insights into how to navigate direct, structural and cultural violence during conflict and displacement, a second key finding was that a great deal can be learned from people with lived experience. Finally, this research revealed that when PACS is informed by rights-based approaches; when those with lived experience have equitable opportunities to determine their own research agenda and contribute knowledge and expertise; and when "nothing about us, without us" is at the forefront of peacebuilding research and activities, then inclusive and accessible positive peace can begin to be realised.

Key words: Peace and Conflict Studies, Disability Studies, disability, conflict, displacement, positive peace, inclusion, access, peacebuilding, appreciative inquiry, intersectionality.

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Acknowledgements

This thesis was made possible by the love and support shared by friends, family and colleagues, as well as a few strangers along the way.

First and foremost, to the people with disabilities, and their families and friends, who contributed to this research. Words cannot express how honoured I feel to have shared in your journeys. I will honour your honesty, openness, wisdom and strength, by dedicating my own future to promoting the rights, freedoms and dignity of people affected by disability, conflict and displacement. This research may have come to an end, but the journey towards inclusive and accessible positive peace has only just begun. Thank you for all you have contributed to this work.

To my friends at Asylum Access Ecuador, thank you for opening your offices, homes and hearts to me. Your support went above and beyond anything I expected, and I am grateful to you all for helping me feel at home in a country that was not my own. Thank you for all the ways you supported this research – from the cups of coffee, to car rides, translations, and of course, for introducing me to the people whose stories are now inspiring an inclusive and accessible movement of positive peace. Thank you also to the Hebrew Immigrant Aid Society (HIAS), the United Nations High Commissioner for Refugees (UNHCR) Lago Agrio, the Refugee Education Trust (RET), Volunteers Organization for International Co-operation (OVCI), and the Mennonite Church, for introducing me to your networks, for providing meeting spaces, and for helping to arrange interviews.

A very special mention to Liza Ordonez Cook, who travelled across the world to make sure the field research flourished, and that I was equipped with all the tools, resources and networks that were needed to succeed. Thank you also to the other translators who worked hard to ensure everyone was heard, understood, and respected.

Richard Jackson and Gill Rutherford, there are no words for how grateful I am for your support, supervision and friendship over these last three years. You two have been the supervision dream team. I have learned so much from you both – your knowledge, wisdom and expertise are without a doubt sprinkled throughout this thesis, and will continue to influence me whatever the future may hold. Thank you also to Heather Devere for your kindness and support throughout this journey.

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List of Abbreviations and Acronyms

AI	Appreciative Inquiry
ASD	Acute Stress Disorder
ATM	Automated Teller Machine
AUC	Autodefensas Unidas de Colombia
BBC	British Broadcasting Corporation
CBM	formerly known as the Christian Blind Mission
CBR	Community Based Rehabilitation
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
DMC	Decisional Making Capacity
DPOs	Disabled People's Organisations
DS	Disability Studies
ELN	National Liberation Army
FARC	Fuerzas Armadas Revolucionarias de Colombia (Revolutionary Armed Forces of Colombia)
GDD	Global Development Delay
GDP	Gross Domestic Product
HI	Humanity and Inclusion (formerly Handicap International)
HIAS	Hebrew Immigrant Aid Society
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome
HoH	Hard of Hearing
ICRC	International Committee of the Red Cross
IDF	Israeli Defense Force
IDP	Internally Displaced Person
IHL	International Humanitarian Law
IHRL	International Human Rights Law
IPI	International Peace Institute
IPRA	International Peace Research Association
IRC	International Red Cross
ISIL	Islamic State of Iraq and the Levant
ISIS	Islamic State of Iraq and Syria
LRA	Lord's Resistance Army

NGOs	Non-Governmental Organisations
OVCI	Volunteers Organization for International Co-operation
PACS	Peace and Conflict Studies
PAR	Participatory Action Research
PDF	Portable Document Formats
PRIO	Peace Research Institute Oslo
PTSD	Post-Traumatic Stress Disorder
RET	Refugee Education Trust
RSD	Refugee Status Determination Processes
SDGs	Sustainable Development Goals
SIPRI	Department of Peace and Conflict Research at Uppsala University
SMS	Short Message Service
TBI	Traumatic Brain Injury
UK	United Kingdom
UN OCHA	United Nations Office for the Coordination of Humanitarian Affairs
UNHCR	United Nations High Commissioner for Refugees
UPIAS	Union of the Physically Impaired Against Segregation
USA	United States of America
VIP	Very Important Person
WHO	World Health Organisation
WOLA	Washington Office on Latin America
WRC	Women's Refugee Commission

Preface: Terminology

D/deaf: In Deaf culture, there are two different spellings for the word deaf. "Deaf" (with a capital D) refers to Deaf culture, and those who identify with that culture. Alternatively, "deaf" (with a small d) is often used to refer to people who do not identify with Deaf culture (Ladd, 2003). By using the term "D/deaf", this thesis acknowledges that people affected by hearing loss have different preferences for terms that reflect their identity.

Disability: Throughout this thesis, the term "disability" is used as defined in the United Nations Convention on the Rights of Persons with Disabilities, meaning "[...] those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others [...]" (Article 1, United Nations, 2006a).

Grey literature: According to the 1997 Grey Literature Conference, grey literature describes information produced by governments, academia, businesses and industries that is not commercially published, and where publishing is not the primary activity of the producing body. It can be best understood through the nature of the document, the types of producers, and the means of dissemination. This includes technical and project reports, working papers, discussion papers, manuals, information sheets, conference papers, and so on (Lawrence, 2012).

Impairment: Impairment is distinguished from disability, and refers to the medically defined condition of a person's body and mind (Wendell, 2017). That is, significant bodily differences culturally marked as "abnormal" (Thomas, 2004a).

Marginalised groups/communities/populations: Throughout this thesis, these terms have been used to describe groups and people who are excluded from mainstream social, economic, cultural, or political life. This includes, but is not limited to, those who are excluded because of race, religion, political affiliation, sexual identity, age, gender, education, financial status or ability (Given, 2008).

PwD: PwD commonly refers to people with disabilities or participants with disabilities. This abbreviation helps to minimise repetition.

Queer and gender diverse communities: While there are a variety of terms referring to different aspects of gender and sexual identities, this thesis uses the phrase "queer and gender diverse communities". This is the preferred terminology used by RainbowYOUTH New Zealand (RainbowYOUTH, n.d.). "Queer" is a reclaimed word that is used by some as a

specific identity, and for others it serves as an umbrella term encompassing diverse sexualities and those who are not sure. "Gender diverse" is an umbrella term for a wide range of identities, including culturally specific ones such as: *tangata ira tane* (Māori), Female-to-Male (FtM), Male-to-Female (MtF), transsexual, *fa'afafine* (Samoan), transgender, *whakawahine* (Māori), trans men, trans women, *akava'ine* (Cook Islands Māori), *fakaleiti* (Tongan), non-binary, gender-queer and gender-neutral people (RainbowYOUTH, n.d.).

Rights: Given that the focus of the thesis is "protecting and promoting the freedoms, rights and dignity of people with disabilities affected by conflict and displacement", to minimise repetition I have chosen to refer to the latter as the "rights of people affected by disability, conflict and displacement".

Preface: A Note on Formatting, Style and Language

This thesis is presented according to the style guidelines of the American Psychological Association (APA), 6th edition, and uses New Zealand spelling based on British English. Traditionally, academic writing has utilised objective and impersonal prose, and has therefore discouraged the use of opinion or first-person pronouns. However, over time this has begun to change, in recognition that there are different views of knowledge, different research practices and different ways of seeing the world and expressing those differences (Hyland, 2002). Given the nature of this research, and the methodological approach of partial-insider research, narrative inquiry and appreciative inquiry, this thesis draws on a variety of narrator voices, including my own. As such, first-person perspective is used throughout the chapters, so that the reader can distinguish between my voice as a Peace and Conflict Studies (PACS) researcher who identifies as disabled, from that of literature quotations and the voices of research participants. Literature quotations are presented in standard APA format, as are participant quotes. However, participant quotes are referenced by their interview number, followed by the type of participant. For example, participants with disabilities are identified with "PwD", interviews with family members of people with disabilities are identified as "Family" and also include the relationship to the family member with a disability when necessary (father, mother, sister, and so on). Service providers are identified as "Service Provider" followed by the organisation they work for.

It is also important to note that interviews were conducted in Spanish with the support of an English-Spanish translator. All interviews were recorded, and the audio transcribed verbatim. Following this, the transcripts were translated into English. Given that multiple translators and transcribers from Ecuador, Colombia, and Venezuela worked on this process, careful attention was paid to translating the interviews as accurately and authentically as possible. However, in working with different languages, regional colloquialisms, words and meanings, a small amount of interpretation was necessary. It is important for the reader to keep in mind the general idea of a quote, rather than become distracted by discrepancies of literal translation. In circumstances where I have clarified terms or completed unfinished sentences, this is indicated by square brackets. If parts of the quote or excerpts have been omitted, square brackets and three periods are shown. For example:

> To live well, to have a job, for my boy to be doing well in Colombia. I had everything necessary there. I worked there and everything. But not here [Ecuador]. […] But, wealthy enough to survive. I don't want riches, but something to get by. (Participant #23, Family)

Other formatting and styles used within this thesis include quotes at the start of every chapter. Each of these quotes are by people with disabilities themselves (or family members), and have been selected because of their relevance to the chapter. Furthermore, given that screen readers (a software often used by people who are blind or have low vision) cannot access or read images, all figures have either been described in the main text or as an image description below the figure itself.

Finally, I would like to elaborate on the use of the term "disability" within this thesis. As will be discussed in the following chapters, there is no universally accepted definition of the term "disability", nor is the term itself even universally accepted. While writing this thesis, I myself have switched between "disabled person", "person with a disability" and "impairment" as I have learned more about the implications of each term. In New Zealand, it is acceptable to use the term "disabled people" (for example, see Office for Disability Issues, 2016). However, in many other countries "disabled people" is strongly rejected for placing the disability before the person. Commonly referred to as people-first language, this is an approach that prefers the word "person" to come before "with a disability", in recognition that we are all, first and foremost, humans, and not our diagnoses. However, others have argued against people-first language (Dunn & Andrews, 2015). For example, my gender identity or ethnicity is not referred to as "person who is woman" or "person who is from New Zealand". Instead the terms "female" and "New Zealander" are used. In the same way, am I a person with a "disability" or "disabled"? Further to this is the distinction between "disability" and "impairment", which will be discussed in greater depth in the next chapter. As summarised by the New Zealand Disability Strategy:

> There are many words and terms that are used to identify disability. The way these are understood differs […]. For some of us, the term 'disabled people' is a source of pride, identity and recognition that disabling barriers exist within society and not with us as individuals. For others, the term 'people with disability' has the same meaning and is important to those who want to be recognised as a person before their disability. […] Not all members of our community identify with disability-focused language. For example, older people and their families and whānau sometimes think that disability is a normal part of the ageing process. People with invisible impairments such as mental

health issues can sometimes identify as part of the mental health community, and not the disability community. Deaf people identify as part of the Deaf community with its own unique language and culture, and do not always identify as being disabled. Most Māori disabled people identify as Māori first. The importance of their cultural identity, which encompasses language, whānau, cultural principles, practices and linkages to the land through genealogy, is paramount to how they live their day to day lives in both Te Ao Māori and Te Ao Pakeha. (Office for Disability Issues, 2016, p. 13)

While there is no one correct choice of terminology, what this shows is that language matters. As such, I would like to note that my personal preference is for the term "disabled person", especially when describing myself. I am proud of my disability identity, and the experiences it has given me. For me, it is not a term that denotes weakness or inability, but strength and beauty (Francis, 2017a). However, given that this research is founded on the principles of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), throughout this thesis I have consistently used person-centred terminology. Although this is not my personal preference, for the purpose of this thesis I have chosen to uphold the language used in the CRPD, including its terminology and definitions. This is because I hope this research will eventually serve to ensure that the CRPD will become a guiding text for PACS research, practice and positive peacebuilding activities. It is my intention that this research will be read and utilised around the world, and that terminology does not become a barrier to considering its content.

Chapter 1 – Introduction: What happens to people like us?

> "What happens to people already living with disabilities during war? How would I escape and where would I hide if there is no electricity to charge my power chair? What happens to people like us?"
>
> - Donna-Rose McKay (Former Head of the University of Otago Disability Information and Support, 2013)

Background

On the eighth of July 2014, the Israeli army launched military Operation Protective Edge in the Gaza Strip. Over a period of seven weeks the Israeli Defense Force (IDF) launched aerial and naval bombardments and deployed ground troops in Gaza, while Hamas fired rockets into Israel. According to reports by the United Nations Office for the Coordination of Humanitarian Affairs (OCHA), approximately 2,131 Palestinians and seventy-one Israelis were killed during the peak of hostilities (OCHA, 2014).

From my peaceful corner of the world I watched anxiously as the conflict unfolded. Having lived in the region, my interest was both personal and professional. My social media feeds began to fill up with selfies taken by Israeli friends in bomb shelters, as the rockets fired from Gaza inched closer to Jerusalem and Tel Aviv. Palestinian friends posted pictures of demolished neighborhoods; the bloodied bodies of family and friends littering the rubble streets they used to walk. As journalists, politicians, bloggers, citizens and anyone with an opinion took to social media to debate the atrocities, one post in particular caught my attention in a way that others had not.

Figure 1. Wheelchair amongst rubble in Beit Lahiya, Gaza (Associated Press, 2014)

As shown in Figure One, the picture was of an old, blue wheelchair positioned on top of a pile of concrete rubble. The report that followed detailed an IDF aerial attack on the Mobarat Felestin Centre in Beit Lahiya, northern Gaza, a home for people with disabilities. The attack had resulted in the deaths of two women with physical and intellectual disabilities, thirty year old Ola Washahi and forty-seven year old Suha Abu Saada. After the attack, the director of the facility, Jamila Alaywa, commented, "They didn't understand what was happening and they were so frightened" (French Press Agency, 2014, line 10). Survivors of the attack, all of whom live with high needs cerebral palsy, acquired head, neck and torso injuries as well as severe burns: "The residents were barely mobile, said neighbours, spending their time in bed or in wheelchairs, and could not escape" (Beaumont, 2014, para. 7).

The report went on to state that occupants of the building were warned of the attack by a "roof knock", a military tactic where a non-explosive mortar is fired before an explosive missile destroys the building (Taylor, 2014). Though occupants are usually given ten minutes to evacuate, cell phone footage has suggested that in some circumstances, the time between the warning and the missile can be as short as fifty-seven seconds (Weiss, 2014). While the act of roof knocking is designed to give able-bodied citizens time to evacuate, the report made me

wonder: what happens to those who are less mobile? In reading about the Mobarat Felestin Centre, I was reminded of a conversation I had had with the former Director of the University of Otago Disability Information and Support office when I was a Master's student. "What happens to people already living with disabilities during war?" Donna-Rose McKay pressed. "How would I escape and where would I hide if there is no electricity to charge my power chair? What happens to people like us?"

I was born with a condition called Phocomelia, which meant that the bones in the lower half of my body failed to develop properly before birth. I learned to walk on a prosthetic leg that became familiarly known as Lucy Leg and have always known that my other leg may need to be amputated too. I am also reminded of all my friends and colleagues who live with disabilities and chronic health conditions; my brother who was recently diagnosed with type one diabetes; a close friend who is a wheelchair user; the little girl with cerebral palsy I used to work with; a colleague who is a mental health service user and the countless others I have met since working in the disability sector. What would have happened to us if we were given fifty-seven seconds to evacuate a building? Would any of us have survived? Probably not.

A Google image search of the terms "war" and "disability" fuelled my curiosity – there appeared to be very little information available for, and about, people with disabilities affected by conflict and displacement. In fact, the search almost exclusively returned images of soldiers in uniform with amputated limbs, forming what Serlin (2006) refers to as arbitrary categories for thinking about disability and impairment. While I found this troubling, I was not surprised. With so many other atrocities occurring during conflict and displacement, is it reasonable to expect state actors, non-state actors, or even humanitarian groups to invest time, effort and resources into protecting an already marginalised community?

A utilitarian response to this question, which holds that actions are right to the degree that they promote the greatest good for the greatest number (Mill, 1995), might not consider addressing the plight of the disabled and unwell as being beneficial to the greater good of a dominant culture. From a Darwinist perspective, the demise of the impaired and sick during conflict and disaster might be justified as an unfortunate, yet necessary, consequence of natural selection, or a bi-product of the survival of the fittest (Duzdevich & Judson, 2014). A capitalist approach, with hints of eugenics, might lean towards sacrificing the wellbeing and protection of those who are deemed as unproductive, economically burdensome, or "useless eaters" (Johnstone, 2001, p. 88), in order to ensure economic security and safety for those

who are fit and able. Indeed, there are many reasons as to why a dominant culture might quietly accept the casualties of people with disabilities, simply as collateral damage. Even when explaining this research to friends and strangers, I have been met with words of shock, disbelief and sympathy, when talking about the experiences of people with disabilities during conflict and displacement. This, however, is often followed by dismissal and an inability to imagine it any other way: "Oh that's tragic," they say. "But that's how it has always been, you can't do anything to change that".

And perhaps they are right. When resources are scarce, maybe it does make sense to invest time, effort and finances into the "able-bodied" and "sound-minded" majority. However, a part of me simply cannot accept this. This is a conclusion I cannot abide, nor allow on the basis of utility.

Research Rationale

According to the World Health Organisation (WHO), it is estimated that fifteen per cent of the global population lives with some form of disability (over one billion people) (World Health Organization, 2018), making it the largest minority in the world (United Nations, n.d.). Here in New Zealand, almost one quarter of the population identifies as disabled, meaning that everyone is impacted by it in some way, shape, or form, even if only as a consequence of the ageing process (Office for Disability Issues, 2016). Indeed, the disability community is one of the only minority groups in the world that anyone can join at any moment, with no say in the matter.

Even so, despite being a phenomenon that is relevant to all people from all walks of life, this thesis shows that the disability perspective remains largely absent within academia and Peace and Conflict Studies (PACS) research. Furthermore, research and grey literature collated from outside of PACS, suggests that we, the disability community, are routinely excluded from matters that affect us, including peacebuilding activities. This is problematic on multiple levels. However, as argued by this thesis, perhaps the greatest concern is that the exclusion of any person, or group, from matters that affect them, jeopardizes and hinders the pursuit of positive peace. As such, a key assumption of this research is that positive peace is inclusive; it is accessible; and it is for all people regardless of disability, ability or any other identity.

As such, my own thesis journey might be thought of as a first step towards bridging the divide between the disability community and PACS. This is achieved through the following key research questions:

1) What can we learn from people with disabilities about the intersectionality of disability, conflict and displacement?

2) What can we learn from people with disabilities about protecting and promoting the freedoms, rights and dignity of people with disabilities affected by conflict and displacement (as outlined in Article 11 of the Convention on the Rights of Persons with Disabilities)?

3) How can PACS research contribute to inclusive and accessible positive peace?

In answering these questions, this research dares to engage in difficult conversations, not only about intersectionality, but also about the underlying causes of exclusion, discrimination and marginalisation, particularly within PACS. Most importantly, this thesis goes beyond simply conducting pure research for the sole purpose of adding to the knowledge-base of PACS, but also by contributing applied research. This includes practical suggestions on how PACS researchers and practitioners can move towards inclusivity and accessibility within their own endeavours. In this way, the potential impact of this research is significant and far-reaching. The thesis itself both advances inclusive and accessible positive peace, while showing others how they too might do the same.

In summary, when I think about the rationale for this research, I am reminded of the residents at the Mobarat Felestin Centre in Beit Lahiya, Gaza. I cannot simply shrug off the attack as a tragic consequence of conflict. We can do better. We must do better; and this research is an attempt to do just that. This research aims to utilise PACS as a means of disrupting dominant ideologies that have created, contributed to, and maintained, inequality and disparity amongst populations affected by conflict and displacement. In the same breath that critics might say, "It has always been this way", this thesis replies, "But it does not have to be."

Thesis Structure

Following this introduction, Chapter Two begins by providing an overview of the disability rights movement, the emerging field of Disability Studies and six key models of disability. These models provide a framework for understanding how society has traditionally perceived and responded to disability, historically and in the present day, as well as the important shift in thinking that has taken place as people with disabilities have started to determine their own

identity and status within society. The historical roots of marginalisation and discrimination are presented, and disablism and ableism are discussed as barriers to equality and inclusion. Various human rights tools for protecting the rights of people with disabilities during conflict and displacement are then discussed, thus bridging the divide between Disability Studies and PACS.

Chapter Three shifts the focus to PACS. After providing a brief history of PACS as an academic field of inquiry, the chapter then examines disability representation amongst its literature. The scope of reviewed literature is extended to include texts, research and reports from other academic disciplines, field reports and media articles. Through this process, academic and anecdotal evidence reveals that people with disabilities often experience discrimination, abandonment, punishment and recruitment during conflict and displacement. Literature detailing best practice for field workers working with refugees and asylum seekers with disabilities is presented, as well as the exclusion of disability communities from post-conflict peacebuilding, the impact of hierarchy amongst different types of disabilities, and finally an example of immunity is given. These experiences are then contextualised within key PACS theories, including Johan Galtung's violence triangle, and his theory of negative and positive peace (Galtung, 1969, 1990, 1996). Having established a foundational understanding of the disability rights movement, Disability Studies, PACS, and the potential for inter-, intra- and trans-disciplinary research and practice, the absence of the voice of the disability community from PACS research and literature is identified and key research questions formed.

Chapter Four is a presentation of the research paradigms that have informed this thesis. The precarious relationship between academia and people with disabilities is discussed, and critical approaches to Disability Studies and PACS are presented in relation to the emancipation of marginalised communities. The chapter then investigates the transformative paradigm as a key approach that has informed the research. The transformative paradigm can be described as a range of research endeavours that have developed from the idea that research ethics is about human rights, social justice and the relationship between researchers and participants (Mertens, Sullivan, & Stace, 2011). The axiological, ontological, epistemological and methodological assumptions of the transformative paradigm are discussed, as well as its benefits, challenges and critiques. Other influential methodologies are presented, such as narrative inquiry and insider research, before appreciative inquiry is discussed in depth as both a research methodology and method. This aspect of the thesis is

particularly important, as it sets the tone for the rest of the research. Based on the premise that society moves in whatever direction it collectively, passionately and persistently ask questions about (Bushe, 2013a), appreciative inquiry challenges dominant and secularised problem-oriented approaches to research by focusing on peak experiences, life-giving moments, courage, inspiration, hope and dialogue that generates change (Grieten, Lambrechts, Bouwen, Huybrechts, Fry, & Cooperrider, 2018). The benefits and challenges of appreciative inquiry as a research methodology are also discussed.

The next chapter, Chapter Five, details the specific methods and processes this research employed to answer the key research questions. After a brief recap of the three questions, reasons for selecting Ecuador as a field location, and Venezuelan and Colombian refugees and asylum seekers with disabilities as participants, are presented. The chapter then discusses whose narratives this research sought out, as well as the mechanisms and justifications behind the selection of those narratives, such as Bronfenbrenner's Ecological Systems Theory (Bronfenbrenner, 1979), Maire Dugan's Nested Paradigm of Conflict Foci (Dugan, 1996) and John Paul Lederach's Actors and Approaches to Peacebuilding Pyramid (Lederach, 1997). Participant recruitment methods, inclusion and exclusion criteria and ethical considerations are then discussed, before the design of the research is outlined. Finally, the chapter presents the strengths and limitations of the chosen research methods and processes.

Chapter Six sets the scene of this research by providing a brief overview of the Colombian armed conflict, Venezuelan crisis, disability rights in both countries, as well as the rights and experiences of people with disabilities in Ecuador. This is followed by Chapter Seven, the first of five findings chapters. Chapter Seven introduces the participants and their narratives. Although appreciative inquiry was utilised as a research methodology, given the extreme trauma many of the participants had experienced, Chapter Seven provides space for their stories to be told, in the way they wanted to tell them. This includes narratives about leaving everything behind in Colombia and Venezuela, the journey of displacement, life in Ecuador and the experience of cultural, structural and direct violence.

The next chapter, however, switches focus by investigating narratives of survival, resilience and hope. Drawing on appreciative inquiry, Chapter Eight addresses the "best of what is" by looking at what is valued about life in Ecuador. Common responses include the tranquillity and security of Ecuador, charitable and humanitarian aid and support from local populations. From my own observations, I then suggest that lived experience of disability amongst

different levels of leadership is an important aspect of promoting and protecting the rights of people affected by disability, conflict and displacement. Chapter Nine continues this conversation with discussions about what a future looks like where the rights of people with disabilities affected by conflict and displacement are being promoted and protected, as well as the participants' suggestions and advice. This includes advice for taking particular courses of action, advice against particular courses of action and recommendations on how to make decisions relating to a safer and more secure future. Finally, I reflect on the challenges of how such recommendations might be enacted.

In Chapter Ten I reflect on the key research questions. After summarising participant responses in relation to research questions one and two (pure research), I then begin to address research question three by reflecting on participant responses and my own observations (applied research). The importance of rights-based approaches within PACS research and literature is discussed, as well as the necessity of changing the discourse around the involvement of people with disabilities in positive peace research and practice, both as leaders and as participants. I then reflect on inclusive, accessible and transformative research methodologies, and the challenges and benefits of appreciative inquiry within the context of Disability Studies and PACS. Chapter Eleven is the final findings chapter that presents the applied aspects of this research by asking: where to now? The limitations and strengths of this thesis are discussed, before a twin-track approach to inclusive and accessible PACS research and practice is suggested as a practical means of actively advancing inclusive and accessible positive peace. The value of this research and its contribution to the field are explored, as well as its future implications. Chapter Twelve concludes the thesis with a summary of all the chapters.

Chapter 2 – Disability: From Charity to Rights

> "By investing in recognizing the rights of persons with disabilities, we're in fact investing in the full recognition of the concept of universality of Human Rights. When we advance the rights of persons with disabilities, we are advancing the rights of every single group in society."
>
> - Catalina Devandas (Special Rapporteur on the Rights of Persons with Disabilities, 2017)

Introduction

As outlined in the introduction, my curiosity regarding the disability narrative during conflict and displacement surfaced following a personal reflection: what if it were me? When thinking about disability, displacement and conflict together, one might assume they are life experiences that are likely to interact with, and have significant impact upon, each other. However, a preliminary review of current literature suggests that in fact, they are life experiences that have had very little collective consideration within academia.

This chapter is the first of two which will peruse key academic disciplines – primarily Disability Studies and Peace and Conflict Studies (PACS) – for relevant literature relating to disability, conflict and displacement. When it comes to research that specifically addresses these subjects together, it is expected that there will be insufficient peer-reviewed content to develop a comprehensive literature review on its own. However, it is possible to draw on other research, models and theories within PACS and Disability Studies, together with anecdotal evidence and literature from other fields, as a means of contributing to the discussion and research at hand. As such, the purpose of this literature review is to collate and assemble what might initially appear to be incoherent and unrelated puzzle pieces, into a cohesive bigger picture, from which my own research can begin to develop.

The aim of this first literature review chapter is to gain an understanding of how people with disabilities have been perceived and responded to, both throughout history as well as in the present day. This will help to inform the chapters, questions, findings and discussions that will follow. Beginning with an overview of Disability Studies and the disability rights

movement, six key models of disability are presented: the moral, charitable, medical, social, social relational and rights-based models. The marginalisation and discrimination of the disability community is then examined, specifically in reference to ableism and disablism. Finally, existing legal protections for people with disabilities affected by conflict and displacement are discussed, such as International Humanitarian Law (IHL), International Human Rights Law (IHRL) and the 2006 United Nations Convention on the Rights of Persons with Disabilities (CRPD).

The Disability Rights Movement and Disability Studies: An Overview

Disability Studies is a relatively new academic field of inquiry (Albrecht, Seelman, & Bury, 2001; Johnstone, 2001). In the same way that disability encompasses a wide range of human experiences, so too does Disability Studies, including, sociology, art, media, history, law, economics, medicine, among others (Cosier & Pearson, 2016; Linton, 1998). Its political and theoretical origins can be traced back to the late 1960s, early 1970s, and in particular, the global disability rights movement which saw people with disabilities organise in large numbers to protest institutionalisation, poverty and discrimination, while challenging society's perceptions of disability as abnormal or as a deficiency (Barnes, 2008; Goodley, 2011; Johnstone, 2001; Roulstone, Thomas, & Watson, 2012). The disability rights movement has been likened to other movements against the oppression, discrimination and marginalisation of groups such as women, ethnic minorities, and queer and gender diverse populations (Barnes, 2008; Goodley, 2011; Johnstone, 2001; Roulstone et al., 2012). Starting in the USA, the movement quickly spread to the United Kingdom (UK) and the rest of the world, as people with disabilities demanded explicit recognition of their rights, not as a matter of charity, but as an entitlement as equal members of society (Bickenbach, 2001).

One of the key outcomes of the disability rights movement's analysis and critiques of traditional and historic representations of disability was the development of Disability Studies as an academic discipline. Given that all social movements require sustained critical analysis of the social issues they seek to address, Disability Studies has been conceptualised as a bridge that links academia to the disability community (Longmore, 1995). In a broad sense, Disability Studies is a field that calls attention to matters of justice, while evaluating, analysing, interpreting and theorising about the presence, place and representation of disability within a dominant culture (Cole, 2012). As suggested by disability scholar and

activist Professor Simi Linton, Disability Studies reframes disability as a social phenomenon, social construct, metaphor, and as its own culture:

> It examines ideas related to disability in all forms of cultural representation throughout history, and examines the policies and practices of all societies to understand the social, rather than physical and psychological, determinants of the experience of disability. Disability Studies both emanated from and supports the Disability Rights Movement, which advocates for civil rights and self-determination. The focus shifts the emphasis away from a prevention/treatment/remediation paradigm, to a social/cultural/political paradigm. This shift does not signify a denial of the presence of impairments, nor a rejection of the utility of intervention and treatment. Instead, Disability Studies has been developed to disentangle impairments from the myth, ideology and stigma that influence social interaction and social policy. The scholarship challenges the idea that the economic and social status and the assigned roles of people with disabilities are inevitable outcomes of their condition. (Linton, cited in Kanter, 2011, p. 408)

As a growing field, Disability Studies draws on a range of theories and movements including Marxism, feminist postmodernism and post-structuralism (Williams, 2001), and aims to reimagine disability: "Disability studies challenges our collective representation of disability, exposing it as an exclusionary and oppressive system rather than the natural and appropriate order of things" (Garland-Thomson, 2005, p. 523).

While varying approaches to Disability Studies each place a different focus on cultural and ideological constructions of disability, they all share a common rejection of individual and medical models as foundational understandings of impairment and disability (Roulstone et al., 2012; Williams, 2001). As will be discussed further in Chapters Four and Five, Disability Studies and disability research considers the person with the disability as the decision maker, as determining their own agenda, and at the centre of any research encounter (Goodley, 2011; Johnstone, 2001). At the heart of disability research is the disability rights movement slogan, "nothing about us, without us".

Models of Disability

Throughout history, impairment and disability has been documented and discussed within all cultures and societies. Social responses, however, have varied as different meanings have emerged out of specific social and cultural contexts. As a result, there is not one single universally accepted definition of disability (Barnes, Mercer, & Shakespeare, 1999; Oliver, 2009). Most literature within Disability Studies begins by deciphering common meanings, understandings and perceptions of disability using "heuristic devices" (Barnes, 2008, p. 4). Commonly referred to as the models of disability, each heuristic device represents a particular type of theory that seeks to explain phenomena through abstract systems and mechanisms.

Models are not synonymous with theory, nor are they explanations in themselves. They do, however, exist to help generate explanations (Llewellyn & Hogan, 2000). Models can be indicative of underlying structures for large and complex diagnostic and defining systems with significant political, social and financial consequences (Smart, 2009). Traditionally, models have been used to define disability, determine causal and responsibility attributions, guide legislation, develop research, inform welfare systems, provide frameworks for professional and clinical practice, as well as for administrative and social planning (Smart, 2009). Within this thesis, key models of disability are discussed in specific reference to important and symbolic shifts in thinking about disability; shifts that will inform the epistemological and ontological understandings of disability inclusion within PACS. I believe it is crucial for any research that is inclusive of people with disabilities to consider the way in which disability is understood, perceived and responded to within the research context. As such, like other Disability Studies researchers and scholars, I am opting to begin this first literature review chapter with a brief overview of six of the most prominent models of disability. This is not only a necessary aspect of exploring relevant literature, but also a means of forming an abstract system of understanding that will inform the research process, findings, analysis and discussions presented in this thesis.

Individual models of disability: The moral and charity models

The academic study and explanation of "disability as difference" is not a new phenomenon (Johnstone, 2001, p. 5). Prior to the 1990s it was common for disability to be discussed within medical, psychological, sociological and anthropological disciplines (Barnes, 2008; Johnstone, 2001) and it was conceptualised as a deviant individual experience within a dominant culture (Johnstone, 2001). Such understandings are what Oliver (1990b) has referred to as individual models of disability. Individual models locate the "problem" of disability within the individual, while explaining the cause of the problem as stemming from functional limitations (Oliver, 1990a).

The moral model of disability is perhaps the oldest and most entrenched. Within this model, disability is considered through a theological lens; that is, as a manifestation of sin or of God's dis/favour, karma, a test, challenge or an abnormality in nature's harmony (Bhanushali, 2007; Mackelprang, 2014; Olkin, 1999). Impairment is thought of as a moral relapse or divine retribution, bringing shame on the concerned individual as well as their family (Olkin, 1999, 2012). As a result, the individual is often hidden from mainstream society and denied their most basic needs and rights (Bhanushali, 2007). Extreme application of the model occurs

when impairment is attributed to transgressions not only of the person with the impairment or their family, but as a consequence of the transgressions of past ancestors (Henderson & Bryan, 2011). The moral model is one of the oldest, yet most persistent, understandings of disability; a model that influences culture, language and ideology even in the present day (Henderson & Bryan, 2011; Kaplan, 1999; Olkin, 2012).

Closely linked to the moral model of disability is the charity model, which is largely driven by compassion and the desire to help people with disabilities through emotive appeals of charity (Bhanushali, 2007). Within this model, disability is considered a tragedy or misfortune that must be alleviated or erased by the generosity of people without disabilities (Clare, 2001). Individuals with disabilities are considered to be "destitute creatures" in need of assistance or "helpless victims" of diseases who would benefit from medical intervention (Davis, 2013, p. 264). While historically this approach has resulted in the provision of much needed resources, services and money for people with disabilities, it has also cultivated feelings of sympathy and the unintended by-product of the devaluation of life (Henderson & Bryan, 2011).

<div align="center">Individual models of disability: The medical model of disability</div>

With the modern era many cultures of superstition and morality were replaced with cultures of reason (Hughes, 2012a). The medical model is one of the most common models of disability that considers impairment as pathological in nature. That is, disability is considered an abnormality in function, a disorder, dysfunction, defect or deformity located within the human anatomy, which is attributed to either inadequate health practices or to bad genes (Barnes & Mercer, 2003, 2010; Bickenbach, 1993; Goodley, 2011; Oliver, 1990b; Silvers, Wasserman, & Mahowald, 1998). Within this model, the medical profession's responsibility is seen as central, while the impairment or disability itself is an objective and standardised entity that can be classified, quantified, measured and managed through medical prevention, cures and rehabilitation (Smart, 2009; Watermeyer, 2013). Within the reviewed Disability Studies literature there are many anecdotes relating to the medical model of disability and the impact it has had on the sense of value and identity of people affected by disability. My own experiences include playing with toys as a child while a handful of medical professionals in white coats observed, poked, prodded, took notes on their clipboards and debated the medical mystery of my condition. Another example is the three-monthly self-funded medical appointments I was required to attend so that a specialist could certify that my legs had not grown back, simply in order to receive state-funded welfare. While these are just two examples of times where my own quality of life depended on the expertise of the medical

profession, as a student of PACS however, I have been even more astounded by one of the most extreme manifestations of the individualised medical model of disability. Increasing in popularity during the 1800s and early 1900s, the re-emergence of eugenics has been linked to medical practices that continue to impact the disability community, even today (Johnstone, 2001).

Eugenics - Life unworthy of life

The term "eugenics" was originally coined by Francis Galton in 1883 to describe "the study of agencies under social control that may improve or impair the racial qualities of future generations either physically or mentally" (Galton, 1908, cited in Mathúna, 2006, p. 5). Eugenics theory was greatly influenced by popular texts and research of the time, including Charles Darwin's *Origin of Species* and his theory of natural selection, August Weismann's theories of germ plasm and regression in nature and Gregor Mendel's laws of inheritance (Fangerau, 2009; Watermeyer, 2013). Galton believed that desirable human qualities were hereditary and that those with undesirable human qualities were a threat to social progress and the probable cause of most criminal activity and social problems (Gopalan, 2016). As such, eugenics aimed to improve the human species over time, by eradicating undesirable traits such as disability, disease, as well as other so-called inherited defects like poverty, prostitution and alcoholism (Wilson & Pierre, 2016). The solution was to ensure that those with socially good genes and desired characteristics bred in greater numbers (positive eugenics), while diminishing the numbers of those with bad genes or undesirable characteristics (negative eugenics). This was achieved through means such as sterilisation and by discontinuing humane care for such people in order to stop the bad genes from being passed on and enfeebling the human race (Fangerau, 2009; Hume, 1996; Kevles, 1999).

While the origins of the eugenics movement were not based in Nazi doctrine, the socio-political climate of 1930s Germany, together with the growing popularity of Western eugenics, gave rise to Adolf Hitler's personal interest in the subject. This lead to eugenics becoming an integral component of the Nazi party's race hygiene scheme (Hume, 1996). At the core of race hygiene was the conception of *Lebensunwertes Leben*, literally translated as "life unworthy of life". As soon as the Nazi Party assumed power, one of Hitler's first acts of legislation was to pass the *Law for the Prevention of Hereditarily Diseased Offspring*. Symbolic of the Nazi's commitment to eugenic principles, the Law embodied negative eugenics by authorising the compulsory sterilisation of any unfit citizen living with undesirable defects or *lebensunwertes leben* (Carney, 2005; MacKellar & Bechtel, 2016).

At the outbreak of World War II (1939), the Nazi government intensified race hygiene efforts by permitting the eradication of people with disabilities from the Reich. Known as T4 (Tiergartenstrasse 4, Berlin), the program was neither a law nor a ministerial decree, but a personal order signed by Adolf Hitler instructing physicians to carry out mercy killings on patients who were assessed as incurably sick. This included psychiatric and neurological diseases, as well as age-related conditions (MacKellar & Bechtel, 2016; Meyer, 1988). As summarised by Johnstone (2001, p. 88):

> The Nazi euthanasia programme attempted to justify the elimination of disabled people on the grounds that they made no contribution to society and were a drain on resources; they were perceived as 'useless eaters' of resources without capital to contribute to the human lot.

It is estimated that under these laws more than 200,000 people with disabilities and other undesirable conditions were euthanized (Barnes & Mercer, 2003; Oliver, 2009). The T4 methods of mercy killings, installed and perfected in psychiatric institutions, subsequently became the chosen method of assembly-line killing apparatus used in Nazi concentration camps (Brandt, Bouhler, Brack, Conti, & Crawford, 2015; Meyer, 1988).

Though the T4 programme caused eugenics theorists around the world to rethink the elimination of disability through euthanasia, the "democratic" or "voluntary" sterilization of people with disabilities remained a common practice well into the 1970s, for example, in Nordic countries and in the USA (Barnes & Mercer, 2010; Rimmerman, 2017; Tilley, Walmsley, Earle, & Atkinson, 2012). As recently as 1995, China enacted a law forbidding the marriage of couples carrying genetic or infectious diseases unless they first agree to sterilisation (Hough, 2013). Furthermore, disability rights advocates and scholars have linked eugenics theories to euthanasia, the New Genetics movement, pre-natal screening and the termination of foetuses with disabilities (Barnes & Mercer, 2003, 2010; Shakespeare, 1998). For example, research from Iceland reveals a 100% termination rate of foetuses diagnosed with Down's Syndrome (Maclean, 2017). I have briefly touched on eugenics and related issues in order to demonstrate the real and life-altering impact that abstract systems of understandings have had, and continue to have, on people with disabilities. Although the eugenics movement of Nazi Germany occurred almost a century ago, it remains very much relevant to the present-day perceptions of disability and the discussion at hand. As summarised by Peter Singer, an avid supporter of euthanasia and one of the most influential living philosophers of our time, "Nevertheless the main point is clear: killing a disabled infant

is not morally equivalent to killing a person. Very often it is not wrong at all" (Singer, 2011, p. 167).

While the strength of the medical model lies in its diagnosis and definitional system, and its ability to help wider audiences understand impairment objectively (Smart, 2009), it has been widely criticised for being used without proper scrutiny and for portraying disability in a biased manner that attributes deficits to bad luck, inadequate health practices or to genes, leading to oppressive practices and social arrangements (Kristiansen, Vehmas, & Shakespeare, 2009). The medical model inherently ignores social and environmental aspects of disability by treating individuals who receive shared diagnoses with standardised treatment plans regardless of their individual needs, resources or assets. That is, it is a "diagnosis-driven" approach rather than an "individual-focused" approach (Smart, 2009, p. 4).

Social model of disability

In the mid-1970s, amidst the growing global disability rights movement, activists and their organisations became increasingly vocal in their dismissal of the individualised medical model of disability (Barnes & Mercer, 2010). In 1976, the UK-based organisation, the Union of the Physically Impaired Against Segregation (UPIAS), publicly articulated their rejection of the medical model within their organisation's manifesto, stating:

> In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. (UPIAS, 1975, cited in Shakespeare, 2013, p. 215)

The distinction that the UPIAS made between "impairment" and "disability" resonated with activists around the world and enabled the construction of a new way of thinking about disability (Barnes & Mercer, 2003). Originally coined in 1983 by Mike Oliver (Oliver, 2013), who shared the Marxist leanings of UPIAS pioneers, Vic Finkelstein and Paul Hunt (Thomas, 2004a), the social model of disability developed in the UK in response to dominant individual and medical ways of thinking about impairment. In particular, it addressed disability in terms of social oppression, cultural discourse, and economic and environmental barriers (Shakespeare, 2013).

The social model of disability draws on three key dichotomies that distinguish it from the medical model. The first distinction is between impairment (physical limitation) and disability (social exclusion). While the medical model seeks to remedy or fix impairment, the social

model seeks to accept impairment and remove disabling barriers within society (Shakespeare, 2013; Watermeyer, 2013). The second key feature is that the social model is distinguished from individualised and medicalised models. Within the social model, disability is understood as a social creation, while the medical model defines disability as a deficit (Shakespeare, 2013). Instead of the emphasis being on the impairment itself, the social model addresses the social conditions that cause disability and the denial of basic civil rights (Olkin, 1999). The third key tenet is the distinct difference between people with and without disabilities and the assumption that people with disabilities are an oppressed group. As such, civil rights, rather than charity, is the solution to oppression. As discussed in the charity model of disability, it is often people without disabilities, professionals, experts and charitable organisations who inadvertently maintain and uphold oppression through charity and pity, resulting in the devaluation of life (Henderson & Bryan, 2011; Shakespeare, 2013):

> The social model demonstrates that the problems disabled people face are the result of social oppression and exclusion, not their individual deficits. This places the moral responsibility on society to remove burdens which have been imposed, and to enable disabled people to participate. […] It is not the disabled person who is to blame, but society. She does not have to change, society does. Rather than feeling self-pity, she can feel anger and pride. (Shakespeare, 2013, p. 217)

Within the social model, the empowerment of people with disabilities can be achieved by utilising methods such as Universal Design (Ortoleva, 2010) which refers to ensuring that everything is accessible to, understood by and used to the greatest extent possible by everyone, without adaptation or requiring little adaptation. While Universal Design is often referred to in relation to the built environment, it also applies to services, supports, the curriculum and technologies as well (Office for Disability Issues, 2016). Other practical interventions include education, laws and their implementation, economic equity and increased physical and social accessibility (Olkin, 1999).

Critiques of the social model

While the social model has revolutionised the way impairment and disability are perceived in many societies, it is not without critique, its simplicity being its most fatal flaw (Shakespeare, 2013). The original concept proposed by UPIAS was quickly shortened to "disability = social barriers" – a sound bite that was easily grasped, identified and used to challenge dominant individualised and medicalised models of disability (Thomas, 2004a, p. 24). However, as has been debated by scholars, particularly feminist writers, the social model has been critiqued for not allowing room to acknowledge that impairment and illness can restrict and limit one's involvement in activities and other life experiences (Crow, 1996; French, 1993; Morris, 1996; Thomas, 2004a): "[…] there is a tendency within the social model of disability to deny the

experience of our own bodies, insisting that our physical differences and restrictions are *entirely* socially created" (Morris, 1991, p. 10). As Shakespeare (2014) highlights, while we want to strive towards ensuring all people can experience the world in an equal way, there are some things that will never be experienced in their fullest by all people at all times: "People are disabled both by social barriers and by their bodies. This is straightforward and uncontroversial. The British social model approach, because it 'over-eggs the pudding', risks discrediting the entire dish" (Shakespeare & Watson, 2001, p. 17). The social model has also been criticised for its authorship, namely, a small group of select activists who are European, heterosexual men, with spinal injuries; for neglecting the importance of individual experiences of impairment; for rejecting medical prevention, rehabilitation and cures; for assuming people with disabilities are oppressed; for oversimplifying the impact of disability and social barriers; and for the lack of practical considerations of creating a barrier-free utopia (Shakespeare, 2013, 2014).

Social relational model of disability

Inspired by the core principles of the UPIAS' approach to disability, the social relational model of disability moves away from dialogue on impairment and disability as distinctly separate entities, and towards discussions of power. Within the social relational model, disability is defined as "[…] a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially endangered undermining of their psycho-emotional well-being" (Thomas, 1999, p. 156). As such, disability is caused when people with impairments are restricted by society from participating in activities and the effect that has on the sense of self, identity, self-esteem, and existential security (Thomas, 2004a). Impairment effects, on the other hand, refer to the restriction of activity that arise directly from impairment. For many people, the lived experience of disability is therefore the interaction between, and the accumulative impact of, disability (or disablism, which is discussed later in this chapter) and impairment effects (Thomas, 1999). As summarised by Reindal (2010, p. 130), "[…] within a social relational view on disability, the impairment effect is not equivalent to the *state of being disabled*. Disability is something *imposed on top* of the impairment effect, due to ideological, social and environmental circumstances". In this way, disability is both about barriers to doing, as well as barriers to being (Thomas, 1999).

For example, as a young person I travelled to Paris, France, with friends on a vacation. When we arrived at the iconic Eiffel Tower, hordes of people were waiting in lines for over an hour to ascend the tower, so we asked the staff if there was mobility access. The staff obliged,

permitting me to skip the queues and use the elevator to ride to the first floor of the Tower. After reaching the first floor I then decided it would be nice to also go up to the top floor for a better view. However, when I went to pay for the ticket, the staff member informed me this would not be possible because of my disability; as I could not stand in the queue at the bottom, she could not allow me to go up to the top, because I was a health and safety risk. In the case of an emergency, I would be required to descend stairs rapidly and she insisted this was beyond my capacity. I protested, of course, highlighting that even though standing in queues would fatigue me for the rest of the day, descending stairs is an activity I find easy. I even offered to demonstrate my stair-descending-skills, but to no avail. "No, I cannot permit you to go up because you are disabled," she repeated. Feeling deflated and suddenly very aware of my imperfections, I could not help but feel bitter as the staff member went on to sell tickets to an elderly couple, a heavily pregnant woman and a family with three children under the age of five. While, upon reflection, this anecdote appears trivial and even comical, it shows a clear difference between impairment effects (inability to stand for long periods of time due to pain, discomfort and fatigue) and disability (restrictions imposed by the Eiffel Tower staff member), as well as the impact of having my psycho-emotional well-being undermined (a sense of inferiority leading to tears; a nice day out with friends marred by marginalisation).

The social relational model is also important as it situates the experience of disability alongside works aimed at understanding oppressive social relations of gender, race, sexuality, class, age, religious and other identities that are marginalised within dominant cultures or contexts (Thomas, 2004a). Key theoretical questions of the social relational perspective relate to power, which will become increasingly important throughout this thesis, particularly as PACS literature is introduced and rights-based approaches to research and practice are discussed.

Rights-based model of disability

Another extension of the social model is the rights-based model of disability, which emerged from Western Europe and the USA during the late 1950s and early 1960s (Johnstone, 2001). Though similar to the social model, the rights-based model (also known as the human rights model) is considered to be more comprehensive, in that it encompasses both sets of human rights, civil and political as well as economic, social and cultural rights (Degener, 2016). Drawing parallels from other movements that have challenged unequal treatment and opportunity for certain sectors of society (for example, women, queer and gender diverse

populations, civil rights, and so on), the rights-based model sees equity and rights as inclusive of all people, and that human rights are universal, inherent and inalienable (Al Ju'beh, 2017).

The rights-based model is grounded in equal opportunity theory, which examines the right to self-determination and society's collective responsibility for ensuring fair prospects of self-determination for all people (Mithaug, 1996). Some individuals and groups of people experience unfair advantages in life for reasons beyond their control. Consequently, society has a collective obligation to improve the prospects of self-determination for individuals and groups who do not have said advantages and who are less well-situated (Mithaug, 1996). In the context of disability, people with disabilities are considered central decision makers, citizens and as rights holders, while seeking to transform unjust systems and practices (Al Ju'beh, 2017). This includes:

- Recognising the existence of structural discrimination against people with disabilities in society;
- Acknowledging the collective strength of people;
- Supporting people with disabilities to determine their own agenda;
- Recognising legislation as a basis for establishing the visibility of the democratically enforceable rights of people with disability;
- Bringing legal sanction against disability discrimination (Johnstone, 2001).

The rights-based model holds that equal opportunity is not a question of charity to be bestowed on marginalised populations, but a human right. The model is based on empowerment (referring to the participation of people with disabilities as active stakeholders) and accountability (the duty of society to implement rights and to justify the quality and quantity of their implementation) (Miller & Ziegler, 2006). Importantly, the rights-based model goes hand-in-hand with one of the most significant developments of the disability rights movement, the 2006 United Nations Convention on the Rights of Persons with Disabilities (CRPD), which will be discussed later in this chapter.

Critiques of the rights-based model of disability are mostly centred around the CRPD, in that it does not extend far enough to include all the rights that it should. For example, the CRPD does not articulate the right to religious freedom, nor does it address the right of an in utero child with a disability to be free from discriminatory treatment (Silecchia, 2013). The CRPD has also been critiqued for the challenges of its implementation, and the disconnect between rights and the every day experiences of people with disabilities (Hoffman, Sritharan and

Tejpar, 2016). A broader review of human rights literature also highlights the hegemonic and Westernised nature of human rights discourse. For example, in 1997 Professor Chris Brown (1997) argued that the Western human rights discourse can be particularly problematic when imposed upon non-Western societies. His critique raised important questions about human rights activism, the philosophy of liberal universalism, and even the very nature of universal human rights (Brown, 1997).

Historical Roots of Marginalisation and Discrimination

The development of the social, social relational and rights-based models of disability are symbolic of a fundamental shift in the way disability has been thought about and responded to over time. However, although these milestones and developments indicate significant advancements towards realising the rights of people with disabilities, research continues to show that globally people affected by disability face higher instances of marginalisation and discrimination than people without disabilities (WHO, 2011). In the context of disability rights, marginalisation refers to the systemic removal of people with disabilities from the mainstream of everyday life, and is one of the most dangerous forms of disability oppression when considering the history of eugenics, institutionalisation, segregated education systems, and so on. (Barnes & Mercer, 2010). Discrimination, on the other hand, refers to:

> […] any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. (CRPD Article 2, United Nations, 2006a)

To cite research that is indicative of marginalisation and discrimination, studies shows that globally people with disabilities have significantly lower levels of education (United Nations Educational Scientific and Cultural Organization, 2017; Walker, Pearce, Abuel-Ealeh, & Mowé, 2013); experience higher rates of unemployment and lower earnings (Barnes & Mercer, 2003; International Labour Organization, 2007; Schriner, 2001; StatsNZ, 2017); are more likely to become victims of sexual or physical violence; and are less likely to obtain police intervention, legal protection, preventive care or access to justice than people without disabilities (Goodley, 2011; Larson, 2014; Rioux, Crawford, Ticoll, & Bach, 1997; Sobsey & Doe, 1991; Westcott & Jones, 1999). Even though disability has existed throughout all of history, the exclusion of people with disabilities from mainstream activities is believed to be a social creation (Oliver, 1990b, 2009). More specifically, Disability Studies scholars agree that from a Marxist historical materialist point of view, disability exclusion is primarily a product

of Western industrialisation and capitalism (Oliver, 2009; Thomas, 2004b). According to Victor Finkelstein (1980), this can be characterised by three key economic-technological phases in history: the pre-industrial feudal society, industrial capitalism, and post-industrial society.

In feudal and medieval times (approximately the fifth century to the fifteenth century) when activity was agrarian, support for the poor, unwell or those affected by disability was generally provided by the family, community and religious institutions (Taylor, 1981). Disability was commonplace, simply an accepted element of peasant life (Gleeson, 1999). Feudal relations were based on subsistence rather than wealth and accumulation, and while people with disabilities generally occupied lower ranks of society, they were expected to participate in the economic life of the community. Other factors influencing the social response to disability and sickness included less need for reliance on community supports for shorter periods of time due to the high mortality rates and shorter life expectancies (Barnes & Mercer, 2003). During this phase, it is believed that although people with disabilities were regarded as individually unfortunate, they were accommodated, rather than segregated (Oliver, 1990b; Rimmerman, 2013). While there is no doubt that life was difficult for people with disabilities during pre-industrial feudal times, Disability Studies scholars have used this phase as a basis to which the next phase, industrial capitalism, can be compared.

The second phase relates to industrial capitalism in nineteenth-century Europe and North America. During this period, people were no longer tied to the land as they had been during feudal times and as production became industrialised, so too did the need for the human body to operate as machines do (Russell & Malhotra, 2009). The rapid spread of the free market economy, wage labour and the implementation of mechanised systems of production meant that "unproductive" employees, such as people with disabilities, were left behind (Barnes & Mercer, 2003; Finkelstein, 1980; Oliver, 1990b). As such, anyone who deviated from physical and cognitive socially defined norms found themselves dependent on the rest of the population or outcast. As summarised by Thomas (2004b, p. 35):

> The profound economic, political and cultural changes brought about by the transition from feudalism to capitalism in the West, and particularly from mercantile to industrial capitalism, offered fertile ground for thinking about the creation of classes of people, including 'the feebleminded', 'cripples', 'invalids', deemed redundant and dependent on the grounds of their incapacity to present themselves as wage labourers.

During this period of history, the social and economic exclusion of people with disabilities pervaded education, religion, law and even became a popular topic for Victorian writers. For

example, Charles Dickens infamously depicted children with disabilities as innocent victims, adults with disabilities as corrupt victimisers whose deformities were outward manifestations of inner depravity, and injuries resulting in disability as punishments for character moral failings (Wainapel, 1996). Further isolation was also caused by the development of inaccessible industrialised towns and cities (Barnes & Mercer, 2003). Consequently, people with disabilities were segregated into workhouses, asylums, colonies, sanatoriums, special schools and other places away from mainstream communities (Braddock & Parish, 2001; Oliver, 1990b).

As discussed in the models of disability, with the age of modernity (fifteenth century onwards) came yet another shift in the Western way of thinking about disability. As capitalism grew, so too did the social and economic exclusion of people with impairments from mainstream society and as a consequence, "disability" was created as an individual problem requiring medical intervention (Oliver, 2009). However, another important by-product of industrial capitalism was the application and imposition of the industrial concept of disability on the rest of the world, with very little regard to indigenous histories, cultures, traditions, circumstances or preferences:

> […] the social origins of impairment and disability bear the clear imprint of Western-style economic, technological and cultural development. Although there may be significant differences in emphasis, there is general agreement that industrialization, urbanization, liberal utilitarianism and medicalization, along with cultural understandings of 'able-bodied normalcy', particularly as disseminated through Western media, have influenced the social construction of disability. This led to the systemic exclusion of disabled people from the mainstream of everyday life. These forces are now being exported more quickly than ever throughout the world. The end result is that the disabling tendencies generally associated with minority world economic and cultural development are being replicated throughout the majority world. (Barnes & Mercer, 2003, pp. 141-142)

Take, for example, the arrival of logging companies in Sarawak, Malaysia, where industrial capitalism and Western capitalist social relations have been imposed onto traditional cultures, undermining traditional cosmology and socio-economic arrangements (Barnes et al., 1999). As young men in the community were tasked with wage labour, traditional economies became significantly restricted and identities redefined. As a result, people with disabilities and older people suffered a diminution in status, leading to an increased dependency on the wider community for support. Similarly, in Masai communities mutual aid and cooperation was traditionally encouraged, meaning that disability was not necessarily a barrier to inclusion. However, with the rise of Western capitalist social relations, single family households have increased, and thus threatened, the social perception of disability and dependency. As

summarised by Barnes, Mercer and Shakespeare, "The interdependence of cultural and material factors is graphically illustrated – with outcomes that transform the link between impairment and disability" (1999, p. 15).

Ableism and disablism

Despite the disability rights movement, people with disabilities continue to report being treated as second-class citizens (Isaac, 2016). A recent line of scholarship situates the continued social and economic marginalisation and discrimination of people with disabilities within the theoretical framework of ableism, which can be defined as "[…] a network of beliefs, processes and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human" (Campbell, 2001, p. 44). Historically, ableism has been used to justify the elevated rights and status of one group over another and is an umbrella term for other "isms" such as racism, sexism, casteism, ageism, and so on. For example, women were historically viewed as biologically fragile and emotional and therefore incapable of bearing responsibility for owning property or voting (Wolbring, 2008). While ableism refers to the preferential treatment of people with certain abilities, such as productivity and competitiveness, those who deviate from these standards are considered as being in a "diminished state of being human" (Campbell, 2001, p. 44).

Within the context of disability, the contraposition of ableism is disablism, which Miller, Parker, and Gillinson (2004, p. 9) define as "Discriminatory, oppressive or abusive behaviour arising from the belief that disabled people are inferior to others". Like other "isms", disablism can be expressed in either "blatant" or "subtle" ways (Meertens & Pettigrew, 1997, p. 54). An example of blatant disablism might be an employer who refuses to employ a person with a disability. However, not all forms of marginalisation or discriminatory behaviour are so blatant or easily identified (Deal, 2007). To demonstrate this, Deal (2007) draws on Gaertner and Dovidio's (2014) research on aversive racism, which addresses the psychology behind, and impact of, subtle forms of unintentional prejudices. In the context of race relations in the USA, specifically European American orientation towards African Americans, Gaertner and Dovidio (2014) argue that aversive racists are not necessarily blatant in their racism towards African Americans, but are instead "pro-white": "The negative feelings that aversive racists have for Blacks do not reflect upon hostility or hate. Instead, their reactions involve discomfort, uneasiness, disgust, and sometimes fear" (p. 14). It might be noted that

these are also emotional responses that have long been associated with impairment and disability (Hughes, 2012b).

Rights and Protection

This chapter has thus far outlined basic concepts relating to the experience of disability, the disability rights movement and Disability Studies. These models are beginning to form the basis of a framework which will be used to contextualise and review the PACS literature in the next chapter. While there is a vast range of Disability Studies research that could be explored in much greater depth, the purpose of this thesis is to bring together the experience of disability (as documented within Disability Studies) with the experience of conflict and displacement (as documented within PACS). That is, it brings together two experiences and areas of research that currently have very little academic crossover, but as these literature review chapters will show, are inherently linked. As such, the last section of this chapter begins the process of bridging the divide between the two fields by introducing conflict-related literature to the present discussions on disability. This will be achieved by reviewing literature on the various tools and instruments that promote and uphold the rights, freedom and dignity of people with disabilities affected by conflict and displacement.

International Humanitarian Law (IHL)

There are good reasons to dedicate attention to the rights of people with disabilities affected by conflict and displacement. As summarised by Reilly (2008, p. 6):

> In all wars and disasters, it is persons with disabilities that are first to die; persons with disabilities that are the first to get disease and infection; and it is persons with disabilities who are the last to get resources and medicines when they are handed out. They are treated as the bottom of the pile.

As such, not only does conflict and displacement cause disability, but it also exacerbates existing challenges and barriers experienced by people who are already living with disability (Crock, Hart, & McCallum, 2015; Crock, Smith-Khan, McCallum, & Saul, 2017). Curious to find out what legal protections are in place to protect the rights of people with disabilities during conflict and displacement, I was encouraged to find that International Humanitarian Law (IHL) has long recognised that groups with "special needs" , such as women, elderly and children, merit special protection in times of conflict. According to the official custodians of IHL, the International Committee of the Red Cross (ICRC), these protections also extend to the respect and protection of "the disabled and infirm". Of most relevance to this thesis is the Fourth Geneva Convention adopted in 1949, which gives protection to civilians during

hostilities and to those in occupied territories. Under Article 16, people with disabilities are amongst those who warrant special protection and respect (Crock et al., 2015). Though the English text of the Convention makes no mention of "cripples" (*les infirmes*), in 1958 an ICRC Authoritative Commentary confirmed that people with disabilities are in fact referred to in the French text and that both versions are equally authentic:

> The obligation to protect and respect the wounded and sick, the infirm and expectant mothers is general and absolute in character. It applies to all parties to the conflict, to all members of armed forces combatant or non-combatant, as well as persons who are placed in the same category by Article 4 of the Third Geneva Convention. (Pictet, Uhler, Siordet, Boppe, Coursier, Pilloud, Wilhelm, & Schoenholzer, 1958, p. 134)

The ICRC commentary also clarifies that the term "respect" in this article means "to spare, not to attack", while "protection" means "to come to someone's defence, to give help and support":

> These words make it unlawful to kill, ill-treat or in any way injure an unarmed enemy, while at the same time they impose an obligation to come to his aid and give him any care of which he stands in need. These rules are even more essential when the wounded or sick person is a civilian, i.e. a person who, by definition, takes no part in the hostilities. (Pictet et al., 1958, p. 134)

IHL and the Geneva Conventions (1949), however, were historically geared towards regulating conflict between State actors. Given that interstate armed conflicts are becoming increasingly rare (Buhaug, Gates, Hegre, & Strand, 2007), I wondered if the Geneva Conventions remain applicable in 2018 intrastate and civil conflicts, and what obligations non-State actors have towards those who warrant "special" protection and respect, such as the disability community. A brief review of the literature revealed that IHL does not necessarily apply to all instances of violence, but only to international interstate conflicts and non-international armed conflicts that satisfy organisation requirements (for example, command structures, military capacity, logistical capacity, internal disciplinary system, communications systems, and so on) and reach a certain level of intensity (Bartels, 2012). For example, riots, isolated acts of violence, protests and single acts of terrorism do not constitute armed conflict under IHL (Global Justice Center, 2012). While Article 3 (common to the four Geneva Conventions), the 1977 Second Additional Protocol to the Geneva Conventions (when ratified by States), and norms of customary law are applicable in non-international armed conflicts, holding non-State actors accountable to these articles, protocols and customs very much remains a grey area (Mack, 2003). Furthermore, as highlighted by Crock et al. (2017), traditional legal systems such as the Geneva Conventions very much fall into the category of paternalistic and charitable perceptions of disability, which were discussed in this chapter's

presentation of the charity model of disability. In summary, while IHL and the Geneva Conventions provide some safeguards for the disability community, literature suggests that applying these safeguards in non-international, intrastate conflicts, while attempting to uphold the ethos of the social relational and rights perspectives of disability, is a complex legal matter that requires specialised analysis beyond the scope of this thesis.

<div align="center">The United Nations Convention on the Rights of Persons with Disabilities</div>

A second key document that outlines the protection of people with disabilities during conflict and displacement is the 2006 United Nations Convention on the Rights of Persons with Disabilities (CRPD). The United Nations (UN) has always played a key role in articulating and promoting the rights and dignity of people with disabilities. However, its most historic commitment occurred in 2001 when the General Assembly of the UN set up an Ad-Hoc Committee to consider proposals for a comprehensive and integral international convention to promote and protect the rights and dignity of people with disabilities. By 2003, the Ad-Hoc Committee had established a Working Group composed of government and non-governmental organisation (NGO) representatives who successfully developed and submitted a draft convention for consideration. After further negotiations, the final Convention was agreed upon and adopted by the General Assembly in December 2006 (Hendriks, 2007). As lauded by former United Nations Secretary-General Kofi Annan, the CRPD was the first and most quickly negotiated human rights treaty of the 21st century (United Nations, 2006b).

The CRPD is an international human rights treaty that promotes, protects and ensures the rights of people with disabilities so that they may have full equality under international law (United Nations, 2006a). Building on several existing UN Treaties and Conventions, such as the Universal Declaration of Human Rights, the CRPD is the first and only international agreement to explicitly stipulate the rights of people with disabilities in international law (Phillips, Estey, & Ennis, 2010). To become party to this Convention, a government must first sign the CRPD, signifying it agrees in principle. Next, the government ratifies the Convention, indicating that it intends to undertake the legal rights and obligations contained in the CRPD. A further Optional Protocol allows individuals to bring petitions to the CRPD Committee, as well as giving the Committee the authority to investigate serious violations of the Convention (United Nations, 2006a). Within the CRPD, Article 11 specifically addresses the States Parties' obligations to people with disabilities during situations of risk and humanitarian emergencies. Though the article does not outline what measures should be taken, it does reference the need for States Parties to ensure that they comply with their

international human rights and international humanitarian law obligations, from recovery, to rebuilding and resettlement (Phillips et al., 2010):

> States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters. (United Nations, 2006a)

At the time of writing this thesis (2018), there were 161 signatories and 177 ratifications to the CRPD, as well as ninety-two signatories and ratifications to its Optional Protocol (United Nations, 2018). However, while the CRPD and other international and domestic human rights instruments and laws represent a major shift in thinking towards disability and impairment (Kayess & French, 2008), the literature reviewed in this chapter suggests there is still much room for improvement when it comes to its implementation. For many countries, human rights laws such as the CRPD represent little more than a paper victory (Perlin, 2012, 2014). That is, a statute that is signed and looks good on paper but fails to be implemented in real life.

In their recently published book, *The Legal Protection of Refugees with Disabilities: Forgotten and Invisible*, Crock et al. (2017) inquire as to whether the CRPD applies to refugees with disabilities. Given that the CRPD was developed without any real consideration given to refugees and displaced persons, some have argued that the rights laid out in the Convention are only applicable to citizens of a country. Crock and colleagues, however, clarify that from a legal perspective, the CRPD and particularly Article 11, must be upheld by state signatories and applied to all people at all times:

> However difficult the circumstances of a host country may be, the CRPD is an instrument that applies to every person on the territory of the state party. This includes refugees and other non-citizens. The human rights enshrined in the Convention apply to all persons regardless of their status in a country. No provision in the CRPD excludes non-citizens from its protections. Nor is there a clause allowing states to derogate from the Convention in emergency situations. As noted earlier, Article 11 of the CRPD *expressly* obliges state parties to assume protection obligations in the context of natural disasters and armed conflicts. (Crock et al., 2017, pp. 26-27)

When all factors are considered – the sheer size of the global population of the disability community, the marginalisation and discrimination experienced, together with the established humanitarian and legal frameworks outlining their protection during conflict and emergency – the questions that remain at the centre of this literature review and research are: what are the

experiences of people with disabilities during conflict and displacement and what role does their narrative play within PACS?

On a final note, it is important to also acknowledge the range of legal and human rights instruments that contribute valuable frameworks relating to the protection of all people during conflict and displacement. For example, these include the 1989 United Nations Convention on the Rights of the Child (CRC), the United Nations Convention relating to the Status of Refugees (also known as the 1951 Refugee Convention), as well as regional and country specific laws, agreements and treaties. Given the word limit of this thesis, these will not be discussed in depth, but are acknowledged as important human rights instruments relating to the subject of this thesis.

Summary

This chapter is the first of two, reviewing relevant literature relating to disability, conflict and displacement. It began with a brief overview of the disability rights movement and the consequential emergence of Disability Studies as an academic field of inquiry. Six key models of disability were then presented and discussed, demonstrating a shift in thinking that has taken place between traditional, individualised and medicalised models of disability, to the social, social relational and rights-based models of disability. Next, the continued marginalisation and discrimination of people with disabilities was contextualised within the frameworks of ableism and disablism, before conflict-related literature was introduced by means of key human rights instruments that directly address the rights of people affected by disability, conflict and displacement.

As highlighted in the introduction of this chapter, the purpose of this literature review is to collate relevant research from within Disability Studies, PACS, as well as from other disciplines, which can help establish a foundation from which my own research can develop. This chapter has started this review process by presenting and discussing key disability models and concepts, which will now become the lens through which the content of the next chapter is analysed. The next chapter, Chapter Three, continues by introducing important PACS literature and theories, alongside anecdotal evidence from the field. In doing so, a theoretical understanding of factors impacting the intersectionality of disability, conflict and displacement is formed, before my own key research questions are presented.

Chapter 3 – Peace and Conflict Studies: An Ableist Discipline?

> "Sustainable peace requires the inclusion of all groups affected by conflict at all stages in the peace-building process."
>
> - Stephanie Ortoleva (Founding President and Legal Director of Women Enabled International, 2010, p. 84)

Introduction

In Chapter Two disability was examined from a theoretical perspective and the significance of the way in which society perceives and responds to people who are considered "different" was revealed. While it may seem peculiar to begin a PACS research thesis with a chapter reviewing literature that would usually sit outside the scope of the discipline, it is this peculiarity that my own research seeks to challenge and address. Chapter Three builds on Chapter Two by shifting the focus from Disability Studies to PACS. Its aim is to examine how disability is represented within PACS research, literature and practice, while investigating the lived experiences of people with disabilities affected by conflict and displacement. To do this, it is necessary to reach beyond the scope of PACS and draw on peer-reviewed literature sourced from other academic disciplines, as well as anecdotal evidence derived from grey literature; that is, materials and research produced outside traditional academic publishing and distribution channels (Lawrence, 2012).

This chapter begins with an overview of PACS, before disability representation is discussed. Evidence from a wide range of sources is then collated, and the experiences of people with disabilities during conflict and displacement is examined. The marginalisation and discrimination of people with disabilities during times of peace, as well as conflict, are then contextualised within the framework of key PACS theories.

The Study of Peace and Conflict: An Overview

For millennia, philosophers, religious thinkers, political activists and others, have decried war while debating, thinking about, writing about and working for peace (Webel & Galtung, 2007). Approaches to the study of peace and conflict, however, have varied throughout

history. This has included the Western approach to the study of peace, which has traditionally focused on the analysis, prevention, de-escalation and solution of conflicts by peaceful means, leading to the benefit of all. Alternatively, war and security studies have tended to focus on strategies for achieving victory and defeat using force, leading to the increased or decreased security of one or more, but not all, of the parties involved. However, PACS as a contemporary academic discipline primarily developed in response to catastrophic conflicts that occurred during the early twentieth century, as well as criticisms against traditional and dominant investigations into the causes of war and conflict (Barash & Webel, 2018; Dar, 2015; Jeong, 2017).

Dar (2015) identifies four key phases of PACS which represent its development into an established academic discipline: the Evolutionary Phase (1648-1914); the Post-evolutionary Phase (1914-1945); the Institutional Developments Phase (1945-1990); and the Contemporary Phase (post-1990). According to Dar, the most important of these phases for academia was the Institutional Development phase, and in particular, the era between 1946 and 1990. Given the disastrous consequences of the World Wars, the Cold War and the near catastrophic Cuban Missile crisis of 1962, the 1950s and 1960s saw scholars and academics increasingly focus their research, theories and practice on the elimination of wars and particularly, the prevention of nuclear warfare. For example, a number of journals were established for the purpose of publishing articles on relevant topics. This included the "Journal of Conflict Resolution: A Quarterly for Research Related to War and Peace" (1957), which later adopted the interdisciplinary Center for Research on Conflict Resolution, "The Journal of Peace Research" (1964), and others. Meanwhile, in Europe, and in particular Scandinavia, the Oslo Peace Research Institute (PRIO) was formed in 1959, followed by the Swiss International Peace Research Association (IPRA) in 1964. The Stockholm International Peace Research Institute was established in 1966 to address core issues such as the prevention of biological weapons and disarmament, and in 1971, the Department of Peace and Conflict Research at Uppsala University (SIPRI) was founded in Sweden (Barash & Webel, 2018; Dar, 2015).

Throughout the 1970s and 1980s, PACS became increasingly influenced by the Gandhian philosophy of non-violence and anti-Vietnam War movements, which gave rise to protest against wars and social oppression. Following this, the Contemporary Phase (post-1990) was again strongly influenced by world events such as the fall of the Berlin Wall (1989), the Gulf War (1990), the Iraqi War (1990), the dissolution of the Soviet Union (1991), and ethnic cleansing and genocide in places such as Rwanda, Yugoslavia, Iraq and Sri-Lanka (Dar,

2015). More recently, PACS has been increasingly influenced by the impact of global warming, climate change and technological advancements, particularly in relation to modern warfare (for examples, see Barash & Webel, 2018; Jeong, 2017).

Notably, throughout the Institutional Developments and Contemporary Phases, PACS also experienced an internal shift in thinking and a broadening of perspective. Dugan and Carey (cited in Dugan, 1989) describe peace studies as "an academic field which identifies and analyzes the violent and nonviolent behaviours as well as the structural mechanisms attending social conflicts with a view towards understanding those processes which lead to a more desirable human condition" (p. 74). While PACS originally developed in response to high impact conflicts and wars, over time it has evolved into a discipline that extends far beyond simply examining the reasons for war and devising methods for its prevention. It now also examines the nature and impact of different forms of violence and injustice including social oppression, discrimination and marginalisation (Barash & Webel, 2018).

This broadening of perspective is where I, as a PACS researcher, enter the picture. While PACS is now a widely researched and taught subject in a large number of institutions around the world, the practical application of its research and theories in 2018 is very different from what it was during the early 1900s. It is not uncommon for PACS to now include subjects such as gender, human rights, business, education, the arts, health and journalism (for example, see Barash & Webel, 2018; Webel & Galtung, 2007). At the time of writing this thesis (2018), major conflicts afflicting the human race and planet include the Syrian Civil War, the Afghanistan War, internal Mexican conflicts, the Iraqi conflict, the Rohingya Conflict, the Somali Civil War, ethnic violence in South Sudan, the Boko Haram insurgency, the Maghreb insurgency, the Libyan Crisis, the Yemeni Crisis, the Moro conflict in the Philippines, the Israeli Palestinian conflict and the instability around the USA and North Korea relations. Furthermore, according to the United Nations High Commissioner for Refugees (UNHCR), the world has reached its highest levels of displacement on record, with 65.6 million people having been forced from their homes. Among them, 22.5 million are refugees, over half of whom are under the age of eighteen. To put this into perspective, the UNHCR estimates that every minute twenty people are forcibly displaced as a result of conflict or persecution (UNHCR, 2018).

While these facts and figures point towards what appears to be a deteriorating situation of global security, the peaceful resolution of conflicts and significant advances in human rights

over the last century also needs to be recognised. For example, the Troubles in Ireland were formally resolved with the Good Friday Agreement in 1998 (Walsh, 2017), in 2016 the Colombian Peace Agreement brought an end to more than half a century of conflict in Colombia (Biel Portero & Bolaños Enríquez, 2018), and most recently, North and South Korea announced plans to end the peninsula's seven-decade war (Fifield, 2018). On a smaller scale, peacebuilding efforts have seen major advancements in the recognition and implementation of the rights of marginalised communities such as women's, children's and indigenous rights, queer and gender diversity rights, as well as disability rights (for example, see Flaherty, Byrne, Tuso, & Matyók, 2015).

Furthermore, in recognition of the large amount of work that is still to be done, in 2016 the United Nations launched 17 Sustainable Development Goals (SDGs), which set global targets for the eradication of extreme poverty and hunger, universal primary education, gender equality, reduction of child mortality, improvements in maternal health, combating HIV/AIDS, malaria and other diseases, environmental sustainability and global development partnerships by the year 2030 (United Nations Development Programme, 2018a). In particular, Goal 16: Peace, Justice and Strong Institutions, aims to significantly reduce all forms of violence, and work with governments and civil society to find lasting solutions to conflict and insecurity by strengthening the rule of law, promoting human rights, reducing the flow of illicit arms and strengthening the participation of developing countries in the institutions of global governance (United Nations Development Programme, 2018b). Given that the 2030 Agenda relies on global cooperation, PACS institutions such as the International Peace Institute (IPI) and PRIO are now starting to look at ways in which they can use their research endeavours to support countries (from high-level officials through to civil society) to implement the SDGs and transform the 2030 Agenda into a reality (Nygård, 2018; Roesch, 2018).

In summary, PACS is an academic discipline that primarily developed in response to early twentieth Century high impact conflicts. Over time, it has evolved and adapted, and is now a widely taught field of academia that draws on anthropology, sociology, political science, international relations, psychology, biology, zoology, ethics, philosophy, theology, history and elements of neuroscience (Barash & Webel, 2018). Given that war, conflict and peace all share the common factor of being relational, PACS has not accidentally developed into a

transdisciplinary field,[1] but it's very aim is to be transdisciplinary across all levels of the human conditions itself. As summarised by Galtung (2010, p. 25), "insights that originate with one discipline can then travel to the next, so that the focus on a trans-disciplinary issue such as peace generates trans-disciplinarity". As a field, PACS encompasses multiple levels of relationships, ranging from inner peace, wellbeing and relationships with the environment, to relationships between individuals (micro), groups or communities (meso), nations (macro) and between regions and civilizations (mega) (Barash & Webel, 2018; Galtung, 2010). Most importantly, the study of peace and conflict is rarely driven by the desire to produce knowledge for its own sake; rather, the core purpose of PACS is to bring about and consolidate peace (Miller, 2005).

PACS and Disability

The next section of this chapter investigates disability representation within PACS. When considered within the context of conflict and displacement, not only is disability caused by conflict, but conflict and displacement also exacerbates existing barriers and challenges experienced by those living with disability (Crock et al., 2015). Even so, according to scholars from a wide range of disciplines, academic attention on the experiences of the disability community during conflict, flight, displacement and return is almost non-existent (Aaron, Curtis, Ghenis, Lane, & Barth, 2014; Crock, Ernst, & McCallum, 2012; Crock et al., 2017; Gottschalk, 2007; Grove, Grove, & Myerscough, 2010; Reilly, 2010; Shivji, 2010; Simmons, 2010). This is particularly true of those living with disabilities that have not been acquired through conflict, such as intellectual, sensory, psychosocial or congenital health conditions (Grove et al., 2010).

As previously mentioned, the two most recent phases of PACS (Institutional Developments and the Contemporary Phase) have seen its research, literature and practice become increasingly sensitive towards different groups, such as gender and ethnicity. As a PACS researcher with a disability, I wanted to find out whether this sensitivity extended to the disability community. In order to understand the scope of relevant literature, I began by searching a selection of peer-reviewed PACS journals for the terms "disability", "disabilities", "disabled" and "impairment" between December 2006 and December 2017. Journals were selected based on the accessibility of their word search functions, while the

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[1] A transdisciplinary field refers to the unity of intellectual frameworks beyond disciplinary perspectives (Stember, 1991).

selected dates respectively signify the establishment of the CRPD, and the date when I began writing my research findings. The search returned the following results:

Table 1 Frequency of the word "disability" and related terms (five PACS journals)

Journal	Term: Disability	Term: Disabilities	Term: Disabled	Term: Impairment	Total
Journal of Peace Research	9 times in 7 articles.	1 time in 1 article.	9 times in 4 articles.	3 times in 3 articles.	22 times in 11 articles.
Journal of Conflict Resolution	5 times in 4 articles.	1 time in 1 article.	1 time in 1 article.	1 time in 1 article.	8 times in 6 articles.
Peace and Conflict Studies	2 times in 1 article.	1 time in 1 article.	0 times.	0 times.	3 times in 2 articles.
Peace Review: A Journal of Social Justice	12 times in 12 articles.	16 times in 8 articles.	13 times in 13 articles.	1 time in 1 article.	42 times in 27 articles.
Journal for the Study of Peace and Conflict[2]	0 times.	0 times.	3 times in 3 articles.	1 time in 1 article.	4 times in 4 articles.

I then searched for these same terms in two current PACS text books; the *Routledge Handbook of Peace and Conflict Studies* edited by Charles Webel and Johan Galtung (2007) and *Peace and Conflict Studies* by David Barash and Charles Webel (2018). Similarly, this search returned the following results:

Table 2 Frequency of the word "disability" and related terms (two key PACS texts)

Text Book	Term: Disability	Term: Disabilities	Term: Disabled	Term: Impairment
Handbook of Peace and Conflict Studies (Webel & Galtung, 2007)	5 times in reference to war as a cause of disability.	2 times in reference to disability as a medical classification for	1 time in reference to disability as a medical classification for	0 times.

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[2] Only available from 2009 and 2016.

		welfare and minority rights.	welfare.	
Peace and Conflict Studies (Barash & Webel, 2018)	0 times.	0 times.	2 times in reference to eugenics in Nazi Germany (p.180) and legal supplementary preface (p. xxv).	0 times.

As demonstrated in Tables One and Two, disability and the related terms were not commonly referenced within PACS peer-reviewed journal articles or text books. It is interesting to note that only twice was disability mentioned in the context of a social or rights perspectives on disability. On both occasions, this was when the term "disability" was buried amongst a list of other human rights, for example, the right to freedom of expression for ethnic or cultural minorities, and the right to healthcare for indigenous people (Webel & Galtung, 2007). All other references to disability and related terms were presented from an individualised and medical perspective of disability, primarily in relation to the economic impact of war, to injury and death, or the "struggle" of disability. In the experience of Kerr (2013), one of the few scholars who has bridged the divide between Disability Studies and PACS, the individualised and medical approaches to disability can negatively impact on peace and conflict related research and practice:

> A medicalized approach, along with a relative lack of qualitative and quantitative data relating to the experiences and needs of persons with disabilities in Northern in Ireland in general, and relating to the Troubles in particular, provides a significant barrier to properly understanding the impact of both the Troubles and the Northern Irish peace process on persons with disabilities and determining how better to address and reshape those impacts. (pp. 828-829)

From a disability rights perspective, I am inclined to agree with Kerr (2013); the presence of medicalised and individualised perspectives of disability is deeply problematic, as is the absence of the disability voice and narrative within PACS peer-reviewed literature. As one of the largest and most marginalised minorities in the world, it might be expected that a transdisciplinary field such as PACS, which is dedicated to understanding conflict, social oppression, discrimination and marginalisation, would be sensitive to the needs and

experiences of the disability community. However, as this literature review has suggested, this does not appear to be the case.

Beyond the Scope of PACS: Documenting the Experiences of People Affected by Disability, Conflict and Displacement

Having discovered the absence of disability narratives from PACS peer-reviewed literature, I then extended the scope of my search to other academic disciplines as well as grey literature. While limited in number, these texts provide insight into the experiences of conflict and displacement from a disability perspective. Listed below are summaries of the key themes found across these texts: discrimination and abandonment; displacement and resettlement; punishment; recruitment for conflict related activities; best practice for field workers; exclusion from post-conflict peace processes; disability hierarchy; and immunity.

Discrimination and abandonment

Contemporary armed conflicts consist of a series of complex stages ranging from un-peaceful to peaceful and are often locked into cycles of confrontations, negotiations and ceasefires (Lederach, 1997). Even though a conflict may not be in an active stage of violence, pre-conflicts can be detrimental to the livelihoods of people with disabilities. The breakdown of economic structures, health care institutions, housing, transportation and other infrastructures increase the vulnerability of people living with disabilities (Ortoleva, 2010). As communities turn their efforts to war economy, services specifically designed for people with disabilities are invariably reduced or disappeared (Grove et al., 2010).

One of the most common themes found in the literature referred to the many barriers people with disabilities must overcome when accessing assistance and protection amidst the chaos of conflict (Shivji, 2010). In the first instance, communication or physical barriers, difficulties in seeing, hearing or understanding, negative attitudes and other obstacles prevent people with disabilities from recognising early warning signs of conflict, making it difficult to respond to impending emergencies. This is often because they need to find alternative ways of escaping or they do not escape at all (Bombi, 2010; Shivji, 2010). Once violence has eventuated, escape can be problematic (Bombi, 2010). While the wider community flees, people with disabilities can be left behind, facing further isolation and violence (Barriga & Kwon, 2010). In 2013, a Human Rights Watch investigation into abuses committed by opposition forces in

the countryside of Latakia, Syria, one interviewee described how he was able to flee with his mother, but had to leave his elderly father and blind aunt behind:

> They were shooting at us from two different directions. They had machine guns and were using snipers. We hid, but my dad stayed in the house. He was killed in his bed. My aunt, she is an 80 year old blind woman, was also killed in her room. Her name is Nassiba. (Fakih, 2013, p. 3)

When an individual is dependent on a support person or family member, separation and disorientation can be fatal, especially if they rely on that person for eating, moving or toileting. Hasty decision-making means that assistive devices and medications are often left behind, making flight and displacement extremely challenging and dangerous (Shivji, 2010). For example, a field report from Darfur revealed that during flight people with disabilities took on average twice as long as those without disabilities to reach safety, mostly because of mobility and transport difficulties. The longer journey significantly increased the risks of attack and further insecurity along the way (Kett & Trani, 2010). Many simply do not survive the journey (Reilly, 2010).

Displacement and resettlement

While people with disabilities are at greater risk of being left behind or being unable to flee during emergencies, there are also additional challenges for those who do manage to escape (Shivji, 2010). It is estimated fifteen per cent of the world's population identify as living with a disability (World Health Organization, 2018), and according to the United Nations High Commissioner for Refugees (UNHCR), there are 65.6 million forcibly displaced persons; that is, internally displaced persons, refugees and asylum seekers (UNHCR, 2018). When bringing these two figures together, one might expect the number of displaced persons with disabilities to rank in the millions. According to the UNHCR, however, less than two per cent of the registered refugee population identify as living with a disability (Pearce, Buscher, & Timoney, 2013).

In 2008 the Women's Refugee Commission launched a major investigation into the situation of displaced persons with disabilities; one of the first and only investigations of its kind. Findings revealed that universally, "people with disabilities remain among the most hidden, neglected and socially excluded of all displaced people today" (Reilly, 2008, p. 2). The disability community is rarely identified or counted during refugee registration and data collection; they are excluded from, or unable to access, assistance programs and specialised services (such as food distribution); they are exposed to physical and sexual violence,

exploitation, harassment and discrimination; they are isolated and vulnerable; and they are rarely recognised or valued as contributors (Reilly, 2010).

When discussing the low reporting rate of disability amongst refugee populations in New Zealand, informal conversations with those working in the sector have suggested that the low reporting figures may be a result of disability being hidden due to the fear of being denied assistance or help. These attitudes are thought to stem from pre-existing stigmas surrounding disability. This is also reiterated on an international level with resettlement countries routinely denying entry to refugees who acknowledge that they are affected by disability, injury or health complications. While traditionally the UNHCR has not considered resettlement a viable option for refugees with disabilities, over the years their official position has evolved. Although they now encourage resettlement countries to accept "Ten or More" refugees with disabilities (who would not usually meet resettlement criteria), very few countries honour this program, citing economic reasons and legislative health requirements. In other words, there is an unwillingness to shoulder the financial "burden" of providing services for refugees with disabilities (Mirza, 2010, 2011). Interestingly, similar arguments were made by the Nazi Party against "useless eaters", that is, people who were considered to be a drain on resources, or who had no capital to contribute (Johnstone, 2001, p. 88). As summarised by Crock et al. (2012), forcibly displaced persons with disabilities face a triple disadvantage: they are stripped of their protections of citizenship; they live in fear of persecution if they try to return home; and they are also challenged by physical, mental, intellectual or sensory impairments. Consequently, "Persons with disabilities living in situations of conflict and humanitarian disaster must surely rank among the world's most vulnerable persons […]" (p. 736).

Punishment

When tensions are high and security is intensified, it is not uncommon for individuals with sensory impairments or who use alternative forms of communication to be perceived as suspicious or as a threat to security, leading to increased instances of harassment, interrogation or detention (Bombi, 2010; Shivji, 2010). Take, for example, media reports from Kukes, Albania, detailing the execution of Vefai Rexhemi, a deaf and mute man, after he failed to hear and respond to a Yugoslav soldier who had instructed him to give the three-finger Serbian victory sign (Finn, Smith, & Williams, 1999); the execution of a young man with Down Syndrome in Kobani, Syria, for being a "Kaffir" (Russia Today, 2014); and the threats, torture and punishment instigated by the Lord's Resistance Army (LRA) against women with disabilities in Northern Uganda (Barriga & Kwon, 2010; Gulu Disabled Persons

Union, 2010). In Northern Uganda, one woman who lived with partial blindness reported that rebels further injured her eyes when she could not identify the whereabouts of neighbours, leaving her totally blind. Another D/deaf woman reported being beaten because she could not respond to their questions (Barriga & Kwon, 2010):

> We lost many lives… In the rural areas it was the worst for persons with disabilities. They could be tortured. The rebels would say that persons with disabilities were the mothers and fathers of the UPDF [government forces]. If they did not find any people [while raiding a village] they would target persons with disabilities. (Lucy Adong, cited in Gulu Disabled Persons Union, 2010, p. 18)

People with intellectual, learning and psychosocial conditions can experience periods of increased vulnerability during conflict because of the nature of their disabilities (Grove et al., 2010). Enforcement methods requiring complete obedience may be misunderstood or misinterpreted as a result of the disability or condition, or they may be more susceptible to suggestive questioning, thus putting themselves at greater risk (Grove et al., 2010). I am reminded of the brutal scene in the 1986 film *Platoon* when US soldiers raid a hut in a Vietnamese village. Chris Taylor (Charlie Sheen) discovers a boy who is mute, and who lives with an intellectual or learning disability, hiding in a hole beneath the floor. Taylor harasses the boy by shooting his rifle at his feet. Frustrated by the boy's grin and lack of response, Bunny (Kevin Dillon) takes over the taunting before beating the boy to death with his gun.

Recruitment

Another theme found in both the academic and grey literature recognises the contribution that people with disabilities have made to war efforts throughout history. Take, for example, World War One London where a D/deaf volunteer battalion was established and trained in drilling and tunnel digging. Other D/deaf persons were employed in factories as munitions workers making and testing shells, fuses and manufacturing products such as tools (Mager, 2014). More often than not, however, contributions are specific to the social status of the individual with the disability and their level of need and ability (Grove et al., 2010). In Somalia, the perception of disability as a burden has resulted in people with disabilities becoming prime recruits for the al-Shabaab militant group (Mohamed, 2012). Poverty, famine and on-going conflict have forced people with disabilities to turn to militant groups for protection, who in turn capitalise on their unique needs. Take, for example Ali Muhamud who was forced to work as a spy for the mujahidins: "I heard the mujahidins were encouraging the disabled people in the major cities like Mogadishu and Baidora to physically involve themselves in the holy war. They tell them to participate in suicide bombing since they cannot fight at the battle front […]" (Mohamed, 2012, para.

11). A local resident confirmed that it is common for the militia to think of disabled people as weapons to use against their enemy:

> They sometimes encourage the disabled people to carry out suicide bombing because they say the only way they can fight a holy war is by sacrificing their life, since they cannot physically engage themselves in fighting. […] When the militia want to bomb their enemies in an open place they do it mostly by sending the mentally ill to their opponents carrying a letter with explosives. (Mohamed, 2012, para. 15)

Similarly, in 2014, the Islamic State released an online video urging people with disabilities to join the Islamic State of Iraq and Syria (ISIS)[3] cause. The five-minute video depicts two D/deaf non-verbal brothers working as traffic police in Mosul, Iraq. Using Sign Language with English and Arabic subtitles, the men state that disability is not an excuse for not serving the cause (Perez, 2015).

According to Grove et al. (2010), the exploitation of an individual's emotional and psychological vulnerability can be attributed to the increase of social isolation of individuals with intellectual disabilities; a direct consequence of decreased or limited support services and networks that are available during conflict: "What we may discern in these reports is another insidious consequence of war; the potential for exploitation of vulnerable in the dissemination of propaganda" (Grove et al., 2010, p. 90).

Best-practice for field workers

One of the more encouraging findings of the reviewed literature was a growing collection of best practice guidelines when working with disability communities during emergency situations. Importantly, these have highlighted the urgent need for promoting sustainable change within practice (Buscher & Pearce, 2015). These guidelines and toolkits include, but are not limited to:

- Disabilities Among Refugees and Conflict-Affected Populations: Resource Kit for Field Workers (Women's Refugee Commission, 2008).
- Need to Know Guidance on Working with Persons with Disabilities in Forced Displacement (UNHCR, 2011).
- Promoting the Rights of Persons with Disabilities Disability Toolkit (UNRWA, 2013).

Guidelines such as the ones listed above generally provide an introduction to, and advice on, key approaches and activities for field practitioners in places of conflict or disaster, with the

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[3] Now referred to as the Islamic State of Iraq and the Levant (ISIL).

aim of ensuring inclusion and equality for forcibly displaced persons with disabilities (Buscher & Pearce, 2015). The guidelines cover subjects such as consultation (as outlined in the mantra of the disability rights movement, "nothing about us, without us"), Disabled People's Organisations (DPOs), identification and registration, CRPD, family, abuse, education, distribution of resources and other provisions, reunification and accommodation (UNHCR, 2011; UNRWA, 2013; Women's Refugee Commission, 2008). Most notably, these guidelines and toolkits demonstrate the importance of employing a rights-based approach to the intersectional experience of disability, conflict and displacement.

Exclusion from post-conflict peace processes

Another emerging area of research and practice is the inclusion of the disability community in post-conflict reconstruction and peacebuilding. For example, South Africa is now regarded as having one of the most progressive stances on disability in the world. As the government sought to address past injustices and build an inclusive society during post-conflict reconstruction, introduced policies actively included the disability community from a rights-based perspective (Irvine, 2015).

Even so, evidence suggests there is still much work to be done when it comes to the inclusion of people with disabilities in post-conflict reconstruction and peacebuilding activities. For example, research conducted by Gottschalk (2007) examined the experiences of people with disabilities in post-conflict Sierra Leone. Findings revealed that the disability community were for the most part disappointed in peace processes spearheaded by the Truth and Reconciliation Commission, which had been "handed down from Geneva" rather than coming from local initiatives (Gottschalk, 2007, p. 5). It was also found that local peace initiatives proposed by Disabled People's Organisations (DPOs) were rarely valued, recognised or funded by large donors, who "only want to fund peace processes that they have conceived, that they know how to implement and have proven successful in other post-conflict contexts" (p. 6). For people with disabilities who engaged in legal court proceedings, publicly testifying against atrocities that had caused their disabilities led to feelings of re-victimisation. Furthermore, a lack of physical accessibility meant that the disability community often experienced exclusion from peace processes, activities, events and meetings.

Similar findings were also reported in an investigation conducted by Human Rights Watch in Northern Uganda, where women with disabilities reported being regularly excluded from community meetings and decision-making processes, experiencing higher rates of gender-

based and sexual violence, limited mobility and a lack of appropriate and accessible healthcare and judicial systems (Barriga & Kwon, 2010). In Northern Ireland, a lack of unity between organisations advocating for disability rights resulted in inequality between services, especially those aimed at supporting different groups of people with disabilities during peacebuilding processes. Victims of the conflict who did not consider themselves "disabled" (preferring the term "injured"), together with injured veterans, were rarely, if ever, mentioned in discussions about disability: "According to people involved in the peace talks, disability was never mentioned in relation to victims and veterans and therefore was not put onto the post-conflict agenda" (Irvine, 2015, p. 165).

This is an interesting point from Northern Ireland, as it is often individuals who acquire disability as a result of conflict who play a significant role in ensuring the needs of the wider disability community are on the post-conflict agenda (Irvine, 2015). However, inclusion should also reflect the diversity of disability populations. This includes the different socio-economic backgrounds, geographic locations, ages, genders and most importantly types of disability (Aaron et al., 2014; Irvine, 2015). Failing to do so can result in a hierarchy developing within the disability community, which can cause resentment, competition, and ultimately weakening the potential of inclusive post-conflict reconstruction and peacebuilding (Irvine, 2015).

Disability hierarchy

The next point that was present within the reviewed literature concerns the disparity between the perceptions and treatment of people with disabilities unrelated to conflict, and people who acquire their disability from conflict itself. While people with disabilities are often perceived as a homogenous group (Aaron et al., 2014) , it is also widely accepted that globally there is an unspoken hierarchy between different types of disabilities (Deal, 2003). At the top of the hierarchy are veterans injured during war "because their disability was gained in service to the country and is of no fault of their own" (Forsyth & Copes, 2014, p. 328). Other disabilities such as congenital, intellectual and psychosocial conditions are ranked nearer the bottom and are generally viewed as less worthy because of a perceived moral weakness and belief that the individual is to blame for their misfortune (Forsyth & Copes, 2014).

The hierarchy of disability is something that I myself have directly engaged with in recent years. After returning home from living in Israel-Palestine, I found myself with a small amount of disposable income. I made contact with an organisation in the Palestinian West

Bank to inquire about sponsoring a child with a disability. In my mind, I would be donating my money to support a young person, whom, perhaps like me, was an amputee or maybe they had acquired some other injury from the Israeli-Palestinian conflict. However, I was instead sent the profile of a young girl who had been born with complex needs unrelated to injury or conflict; and for a fleeting moment, I felt a sense of disappointment. The feeling was not strong, nor did it last, but after giving it some more thought, I realised the significant implications even this small feeling could have on the wider pursuit of equity and equality. Even I, as a human rights researcher and advocate, and as someone with a congenital disability myself, felt disappointed when I realised I would not be sponsoring the hero child with a disability, who I had initially sought. Upon further reflection, it also made me realise that almost every charity drive I could think of focused solely on emotive appeals for money to support people disabled by conflict, and not people with disabilities unrelated to conflict or injury. While this story exposes my own vulnerability and shortcomings, which I am certainly not proud of, it also demonstrates how the individualised models of disability have conditioned society (myself included) to prioritise and value some experiences over others. Having caught myself red handed, followed by a period of processing and reflection, I committed to sponsoring the little girl and her family in the years that followed.

As discussed in the last section, the reviewed literature also suggests that inclusion in community development and peace building is largely reserved for war-injured veterans, and often fails to address the unique needs of the wider disability community (Grove et al., 2010; Irvine, 2015). For example, this has been seen in both Mozambique and Palestine where veterans with disabilities are traditionally held in high regard and included in community and governmental decision-making processes. Similarly, in Afghanistan and El Salvador disability organisations have capitalised on the status of conflict-injured persons in an attempt to represent all people with disabilities, including those that have not been acquired by conflict-related injuries (Irvine, 2015).

This disparity was also a key finding in research conducted by Armstrong and Ager (2005), who analysed the societal perceptions and consequential treatment of people with different types of disabilities in Afghanistan. They concluded that Afghan society makes clear distinctions between traumatic and congenital disability, but that awareness is much greater for people in the former category. In a series of interviews with people with disabilities and their families, responses revealed that people living with congenital conditions have a much lower status in society, less access to services, are treated in a paternalistic manner, are

"cared" for rather than enabled, are less visible in public, are uncertain of their economic productivity and independence, and are considered to need more care, financial support or curative services than those with traumatic injuries:

> Experience of medical care was also different for traumatic and congenital disabilities. War victims had accessed services and regained function […] people with congenital disability within their community recalled more negative responses: The doctors don't help them, the doctors says, 'Go away to your home, we can't help your children'. (Armstrong & Ager, 2005, p. 89)

It is important to acknowledge the hierarchy between types of disabilities, as at its core is the concept of worth (Forsyth & Copes, 2014). In Sierra Leone, clear distinctions were also seen not only between war-related disabilities and pre-existing disabilities, but also between advocacy for ex-combatants and victims. Victims of amputation (a common war injury) disputed that programmes benefitting ex-combatant amputees were neglectful of civilian amputees. People with disabilities who were neither victim nor veteran (such as congenital amputees, like myself), received even less support and did not benefit from the peace processes in any way (Irvine, 2015).

Immunity

I have included this final category, not because of its academic credibility, but because it references an article that challenges the rest of the academic and grey literature addressed in this chapter. In 2015, the Australian Broadcasting Corporation (ABC) published an article detailing the Islamic State's release of Yazidi captives in Mosul, northern Iraq, all of whom were older persons, disabled or sick. Khodor Domli, a Yazidi rights activist in the south-west of Kirkuk who was present during the release, believed there were at least 350 people: "Some are wounded, some have disabilities and many are suffering from mental and psychological problems" (Australian Broadcasting Corporation, 2015 para. 4). According to the article, the release took officials by surprise. However, no further details about why they were released have been made public. While it is unclear why this event occurred, it appears that in this case, disability, impairment and age served as an immunity.

PACS Through a Disability Lens

So far, this chapter has outlined the history and aim of PACS, before highlighting the absence of disability from its literature and practice. The chapter then drew on academic research from other disciplines, as well as grey literature, to gain an understanding of the intersectional experience of disability, conflict and displacement. This chapter has been structured in a

strategic way, whereby each section builds upon the last, the purpose of which is to provide the necessary concepts for this next discussion, which seeks to contextualise disability alongside key PACS theories.

<div align="center">Positive peace, negative peace and the violence triangle</div>

As the reviewed literature suggests, around the world people with disabilities continue to face the daily threat of ableist ideologies, disablism, marginalisation and discrimination. When these experiences are considered from a PACS perspective, it seems appropriate to conclude that even during times of "peace", people with disabilities are often excluded from the peaceful lives that people without disabilities are afforded. I write the word "peace" in inverted commas for the reason that the question remains: can it really be considered "peace", if some are excluded from experiencing said "peace"? To understand the importance of this question, I have found it useful to draw on Johan Galtung's (1990) writings on violence, particularly in relation to positive and negative peace, both of which are key theories within PACS research and practice. In his article entitled "Cultural Violence", Galtung (1990) describes what has become known as the violence triangle. As depicted in Figure Two, the violence triangle differentiates between three distinctive, yet interlinked, types of violence: direct, structural and cultural violence.
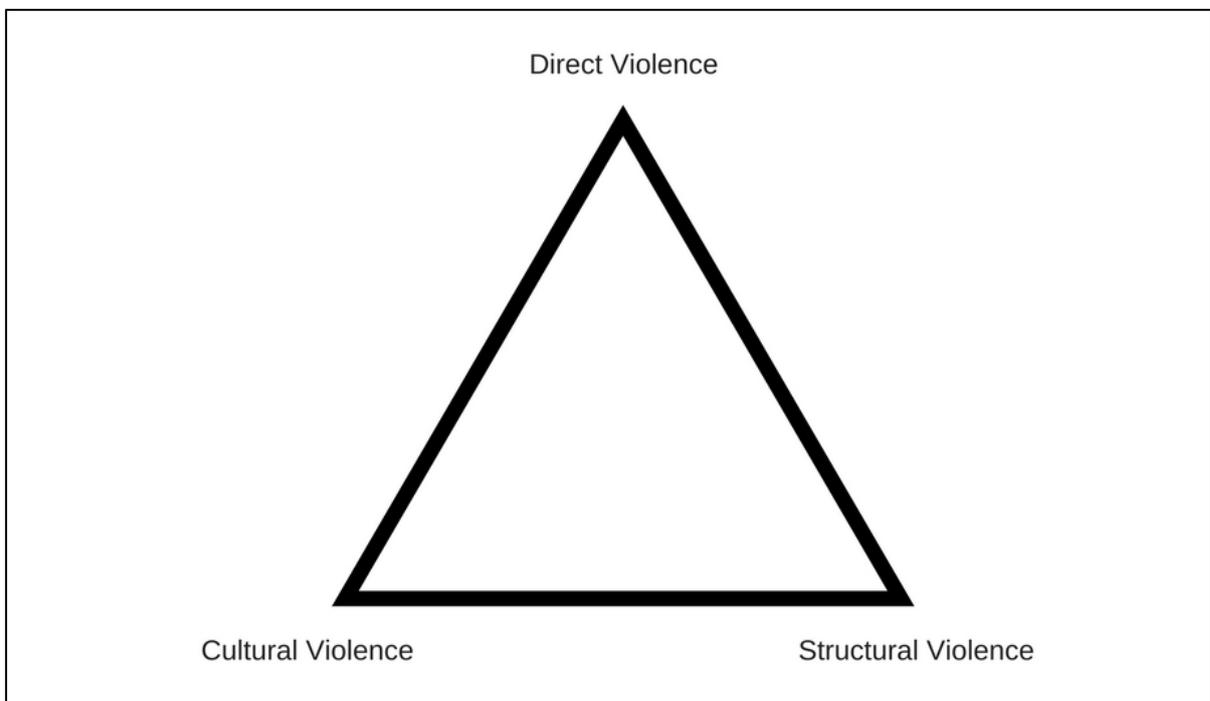
Figure 2. Visual representation of the violence triangle, described by Galtung (1990).

[Image description: A picture of a triangle. The bottom right corner of the triangle reads "Structural Violence", the bottom left corner reads "Cultural Violence" and the top corner of the triangle reads "Direct Violence".]

Galtung (1996, p. 197) defines violence as "avoidable insults to basic human needs, and more generally to *life*, lowering the real level of needs satisfaction below what is potentially possible." Direct or personal violence refers to violent acts that can be seen or heard, and the consequences of which can be traced back to a concrete actor. It is the most visible and obvious type of violence and includes any verbal, emotional and physical violence that harms the mind, body and spirit (Galtung, 1996). While violence is a threat in all communities, it is of particular concern to people with disabilities. For example, a review by Hughes, Bellis, Jones, Wood, Bates, Eckley, McCoy, Mikton, Shakespeare, and Officer (2012) pertaining to the prevalence and risk of violence against the disability community found that children with disabilities were almost four times more likely to experience violence than children without disabilities and 2.9 times more likely to become victims of sexual violence. Children with psychosocial, neurological or intellectual disabilities appear to be among the most vulnerable, with 4.6 times the risk of sexual violence than their non-disabled peers. A further review of literature relating to adults with disabilities revealed they are 1.5 times more likely to be a victim of violence than adults without disability, while people with mental health conditions were at nearly four times the risk of experiencing violence (Hughes et al., 2012). The rate of sexual violence is particularly alarming, with studies revealing that most victims are abused more than once (Sobsey & Doe, 1991), and that 97% to 99% of the abusers are known and trusted by the victim (Baladerian, 1991).

When these statistics are considered alongside research that demonstrates a spike in sexual assault and gender-based violence during periods of conflict (Ward & Marsh, 2006), anecdotal evidence suggests that so too does the sexual abuse and gender-based violence committed against people with disabilities. Certainly, the reviewed literature in this chapter has shown that people with disabilities experience higher levels of direct violence during conflict, including abandonment, the denial of basic needs and necessities, punishment for living with a disability and forced recruitment for conflict related activities.

Structural violence, on the other hand, is a form of violence that occurs when social structures – such as economic, political and religious institutions – invoke oppression, social injustice and subjugation by preventing basic needs from being met (Meluch, Reed, Cline, &

Hernandez, 2016). Although structural violence has real victims (often entire social groups), it has no real or identifiable perpetrators (Galtung, 1969; Høivik, 1977). Structural violence is injustice and exploitation built into social systems that benefit some and not others by privileging select classes, ethnicities, genders and nationalities (Hathaway, 2013). I would add "abilities" to this list. Like direct violence, structural violence against people with disabilities is widespread. The reviewed literature indicates that structural violence against people with disabilities occurs systematically during conflict, flight and displacement (for example, in refugee camps and places of asylum) as well as within peacebuilding processes. For example, services designed specifically for people with disabilities are amongst the first to be reduced or eliminated during conflict (Grove et al., 2010). With the breakdown of already structurally violent economic structures, health care institutions, housing, transportation and other infrastructures, people with disabilities are at an even greater risk of direct violence, or what Thomas (1999) refers to as barriers to doing. As highlighted by Galtung (1969, p. 180) "if the absence of personal [direct] violence is combined with a pattern of structural violence, then personal violence is nevertheless around the corner […]".

The third corner of the triangle refers to cultural violence. These are the symbols, beliefs and ideologies within a culture that can be used to justify structural and direct violence (Galtung, 1990). Cultural violence comes in the form of religion, law, language, art, empirical science, and cosmology, and is enabled by institutions such as schools, universities and the media (Galtung, 1996). Within the context of disability, Thomas (1999) refers to this as barriers to being. In Chapter Two, six conceptual models of disability were presented. The individualised moral, charitable and medical models have been strongly rejected by many within the disability community for being what Galtung might describe as culturally violent and ableist. The very notion of ableism itself is a culturally violent ideology that is so deeply rooted in most aspects of everyday life that it is inadvertently used to enable and justify disablism (structural violence) and direct violence against people with disabilities.

As such, the violence triangle contextualised within the experience of disability might look something like Figure Three below:
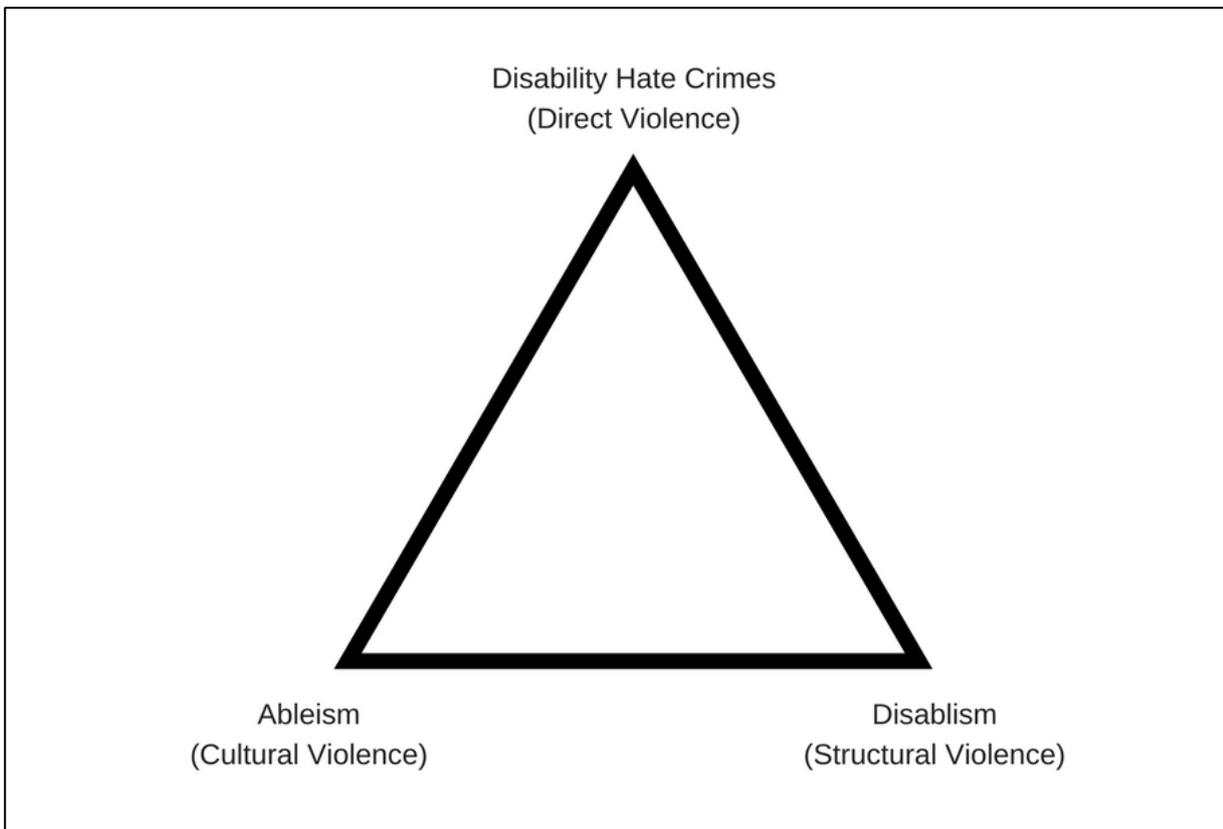
Figure 3. Galtung's violence triangle (1990) through a disability lens.

[Image Description: A picture of a triangle. The bottom right corner of the triangle reads "Disablism (Structural Violence)", the bottom left corner reads "Ableism (Cultural Violence)" and the top corner of the triangle reads "Disability Hate Crimes (Direct Violence)".]

According to Galtung (1969, 1990) there is an important difference between negative and positive peace. Negative peace refers to the absence of direct violence, while positive peace is the absence of direct, structural and cultural violence, as well as the presence of social justice. However, as Wolbring (2014, p. 188) highlights, "The invisibility of disabled people in the culture of peace discourse can be interpreted as evidence of a failure of a culture of peace and its discourse and comes with consequences for disabled people". Based on Galtung's understanding of violence, assessing the needs of people with disabilities during conflict, displacement and in post-conflict settings is a complex and multifaceted endeavour:

> An assessment must be undertaken of the impact of direct and indirect violence, both as a creator of disability and as to how it impacts structural and cultural conditions that will have bearing on the rights and quality of life of persons with disabilities in ways ranging from access to services to employment opportunities. (Kerr, 2013, p. 829)

Kerr (2013) also links the disability community's experience of direct, structural and cultural violence to Lederach's elicitive approach to conflict resolution and peacebuilding (Lederach,

1995). The elicitive approach to peacebuilding and conflict resolution is focused on the empowerment of individuals to participate in resolving their own conflicts. This is in contrast to the prescriptive approach, in which conflict resolution and peacebuilding knowledge is held and imparted by experts. The prescriptive approach strongly reflects the ethos of the individualised and medicalised models of disability: "Within both these systems, knowledge and solutions are externally imposed with little or no consultation. The 'experts' are imparting their knowledge; they will 'fix' the problem. Those most directly affected by the conflict, are denied meaningful input and voice" (Kerr, 2013, p. 834).

My interpretation of Galtung's theory of positive peace is that for peace to be positive it must be inclusive of, and accessible to, *all* people affected by both its absence and its presence. This includes people with disabilities. When considered alongside Lederach's (1995) elicitive approach to conflict resolution and peacebuilding, people with disabilities must be empowered within their own setting to build their own pathways of transformation (Kerr, 2013). So, with that being said, is PACS contributing to the continued marginalisation of people with disabilities by excluding the disability narrative from its discourse? Based on the reviewed literature and key texts, I would suggest that yes, it is, though perhaps subtly and unintentionally. According to the violence triangle, PACS as a discipline may well be culpable of inadvertently enabling aversive ableism, a form of cultural violence that creates barriers to positive and sustainable peace. If this is the case, we must now consider ourselves informed about the impact that direct, structural and cultural violence is having on the largest minority in the world. It is therefore our responsibility as PACS students, researchers and practitioners to work collectively towards removing all barriers that hinder the full and effective participation of disability communities in positive peace on an equitable basis with others.

Noticing the Gap: "Nothing About Us, Without Us"

Unlike traditional theses that review relevant literature, identify a gap and then formulate research questions aimed at filling that gap, these two literature review chapters have instead highlighted the absence of the world's largest minority from PACS, while identifying the wider impact this could have on the global disability community. Not only is the absence of disability from the discourse indicative of underlying ableist ideologies, but it has also been suggested that as an academic discipline, PACS may be contributing to cultural violence against the disability community, even if unknowingly and unwittingly. That is, by excluding the disability community from its discourse, PACS is reinforcing barriers to doing and

barriers to being (Thomas, 1999), which is enabling ableism (cultural violence) and disablism (structural violence). Not only does this have an impact on the wider discrimination and marginalisation experienced by people with disabilities (that is, structural and direct violence during both times of "peace" and conflict), but it also goes against the very ethos of PACS and its pursuit of positive peace. As highlighted by disability rights advocate and scholar, Stephanie Ortoleva (2010), to meet the needs of people with disabilities and discontinue further marginalisation, it is essential for human and legal rights laws, political processes, government institutions, policies, infrastructures, systems, and facilities to actively engage people with a lived experience of disability: "There is no one better than women [people] with disabilities themselves to give voice to these issues, and they can only do so with a seat at the table" (p. 142).

At the outset of this thesis, Disability Studies and PACS appeared to be two academic fields that were of little relevance to each other. However, these two chapters have proposed the opposite. Both the disability rights movement (and consequential development of Disability Studies) and the development of PACS as an academic discipline, occurred almost simultaneously. Both were birthed from similar historical contexts, in response to violence, injustice and dominant cultural ideologies. Furthermore, both disciplines share many epistemological underpinnings, including both being multidisciplinary (different disciplines working together, drawing on disciplinary knowledge), interdisciplinary (integrating knowledge and methods from different disciplines, using a synthesis of approaches) and transdisciplinary (creating a unity of intellectual frameworks beyond the disciplinary perspectives) (Stember, 1991). Given that both fields of inquiry have a shared goal of progressing towards an increasingly equitable, harmonious and peaceful world and the betterment of the human condition, it is clear that there is significant potential for these two disciplines to complement and inform each other. Indeed, I assert that a multi-, inter- and trans-disciplinary relationship between the two fields is not only desirable, but mutually beneficial.

Research questions

Throughout these two literature review chapters, the purpose of my own research has begun to form organically. However, having noticed the gap, I faced the difficult task of deciding on research questions. A qualitative research question articulates what a researcher wants to know about the perspectives of people involved in particular social phenomena (Agee, 2009). While the goal of research is to identify a gap in academic literature and then contribute

something unique to fill the gap, by noticing such a large chasm in the literature, I was presented with an even bigger challenge: where do I even start? Furthermore, by focusing so intently on "spotting the gap" and formulating a research question, I risked missing underlying assumptions that have remained unchallenged in existing literature: "gap-spotting tends to underproblematize the existing literature and, thus, reinforces rather than challenges already influential theories" (Alvesson & Sandberg, 2011, p. 247).

Given the limited nature of existing literature, I was also faced with a unique opportunity to not only use this research as a means of contributing to the PACS knowledge base, but also to contribute to its practice and application. This meant going beyond simply affirming the absence of the disability narrative, which as previously discussed, has already been highlighted by scholars and practitioners alike. It also meant going beyond simply injecting the disability perspective into the PACS knowledge base. With this in mind, I made a conscious decision to form research questions that would lead to both pure and applied research outcomes. Pure, or basic, research is theoretical in nature and aimed at expanding an existing base of knowledge. This is in contrast to applied research, which are types of inquiry designed to practically solve specific problems or questions (Surbhi, 2017).

Consequently, my questions developed from two key aims. The first aim is to challenge the on-going marginalisation of people with disabilities affected by conflict and displacement, by intentionally de-subjugating, valuing and promoting their knowledge, both within PACS, as well as wider academic literature (pure research). The second is to conceptualise and demonstrate ways in which PACS research can actively challenge the disability community's experiences of direct, structural and cultural violence (applied research). In order to achieve these aims, the three key research questions my thesis seeks to address are as follows:

1) What can we learn from people with disabilities about the intersectionality of disability, conflict and displacement?
2) What can we learn from people with disabilities about protecting and promoting the freedoms, rights and dignity of people with disabilities affected by conflict and displacement (as outlined in Article 11 of the CRPD)?
3) How can PACS research contribute to inclusive and accessible positive peace?

Summary

This chapter is the second of two literature review chapters addressing the intersectionality of disability, displacement and conflict. Beginning with an overview of PACS as an academic

discipline, disability representation within PACS was then discussed. A broad review of PACS literature revealed a significant absence of the disability narrative from its research and practice. This was clearly demonstrated when searching for key disability terms within journals and texts. The few times disability and its related terms were mentioned were mainly in reference to individualised understandings of disability, which have been rejected by the disability community. Following this, literature from other academic disciplines, together with grey literature, were examined and a summary of key themes relating the experiences of people with disabilities during conflict and displacement was presented. The marginalisation and discrimination of the disability community was then considered alongside key PACS theories. Finally, the research gap was discussed, and my own research questions were presented.

Together, Chapter Two and Chapter Three have collated histories, concepts, theories and anecdotal evidence from Disability Studies and PACS, as well as other academic and grey literature, to create a foundation from which my own research purpose and questions have organically developed. In Chapter Two, an overview of Disability Studies and key models of disability detailed common abstract systems for understanding disability, and the subsequent treatment of those affected by it. Evidence in support of social, social relational and rights-based approaches to disability was presented and contextualised within a wider human rights discourse. Chapter Three complemented Chapter Two by drawing the two fields together. When considering the purpose of PACS, together with the absence of disability from its discourse, we are left with something of an oxymoron: a shared pursuit of positive peace that is inaccessible to, and excludes, the largest minority in the world. However, when considering the histories and epistemological underpinnings of both Disability Studies and PACS, it is clear that there are many similarities and shared goals between the academic fields. As such, my own research questions do not seek to solely address the detrimental effects of exclusion and absence, as I feel this point has been made. Instead, the purpose of my own research is to introduce the disability perspective to PACS in a way that benefits both disciplines, as well as the disability community itself. In doing so, it is my hope that PACS research and practice becomes a leading example in the pursuit of inclusive and accessible positive peace.

The next chapter of this thesis takes the next step in the research process, by examining the methodological approaches my own research took when answering the key research questions presented in this chapter.

Chapter 4 – Methodologies that Transform

"I am different. But not less."

- Dr. Temple Grandin (American professor of animal science and autism spokesperson, 2012)

Introduction

How should disability research be conducted, who should conduct the research and what are the underlying ideologies of the research practice? These are three questions that have been hotly debated within Disability Studies in recent years (Danieli & Woodhams, 2005; Kitchin, 2000; Sullivan, 2009). Having highlighted the absence of the disability narrative from academic inquiry and peacebuilding activities, and then argued in favour of inclusion and accessibility within PACS research and practice, I am now faced with the challenge of *how* to respond to the key research questions that were presented at the end of Chapter Three. Before examining the details and design of inclusive and accessible PACS research, it is first important to understand the "what" of this thesis: *what* is it that this research is trying to achieve? *What* assumptions is this research based upon? And *what* research paradigms will allow the complex, embodied relationship between people with disabilities and their natural social environments to be captured in a meaningful and dignified way (Mertens et al., 2011)?

This chapter begins with a brief history of disability research, including positivist, interpretivist and emancipatory approaches, and details the responses of people with disabilities to historical developments and trends in academia. Critical theory is examined as a useful tool for challenging research paradigms that have traditionally subjugated the disability narrative, before the transformative paradigm is suggested as a possible framework for conducting research that empowers and emancipates marginalised populations. The axiological, ontological, epistemological and methodological assumptions of the transformative paradigm are discussed, specifically in relation to the lived experience of disability. Narrative inquiry, insider research and appreciative inquiry are examined as research methodologies that have significantly impacted this thesis. Finally, the chapter concludes with a discussion on the benefits and risks of appreciative inquiry and the challenges of doing things differently as a "bricoleur", that is, someone who moves beyond

specific disciplines to peer through a new conceptual window of research and knowledge production (Kincheloe, 2005).

Researching Disability

Disability has long been a point of interest for researchers. In the name of "cutting edge science", "the disabled" have been "imprisoned in nursing homes, surgically mutilated, sterilized, lobotomized, euthanized, shocked into passivity, placed in chemical and physical straitjackets, denied education, denied employment, and denied meaningful lives", all of which were carried out with the best intentions of finding the cause and cure of disability (Mertens et al., 2011, p. 227). Social researchers and sociologists have also long studied disability, for the most part, in an attempt to discover the "true" incidence of disability amongst populations (Danieli & Woodhams, 2005). Utilising quantitative methods of data collection such as the survey, traditional positivist approaches hold that the social world can be analysed in the same value-free way as the natural world can, that causal explanations are essential, and that knowledge obtained from research is independent of the assumptions underpinning it and the methods employed to obtain it (Oliver, 1992).

As outlined in Chapter Two, the disability rights movement of the late 1960s and early 1970s boldly challenged positivist approaches to disability and its research, highlighting the negative consequences that objective and detached research can have on oppressed communities (Sullivan, 2009). Take, for example, the widely cited British study conducted in 1972, whereby institutionalised people with disabilities sought the support of academic researchers in their struggle for more control in their daily lives. However, residents soon felt alienated by the academics, who instead of listening to and addressing the needs of the residents, followed their own research agenda. In their final report, the researchers concluded:

> To be admitted into one of these institutions is to enter a kind of limbo in which one has been written off as a member of society but is not yet physically dead. In these terms, the task that society assigns – behaviourally though never verbally – to these institutions is to cater for the socially dead during the interval between social death and physical death. (Miller & Gwynne, 1972, p. 80)

Although the researchers saw institutional life as a living death, they rejected the residents' complaints and instead recommended a reworking of the traditional model of institutionalisation. Feeling betrayed, the residents denounced academic social scientists as "parasites" (Hunt, 1981, as cited in Barnes & Mercer, 1997, p. 2).

Until recently, the voices of people with disabilities have largely been excluded from academic discourse (Kitchin, 2000). Scholars with lived experience of disability, such as Michael Oliver (1992), have critiqued the traditional expert model of disability research for its individualised and medical ideological underpinnings. Specifically, Oliver emphasises that research conducted by researchers without disabilities often serves the agenda of the expert rather than the disability community, while failing to represent the knowledge and experiences of people with disabilities or implement change:

> […] such research does not fundamentally alter the social relations of research production and not for nothing has this kind of research been called in another context "the rape model of research" (Reinharz, 1985) in that researchers have benefited by taking the experience of disability, rendering a faithful account of it and then moving on to better things while disabled subjects remain in exactly the same social situation they did before research began. (Oliver, 1992, p. 109)

In response to positivist, individualised and medicalised approaches to disability and its research, scholars called for research strategies that were both emancipatory and empowering (Kitchin, 2000). Constructivist philosophies soon began to develop, which hold that truth and meaning do not exist as an external objective reality, but are created by interacting with the world, and that meaning is therefore constructed and not discovered (Given, 2008). As such, it is possible for multiple, contradictory, yet equally valid accounts of the world to exist. Similarly, interpretivist philosophies assert that natural reality and social reality are different, and therefore require different methods of inquiry (Gray, 2018). While interpretivist and constructivist philosophies are considered to be an improvement on positivism, particularly their attempts to improve existing social relations and increasingly involve research subjects, others believe these approaches remain insufficient. According to Oliver (1992), interpretivist and constructivist philosophies fail to change the social relations for people with disabilities and the relationship between the researcher and the researched (people with disabilities), by continuing to allow the researcher to maintain the majority of control. Paralleled with a growing body of critical social research literature aligning itself with oppressed groups, Oliver and other disability scholars subsequently began to promote emancipatory approaches to systemic inquiry (Danieli & Woodhams, 2005). Similar to participatory action research (PAR), the emancipatory paradigm holds that:

- Research is political in nature;
- The skills of the researcher must be put at the disposal of people with disabilities to redress power imbalances;
- Who, what and how must be determined by people with disabilities;

- Focus must be put on the strengths and coping skills of people with disabilities rather than their deficits;

- Research must examine the contextual and environmental factors that facilitate or impede integration of people with disabilities (adapted from Mertens et al., 2011, p. 229).

However, the emancipatory research paradigm is not without critique either. Important ethical questions have arisen, such as: what if legitimising, honouring and validating marginalised voices means supporting narratives and discourses that promote an individualised medical perspective of disability? As highlighted by Danieli and Woodhams (2005), there is potential for conflict between the political imperatives of emancipatory research and the epistemological requirements of producing accurate accounts of disability. Other challenges include the lack of funding allocated to PAR (Mertens et al., 2011), applying the emancipatory approach to research inclusive of psychiatric survivors (Beresford & Wallcraft, 1997) or people with intellectual or learning disabilities (Booth & Booth, 1997), and questions over who owns the research (Shakespeare, 1997). For Shakespeare (1997), one of the greatest challenges of carrying out emancipatory research in its purest form is the obligation to turn over total control to the participants, rather than the researcher retaining an element of choice and control over the process. According to Shakespeare, the criteria for emancipatory research are too strict, especially when considering the time and resource limitations of institutions, which will be discussed later in this thesis.

Critical Theories

Shakespeare's (1997) critique of emancipatory research raises an important question: is there space within academia to reflect upon, and if necessary critique, underlying and unchallenged assumptions within well-established disciplines? My own research seeks to bring together two fields of academia, based on the premise that PACS is, for want of a better description, subtly and unintentionally ableist. But is there space for such a critique? It is this question that drew me to literature on critical theory. Coined by Max Horkheimer in 1937, critical theory is considered a means of challenging ideological mystification, class oppression and hegemony, with the goal of changing society for the better (Felluga, 2015, p. xxiii). As a common feature of post-structuralism research, critical theory is recognised for its interpretivist approach, interest in critically challenging social realities, emancipatory interest in knowledge, and the attention it draws to the political dimension of research (Alvesson & Sköldberg, 2000). Since its outset, a wide range of descriptive and normative bases for social inquiry have emerged

(Hosking, 2008), including feminist theory, critical race theory, critical legal studies (Felluga, 2015; Lincoln, Lynham, & Guba, 2011), critical disability studies (Hosking, 2008; Reaume, 2014), critical terrorism studies, and critical peace studies (Jackson, 2013, 2015). Within the field of PACS, critical theorists have increasingly drawn on Foucauldian insight regarding knowledge and power to challenge privileged narratives and discourses maintained by scholars and practitioners. This has included the de-subjugation of terrorism discourses (Jackson, 2012), the inclusion of youth and gender in conflict and peacebuilding (Berents & McEvoy-Levy, 2015; Isike & Uzodike, 2011; O'Reilly, 2016), conscientious objection, nonviolence and pacifism (Jackson, 2017). I hope that my own research will serve to ensure that disability is added to this list of important works.

The objective of critical theory is to increase human freedom, explain oppression, end the domination of certain social constructs defined by class, gender, power and race, and so on, while transforming society, leading to human emancipation (Hosking, 2008). In a sense, Disability Studies is just that: a critical reflection on power relations and everyday obstacles, which have undoubtedly transformed the way we perceive, and respond to, people with disabilities. Similarly, PACS developed in response to the catastrophic consequences of early twentieth century wars and critiques of traditional and culturally dominant investigations into the causes of war and conflict (Barash & Webel, 2018). Even so, as stated by Jackson (2013), PACS has tended to lack engagement with critical social theories and is consumed by empirical and positivist approaches to research. This includes a fixation on data sets, quantitative data analysis and the collection of fieldwork data, often at the expense of important meta-theoretical and philosophical debates over ontology and epistemology. Such fixations reveal an unchallenged assumption that conflict must be solved. Indeed, in much the same way the medical model of disability is engrossed with "fixing" people with disabilities without considering disability as a natural and diverse human experience, so too is the notion of "solving" conflict, without considering the role of conflict in addressing issues of social justice, oppression, domination and emancipation. As highlighted in the reviewed literature, un-critical approaches to PACS have, and continue to be, detrimental to the disability community; both in its exclusion of the disability narrative from its literature and discipline, as well as in its contribution to the ongoing direct, structural and cultural violence routinely experienced by people with disabilities.

While there are many avenues that could be explored in relation to critical perspectives on peace, conflict, disability, oppression, and so on, the purpose of this brief exploration of

critical theory has been to highlight the importance of challenging and debating dominant ideologies within academia. In answer to the question of whether there is space within PACS for challenging and critiquing underlying and unchallenged ideologies, the answer is yes. Not only is there space, but it is an obligation. This is particularly important when conducting research with communities, such as people with disabilities, that have been marginalised in significant and systemic ways. In the same way that it is not enough for PACS to only report on violence alone (Galtung, 2010), it is also not enough to simply highlight disability discrimination and marginalisation, and then inject the disability perspective into existing ideologies, especially if it is those underlying and unchallenged ideologies that led to exclusion in the first place. Such research is not transformative, nor does it serve to change the social conditions of the disability community. It is instead our responsibility, as PACS researchers, to critically examine *why* such voices have been excluded from the discipline, while asking *how* we can ensure our own research design and outcomes actively challenge and deconstruct ideologies that contribute to direct, structural and cultural violence.

Transformative Paradigm

Having established the importance of critical approaches in advancing the emancipation of people with disabilities and the transformation of their social situations, the next section of this chapter outlines key paradigms, philosophies and modes of inquiry that have influenced my own methodological approaches within this research. Based on works derived from Guba and Lincoln's (1994) writings on competing paradigms of inquiry, the social science understanding of the term "paradigm" has been likened to a world view. That is, it is a set of experiences, values and beliefs that affect the way an individual perceives reality and responds to that perception. Perception and response have been key themes throughout this thesis, particularly in relation to disability and the impact that such perceptions can have on research and peacebuilding endeavours. Understanding paradigms and their underlying assumptions is important, as it helps researchers to develop a framework for their inquiry, which then serves as a guide for the entire research process, including strategies, methods and analysis (Antwi & Hamza, 2015).

Earlier in this chapter, reviewed Disability Studies literature called for research paradigms that are empowering and emancipating for the disability community. While examining various paradigms, I found that the transformative paradigm strongly resonated with dual pure and applied aspects of my research. As a recent addition to the research community, the transformative paradigm has been described as a range of research endeavours that can lead to

extraordinary outcomes, revolutionise entire disciplines, create entirely new fields and disrupt traditional theories and perspectives (National Science Board, 2007). Underpinning the paradigm is the belief that research ethics concern the continuance of human rights, the pursuit of social justice, cultural respect and reciprocity between the researcher and participant (Mertens et al., 2011). The role of a transformative researcher is reframed as one who "recognizes inequalities and injustices in society and strives to challenge the status quo, who is a bit of a provocateur with overtones of humility, and who possesses a shared sense of responsibility" (Mertens, 2007, p. 212). Rooted in the human rights agenda, transformative research consciously includes people who have been excluded from mainstream society and discourse (Mertens, 2007). Listed below are summaries of the key axiological, ontological, epistemological and methodological assumptions of the transformative paradigm.

Axiological assumptions

Axiology is a branch of philosophy that asks about the nature of ethical and moral behaviour. It is the most important of the transformative paradigm's assumptions, as it drives the formulation of the other three: ontological, epistemological and methodological (Mertens, 2010). As set out in the Belmont Report (National Commission for the Protection of Human Subjects of Biomedical Behavioral Research, 1978), research involving human subjects is based on three key principles of ethics. The first principle is *respect*, referring to the protection of participants during research and their courteous and respectful treatment. Informed consent is essential, and the researcher must remain truthful in their research endeavours. The second principle, *beneficence*, refers to the philosophy "do no harm" by minimising risk to research participants. *Justice*, the third principle, ensures procedures are reasonable, non-exploitative, well considered and administered fairly.

Based on these three key principles, the transformative axiological lens specifically calls for the respect of cultural norms and diversity, beneficence in terms of human rights and the furtherance of social justice (Mertens, 2009). In the context of disability research, this means recognising diversity within the disability community, and asking questions that consider the intersectionality between disability and gender, ethnicity, dominant and minority group narratives and privilege, quality of services for different groups, and other lived experiences (Mertens et al., 2011).

Ontological assumptions

While traditional methods of inquiry identify variables that can be measured and analysed in

the search for an objective truth, the transformative ontological assumptions hold that reality is socially constructed. Furthermore, select individuals are in positions of greater power and influence, while other less powerful people have a higher chance of being excluded from decision-making processes (Mertens, Holmes, & Harris, 2009). The ontological assumptions of the transformative paradigm reflect the work of French philosopher, Michel Foucault (1980), who referred to subjugated knowledge as knowledge that has been disqualified as non-conceptual, hierarchically inferior, beneath the required level of erudition and rejected by the mainstream: "Subjugated knowledges are thus those blocs of historical knowledge which were present but disguised within the body of functionalist and systematizing theory and which criticism – which obviously draws upon scholarship – has been able to reveal" (p. 82). According to Foucault there are two subtypes of subjugated knowledge: erudite and disqualified. Subjugated erudite knowledge refers to expert or qualified knowledge that has been buried in the formulation of dominating systems of knowledge. By contrast, subjugated disqualified knowledge is knowledge that lacks expertise and qualification and is disqualified for not having met the criteria of recognised knowledge (Harwood, 2001). I would argue that people with disabilities, both as experts of their own personhood and as people whose expertise has not been recognised by dominant individualised and medicalised systems of knowledge, experience both subtypes of subjugation.

Similarly, the transformative lens explicitly acknowledges the social, political, cultural, economic, ethnic, racial, gender and disability values that define and influence different realities (Mertens, 2007). As highlighted by Gaventa and Cornwall (2008), power and knowledge are intrinsically linked, and as such, it is important to recognise that particular versions of reality are often deemed "real" or "true" by those who are in more powerful positions. Knowledge and power are also key concepts of the social relational model of disability (Thomas, 2004b). The transformative paradigm's ontology asks: how is reality defined and by whom? Whose reality is given privilege? What are the social justice implications of accepting realities that have not had their power differentials critically analysed (Mertens, 2007)? In academic research, this includes how a researcher defines their research problem, the development of their questions, and other elements of systematic inquiry. It is therefore the responsibility of the researcher to uncover the different socially constructed realities, including their own, and to "interrogate" them as to which version of reality furthers social justice and human rights the most (Mertens et al., 2011, p. 231).

Epistemological assumptions

The third set of assumptions describes the nature of knowledge and the relationship between the "knower and that which would be known" (Mertens, 2010, p. 2). Specifically, transformative epistemology is characterised by the understanding of culture and trust building through a close collaboration between the researcher and the participants, community leaders and other community members. Methods and language of communication are selected by participants themselves and the research is designed with careful consideration for cultural norms (Mertens, 2007, 2009).

As noted earlier, people with disabilities have become increasingly disillusioned with research that does not change their social situations, even going so far as to refer to social researchers as parasites (Barnes & Mercer, 1997). According to Mertens (2007), the transformative paradigm's epistemological assumptions can lead to a cyclic model of research that includes partnerships, recognition of power differences and trust building through culturally competent practices: "The goal is to have research that contributes to sustainable change in a community, hence the need to have a cyclic and mixed methods approach" (p. 218). To demonstrate this, Mertens et al. (2011) present an adaption of the American Sign Language Community's Terms of Reference. I have found this adaption particularly helpful when considering the epistemological assumptions of my own research design:

1) The construction of meaning and knowledge within the disability community rests with the members themselves.

2) Investigators should recognise the right of the participant to have all things they value fully considered during all interactions.

3) Worldviews of the disability community should be taken into account during all interactions that have impact on the community.

4) When applying the disability community's terms of references, researchers should recognise diverse experiences, understandings and ways that reflect contemporary cultures.

5) The views and perceptions of the critical reference group should be reflected in processes validating and evaluating the extent to which disability community's terms of reference have been taken into account.

6) Investigators should negotiate with disability groups to establish appropriate processes to consider and determine the criteria for deciding how to meet cultural imperatives, social needs and priorities.

Unlike other research paradigms, transformative research has no specific set of methods or practices of its own. Drawing on a range of theories, methods and techniques, quantitative, qualitative or mixed methods can be used (Mertens et al., 2011). However, as noted by Mertens (2009), it is crucial to employ qualitative methods when establishing the methodology and in particular, the dialogue between the researcher and disability community. The transformative lens assists the researcher to reframe their understanding of worldviews and methodological decisions, which are made with strong consideration for contextual and historical factors, especially in relation to discrimination and oppression. For example, traditional approaches to sampling, such as those as used in positivist research paradigms, should be reframed in a way that evades homogeneity, considers diversity and privilege and avoids causing harm to populations by using demeaning and self-defeating categorisation (such as "at risk" people) (Mertens, 2007).

Benefits of the Transformative Paradigm

I have chosen the transformative paradigm as a source of inspiration within my own research design as it inherently aligns with my personal values, as well as the social relational and rights-based models of disability. At its core is social justice, human rights and the beneficence of marginalised populations. Lived experience is valued, and agency of the most affected is encouraged; participants are active decision makers rather than reliant on the decisions of others (Stace, 2011). Furthermore, by being attuned to diversity within communities, building on strengths rather than deficits, developing solidarity with other marginalised groups and changing identity politics to socio-cultural perspectives, the transformative framework reflects the values of the disability rights movement. Importantly, it also recognises, and responds to, the intersectionality between discrimination and disability, gender, race, ethnicity, age, religion, status and other categories of diversity that have the potential to be used as the basis for marginalisation and oppression (Mertens et al., 2011). When evaluating whether the transformative paradigm can really altar the status quo, and after reviewing Mertens' works, Tarsilla (2010) concludes that the transformative paradigm is indeed capable of altering the status quo, while being instrumental in bringing about social change and social transformation.

The transformative paradigm is also well suited to peace and conflict research. While I am unaware of Mertens' disability specific approach being applied within PACS, in a broader sense, transformative paradigms have been instrumental within the PACS discipline. As

previously discussed, critical approaches to PACS and related fields have focused intently on underlying axiological, ontological, epistemological and methodological assumptions, particularly in relation to power, privilege, oppression, decolonisation and more. Lederach's (2003) theory of conflict transformation was also born from the concern that quick solutions to deep social-political problems do not lead to significant change. His conflict transformation framework emphasises peace as embedded in justice, the building of relationships, community and social structures through human rights and nonviolence. In earlier works, Lederach (1995) also suggests that for meaningful structural change, individuals must be socially empowered within their own setting:

> We begin with the fundamental view that people in a given setting are a key resource in the educational process. Their understanding of that setting and of themselves comprises the pipeline to discovery of important categories of thought, meaning-in-context, and creative action. […] this integrated framework suggests that identifying, understanding, and handling problems in a setting is best accomplished through participation and empowerment of people within that setting. (p. 32)

Another link between PACS, critical theory and transformative paradigms is found in Foucault's theory of knowledge and power. The transformative paradigm is a tool that can be used for de-subjugating both the knowledge of people with disabilities, as well as people affected by conflict. The ontological assumptions of the transformative paradigm allow for the realities of people who have traditionally held less powerful positions to re-emerge, the epistemological assumptions encourage an interactive link between the researcher and the participant, and the methodological assumption accommodates cultural complexities by allowing flexibility within the methodology. Finally, at its core are the axiological assumptions of respect, beneficence and justice. As proposed by Foucault (1980, p. 82) there is untold value in de-subjugating disqualified knowledge:

> I also believe that it is through the re-emergence of these low-ranking knowledges, these unqualified, even directly disqualified knowledges […] and which owes its force only to the harshness with which it is opposed by everything surrounding it – that it is through the re-appearance of this knowledge, of these local popular knowledges, these disqualified knowledges, that criticism performs its work.

Finally, and perhaps most importantly, the transformative paradigm challenges individualised, medicalised and eugenic perceptions of disability, and the assumptions that disability must be eradicated or fixed (Garland-Thomson, 2012). Not only can the re-emergence of such knowledge benefit those who voluntarily participate in this research, but it could also lead to the beneficence of wider communities:

> The subjugated knowledge that comes from disability might be understood as an asset rather than a liability, not just in terms of diversity or human rights categories, but as

what might be called an advantageous minority skill set. […] Disability can develop advantageous expertise as one navigates barriers and unsupportive material and attitudinal environments. (Garland-Thomson, 2012, p. 346)

Critiques and Challenges of the Transformative Paradigm

As a recent addition to the research world, Mertens' transformative paradigm (specifically in relation to disability) has not yet been through a rigorous process of review, and as a result, constructive critiques are few and far between. A review of the paradigm by Romm (2015) highlights its similarities to the critical systemic approach and postcolonial indigenous paradigms, and notes that the paradigm itself remains "overly Western-oriented" (p. 424). Through the processes of examining my own ontological and epistemological assumptions as a researcher, I also considered the wider critiques of post-positive research paradigms. For example, traditional critiques by positivist researchers claim that action research is undisciplined, statistically unsophisticated, does not lead to defensible generalisations, fails to create a system of theory and is practiced by amateurs (Hodgkinson, 1957). Postmodern critiques include issues of reflection, subjectivity, experience and the promise of empowerment and emancipation (McTaggart, 1994). For example, James Frideres (1992) rebukes PAR for having an ideological bias that only oppressed people can produce facts that have truth value; for its confused research goals; for being too focused and limiting; for restricting the development of general skills communities may need for future challenges; and for being methodologically naïve in assuming participants have equal knowledge about reality (including the skills to actively participate in data collection and analysis). Furthermore, while action researchers argue that PAR can be empowering, liberating and emancipatory, others have criticised it for its false promise of empowerment, which often leads to disappointment (McTaggart, 1994).

Some of these critiques raise valid points and highlight the importance of rigorously upholding academic and ethical responsibilities; justifying the axiological, ontological, epistemological and methodological assumptions of chosen research paradigms; and managing both the expectations of the researcher and those who participate in the research. However, it is difficult to accept that post-positivist research paradigms are undisciplined, unsophisticated, or as Frideres (1992) criticises, are based on the ideological bias that only oppressed people can produce facts that have truth value, and that not all participants have equal knowledge about reality, or the skills to participate. As this chapter has repeatedly stated, such assumptions have been used to justify the exclusion of people with disabilities

from academic inquiry, and inherently oppose the social, social relational and rights-based models of disability. While it is valid that people with disabilities are not the *only* people who can produce facts that have truth value, positivist attitudes such those expressed by Frideres have been used to justify the ongoing marginalisation of the disability community, particularly the act of being spoken for, or, on behalf of, by people without lived experience (Oliver, 1992). Although the voices of people with disabilities are not the only voices that have truth value, we must be present and prioritised in all matters that affect us: nothing about us, without us. Furthermore, according to the social model of disability (and other models), it is society's responsibility to ensure that the disability community is empowered with the right skills and support to make sure that happens. As argued by Max Horkheimer (1972), positivism falsely represents human social action, and in doing so, supports the status quo rather than challenges it.

When thinking about utilising the transformative paradigm within my own research, it has also been important to reflect upon and clarify my own concerns regarding its application. My first question is about ontology and relates to whether there are multiple socially constructed realities (constructivism) (Andrews, 2012), or one reality about which there are many opinions and power influences that determine which version of reality is given privilege (transformative paradigm) (Mertens, 2009). While I do not feel confident holding fast to one perspective over the other, I do concur with the notion of uncovering various versions of reality, particularly knowledges that have been subjugated (Foucault, 1980), before determining which version is most in accord with furthering social justice and human rights (as outlined in the transformative paradigm).

Second, given that not all people agree with the social models of disability, it is important to recognise that when a research decision is based on a particular paradigm or model of disability, whether consciously or not, the researcher is exercising power over the research subject and generating data to support their own agenda:

> Ironically, then, rather than emancipatory research and the social model becoming a means of legitimising the views of the previously silenced disabled people, it can potentially become a means of silencing those whose views do not conform to those of the 'expert' researcher. (Danieli & Woodhams, 2005, p. 288)

This critique is particularly challenging for me because I, as a person with a disability, have greatly benefitted from the development of the social, social-relational and rights-based models of disability. As a disability rights advocate, this is something I will need to carefully

consider throughout the research process, so as not to impose my views on those I engage with.

Finally, as highlighted by Stace (2011), research cannot be judged transformative until it translates into on-going and reviewable improvements to practice benefitting people with disabilities. While transformation is the goal of this research, it is important to acknowledge that it has not yet happened and there is a very real possibility that it may not happen at all. With this in mind, the next section of this chapter will outline the other research methodologies that have informed my approach to this inquiry.

Transformative Methods of Research

Disability, displacement and conflict are complex life experiences that when considered together, have received very little academic attention. Considering the historically strained relationship between people with disabilities and researchers, I have attempted to establish a eclectic and holistic methodological approach. Often referred to as "bricolage", such approaches typically employ various methodological strategies as they are needed within an unfolding research situation, and exist "out of respect for the complexity of the lived world" (Kincheloe, 2005, p. 324). At its core, the approach of this research is epistemologically and ontologically aligned with the disability rights movement and Foucauldian thought regarding knowledge and power, yet flexible and malleable enough to evolve, develop or even abandon as new information, details and realities come to light.

Narrative inquiry

When conducting research that draws on subjugated knowledge, it is necessary to use research methods that value knowledge while being attentive to those who are telling their stories. Narrative inquiry is an example of a research method suited to the task (Harwood, 2001). Also referred to as narrative analysis, narrative inquiry is a multidisciplinary qualitative research paradigm that emerged during the twentieth century, representing what has been called the "narrative turn" in the human sciences (Riessman, 2008, p. 14). As an umbrella term for research methods focusing on story as the object of inquiry (Riessman, 1993), narrative researchers study how humans experience the world, as narrated by those who experience it (Joyce, 2015). It is both a phenomenon and method, in that it describes the structured quality of experience as well as the patterns of inquiry for its study (Connelly & Clandinin, 1990). As a distinct discourse, narrative inquiry spotlights meaning making through the shaping or ordering of experience, understanding of action, organisation of events

and objects into a meaningful whole, as well as the observation and connecting of the consequences of events and actions over time (Chase, 2011). More than simply an uncritical collecting of stories, narrative inquirers look at how a story is constructed, for whom and why, as well as the cultural discourses it draws upon (Trahar, 2009).

Narrative as a method of inquiry has become increasingly common within Disability Studies (Smith & Sparkes, 2008). While the intent of narrative inquiry is not to produce factually accurate or verifiable accounts of life, it has been suggested that through narrative, "individuals with disabilities can themselves challenge stereotypes that have historically sought to subjugate them" (Smith-Chandler & Swart, 2014, p. 421). While there is risk in representing disability in an idiosyncratic and idiographic way which upholds individualised approaches to disability, narratives and storytelling can help shed light on the human condition. It is important for narrative inquirers to retain accurate understanding of the politics of both the experience of disability and the construction of the categories we use to speak about it. Narratives or stories about the experience of disability and impairment – often personal, sometimes political or spiritual – can offer their own definitions of disability, which experts and professionals would benefit from listening to (Williams, 2001). Based on this premise, by exploring different disability narratives it is possible to challenge static beliefs and stereotypes regarding impairment:

> […] via storytelling, alternate voices of disability can be heard from the unique perspectives of the individuals themselves. By expanding methodologies that attend to aspects of internalized oppression, we can gain a more holistic understanding of the variegated experiences of disabled individuals and the way in which these experiences manifest in neoliberal contexts. (Smith-Chandler & Swart, 2014, p. 425)

Within the framework of narrative inquiry, focus, interests and definitions of narrative differ according to discipline and individual researchers (Polkinghorne, 1995). In his discussion on paradigmatic analysis of narrative research, Polkinghorne identifies two broad approaches to narrative research: *narrative analysis* and *analysis of narratives*. The former, narrative analysis, refers to the collection of event descriptions before they are synthesised into a story. The latter, analysis of narratives, is an approach whereby the researcher moves from stories to common elements, collecting storied data that is then analysed through paradigmatic processes. When considered alongside the transformative paradigm, analysis of narrative seems to be the most fitting approach for looking at the narratives of people with disabilities affected by conflict and displacement. As highlighted by Mertens et al. (2011), the researcher does not predetermine lines of inquiry, but instead lines of inquiry are determined by the

narrator who has the opportunity to identify and direct what issues, challenges and successes they value and want to communicate.

Other approaches to narrative inquiry that have informed my research include storytelling as lived experience, narrative practices and narrative environments, and the researcher and their story (as summarised by Chase, 2011). S*torytelling as lived experience* refers to the study of narrative by researchers who are interested in how people narrate their experiences. Storytelling is essential to understanding what a narrator is communicating, and how they construct meaning, identity and reality. I am interested in this approach because of its potential to provide insight into contradictory and hegemonic discourses, particularly the way in which an individual's story is or is not impacted by dominant discourse and the potential for disrupting oppressive discourses (Chase, 2011). Storytelling as lived experience has been utilised within disability research, in particular, regarding identity and the lived experience of disability and impairment (for examples, see Adame & Knudson, 2007; Hole, 2007).

Narrative Practices and Narrative Environments is an approach to narrative inquiry that focuses on the relationship between narrative practices and narrative environments. Described by Gubrium and Holstein (2009, p. xviii) as "reflexive interplay", narratives are considered as shaping and being shaped by narrative environments, which are reflexively intertwined. Particular attention is given to narrative reality, a term that suggests the context in which stories are told are just as much a part of reality as are the narrative texts. Furthermore, it is about understanding what is not said, about what, why, how and by whom. This approach to narrative inquiry aligns with the values of the social model of disability, which holds that physical and social environments determine the difference between impairment and disability, which in turn affects identity and narrative. In this way, understanding the narrative environment is crucial to not only de-constructing personal narratives, but also the narrative environment and the relationship between the two (Chase, 2011).

Finally, *the researcher and their story,* as the name suggests, brings into consideration the life stories and experiences of the researcher. This is often used to develop a more equitable relationship between the researcher and the research subject. It has also been used in the context of the researcher drawing on their own experiences and narrative to explore the questions at hand (Chase, 2011).

Insider research

As a researcher with a disability, the discussion around the researcher and their story provides an ideal opportunity to think about and acknowledge my own experiences in relation to the themes of this thesis. Insider research is relatively commonplace within the humanities and presents both advantages and disadvantages to research. The benefits include deeper levels of understanding afforded by prior knowledge, shared language, closer and regular contact with the field, detailed consideration of the social actors at the centre of the social phenomenon, easier access to and selection of participants, better informed, quicker establishment of rapport and trust and more open lines of communication due to the researcher's continuing contact with the field (Taylor, 2011).

In its purist form, inclusive research embraces the involvement of people with disabilities (including people with intellectual, learning and psychosocial disabilities) not only as participants, but as researchers themselves (Nind & Vinha, 2014). With much of the disability discourse having been dominated by people without disabilities (Kitchin, 2000), staunch disability studies scholars such as Oliver (1992) have argued in favour of disability research endeavours being driven and led by researchers with disabilities, referring to the mantra "nothing about us, without us". Others, while acknowledging the challenges associated with non-disabled researchers conducting disability research, have also highlighted the benefits of outsider research and collaborations (for example, see Stone & Priestley, 1996). Having worked closely with many passionate activists and academics with and without disabilities I do not believe that disability issues should be limited to researchers with disabilities alone. Indeed, there are many valuable opportunities when people with diverse experiences collaborate within transformative paradigms of research. However, in saying that I do believe there is value in people with disabilities collaborating with other people with disabilities, the benefits of which should not be ignored.

Even so, scholars such as Asselin (2003) have identified a number of disadvantages of insider research, including a researcher's assumption that they know the culture of the subject. Taken-for-granted assumptions have the potential to limit a researcher's ability to identify and address underlying issues and miss important pieces of data. Another caution is the researcher's inability to remain objective. While I understand the sentiment behind this disadvantage, I lean more towards Fine's (2009) point that there is no objective truth within research, nor its design; that we, as researchers, imprint on our research regardless of how careful we are to remain detached. Furthermore, I find the assumption that researchers *should*

be detached, problematic. Prematurely identifying problems and issues as a result of prior knowledge is indeed a risk of insider research. It is also something that does not lend itself to the transformative paradigm. However, as highlighted earlier in the chapter, inquiry conducted by detached researchers has tended to result in negative consequences for research subjects affected by disability (Sullivan, 2009), consequences I wish to avoid.

Other criticisms of insider research include role confusion, conflicts, betrayal or mistrust, differences in social worlds, the effects of field withdrawal, interpersonal dynamics and the researcher's reduced ability to manage participant expectations, as well as the expectations of those they are working with, such as service providers (Asselin, 2003; Taylor, 2011). To avoid the pitfalls of insider research, Asselin (2003) recommends researchers assume they know nothing and begin their data collection with a fresh perspective. This might be achieved by writing down thoughts and beliefs about the social phenomenon before data collection begins, then putting it aside: "In essence, the researcher acknowledges the assumptions and 'brackets them from the study'" (p. 100). Again, while this sounds like a good idea in theory, in practice I will never be able to totally bracket my own experience of disability and the assumptions that come with it. Though I certainly do not claim to be a full inside researcher, that is, I do not have lived experience of conflict or displacement, I do, however, identify as being part of the largest minority in the world, the disability community. As outlined in the transformative paradigm, there are many realities in existence; some I identify with to a greater extent than others, and some not at all. My role as a partial-insider researcher is to uncover the different socially constructed realities, including my own, and to distinguish which versions of reality further social justice and human rights (Mertens et al., 2011). Another recommendation is to maximise accountability and transparency by being reviewed regularly by independent or external advisors and ensuring methods of data collection are concisely and accurately documented (Asselin, 2003). For me, this has included regular reviews and supervision meetings with experts from both PACS and Disability Studies.

Appreciative inquiry

Another research approach that has significantly influenced my research design is appreciative inquiry, the study of what gives life to human systems when they function at their best (Whitney & Trosten-Bloom, 2010). Developed by researchers at Case Western University, appreciative inquiry began as a method of inquiry that allowed corporations and organisations to improve their structures, competitiveness, profitability and sustainability (Michael, 2005). While appreciative inquiry developed in response to the centrality of

problem solving in managerial work and organisational behaviour, it has since been applied across disciplines with individuals, families, organisations and even nations (Rogers & Fraser, 2003). Founded on the heliotropic principle, appreciative inquiry is based on the premise that society moves in whatever direction they collectively, passionately and persistently ask questions about (Bushe, 2011). For example, when human problems and conflict become the focus of an inquiry, the number and severity of those problems often grows. Similarly, when peak experiences and best practice become the focus, these phenomena too begin to flourish (Ludema, Cooperrider, & Barrett, 2001).

Traditional academic inquiry begins with the identification of a problem (also known as the research problem or question), followed by the collection of information and data about that problem, before recommendations on how to implement change and fix the problem are made. Appreciative inquiry sets out to challenge this unquestioned commitment to the secularised problem-oriented approach by highlighting how deficit discourses and the traditional problem-solving approach often leads to an exaggerated focus on weakness (Cooperrider & Srivastva, 1987; Grant & Humphries, 2006). Take, for example, research conducted by Bernie Carter (2006) on best practice with children who have complex needs. Carter felt a problem-oriented approach would potentially limit the inquiry, focus too much on deficiencies, and fragment the world or cause separation between stakeholders. Appreciative inquiry, on the other hand, offered a mode of inquiry that actively celebrates success, achievement and what was already working; "Simply put, AI [appreciative inquiry] researchers aim to find out 'what's right' and help 'enhance it'" (Carter, 2006, p. 50).

Appreciative processes hold that you can create change by paying attention to what you want more of, rather than focusing on what you want less of (Bushe, 2005). Appreciative inquiry aligns itself with the ontological position of social constructionism, which holds that language, knowledge and action are inextricably linked (Grant & Humphries, 2006), a theme also found in narrative inquiry. In appreciative inquiry the process of the interview is as important as the collected data. While key theorists use the term "organisation" to refer to key stakeholders, I have adapted this term to reflect Disability Studies and PACS research. I use the term "community" in place of "organisation" and "participants" instead of "organisational members" (that is, people with disabilities and their allies) (Cooperrider, Whitney, & Stavros, 2008). Appreciative inquiry is based on the following 4D principles:
- *Discovery:* Within an interview the primary task is to identify and appreciate the best of "what is". This can be accomplished by focusing on peak times of excellence, or

times when research participants felt most alive and effective. In the case of disability research, this might include moments when people with disabilities felt most equal, most able to actively participate in the community, most included, most valued or safe.

- *Dreaming:* Once the research participants discover their positive core, the next step of the interview process is to imagine and envision its future. Participants are asked to imagine their community at its best in relation to the discovery phase and common dreams are identified.

- *Designing:* With a common dream identified, attention is turned to creating the ideal situation in which the research participants can achieve their dream and "what might be".

- *Destiny:* In this phase, research participants discuss what they can and will do to contribute to the realisation of the dream. Action commitments then serve as the basis for ongoing activities (Cooperrider, 2012).

As might be expected, appreciative inquiry has undergone due critique, often by scholars who, through its practice, have been made aware of its limitations (Bushe, 2011). One of the primary concerns includes the tendency of inexperienced researchers to focus exclusively and passionately on the positive, or "warm, fuzzy group hugs" (Fitzgerald, Murrell & Newman, 2001, as cited in Grant & Humphries, 2006, p. 404). Keeping in mind the importance of acknowledging different human realities (Pratt, 2002), the privileging of certain realities (Foucault, 1980; Mertens, 2007), and the danger of ignoring the shadow of human experience (Reason, 2000), appreciative inquiry scholars caution that systems deeply embedded with unexpressed resentment and repression are unlikely to tolerate appreciative inquiry as a research method until there has been a process of expression and forgiveness (Bushe, 2005). It is important for practitioners and researchers to avoid turning a blind eye to negative and difficult experiences, but instead choose appreciative inquiry as a starting point from which to work rather than an endpoint (Michael, 2005). While appreciative inquiry focuses on the positive in order to aid generativity, dialogue about the negative can also be generative of change (Bushe, 2007).

Care also needs to be taken when asking participants to dream about alternative realities and "things that could be" when they might not have had the opportunity to see or experience a more positive reality than the one they are in (Bushe, 2005). In the case of disability, how can one dream of an inclusive and equal society for people of all abilities, if one has only been exposed to barriers to doing and barriers to being? In the case of peace, conflict and

displacement, how does an individual who has only ever known unrest, instability and conflict, dream of positive peace? If repression is present within a system, as it often is with marginalised communities, even the very act of naming an ideal reality can lead to ridicule and embarrassment (Bushe, 2005).

Given that this research will be guided by the transformative paradigm, I believe the key principles of appreciative inquiry provide a channel for honouring the values of both Disability Studies and PACS. The following four points outline my reasons for integrating the 4D approach into my research. First, research on the negative human experience of disability and conflict appears to be readily and widely available. As the reviewed literature has revealed, both Disability Studies and PACS exist in order to acknowledge, challenge and address problems, tragedies and issues faced by human kind affected by disability or conflict (respectively). While documenting the experiences of disability and conflict is an important contribution, it does not necessarily lead to transformation. Focusing on strengths rather than deficits is key to the social model of disability, the disability rights movement, emancipatory research, and transformative research, as well as appreciative inquiry.

A second reason for leaning towards a positive line of inquiry concerns the well documented and strongly felt power imbalance between people with disabilities and experts, professionals and researchers. As highlighted by Carter (2006, p. 51):

> However carefully and sensitively I have worked previously as a researcher, I've always experienced a tension of starting from a research problem (which is almost always a 'problem with practice problem'. There's always an implicit critique of the way that things are being done in the field; a subtle (or maybe not so subtle) message that researchers/academics know more and know best. This means that researchers, even if they do not see themselves in this way, may be perceived as people set apart from, yet critical of, practice.

This can lead to disconnect and a power imbalance between the researcher and researched, or in this case of Disability Studies, the researcher and the disability community. On the other hand, focusing on positive experiences and what is working can reduce interviewer-interviewee "power games" (Michael, 2005, p. 228).

My third reason relates to appreciative inquiry protocols that encourage listening to, and the promotion of, marginalised voices (Bushe, 2011). Within every culture, organisation, group or community there are marginalised voices. These voices have always existed in the margins of social systems, and are often where important innovations reside (Bushe, 2011; Whitney &

Trosten-Bloom, 2010). In this way, appreciative inquiry provides the means to draw on, recognise and acknowledge those voices, such as the voice of people with disabilities affected by conflict and displacement, and enhance what has or is working well for them. This reflects the key values of the transformative paradigm, which holds that research should lead to transformation and change; advance social justice, human rights and the beneficence of marginalised communities; and focus on strengths rather than deficits (Mertens et al., 2011).

Finally, researchers have found that appreciative inquiry can offer a range of other benefits. These include participants being more eager to share stories about successes; more likely to share information in a candid and unrehearsed way as they consider experiences in a new light; speaking more freely and less defensively; and one researcher reported appreciative inquiry leading to an extra level of security as the participants' need to defend weaknesses and shortcomings was reduced, as was the fear of reprisal from external bodies (Michael, 2005).

Appreciative Inquiry: The Challenge of Doing Things Differently

While appreciative inquiry is an approach to research embedded in positive transformation, its philosophies also create tensions between itself and the other research paradigms I am drawing on. The first and probably greatest tension is between appreciative inquiry's focus on positive reporting and the axiological assumption of emancipatory research and the transformative paradigm, which holds that investigators should recognise the right of the participant to have all things they value fully considered during all interactions (Mertens et al., 2011). Transformative research in its purist form should be totally open to documenting negative experiences within a deficit framework, if that is what a participant values. As Grant and Humphries (2006) ask, are research participants really able to openly choose the discourse and vocabulary with which they construct their realities and negotiate meanings? By subtly imposing positive discourses and vocabularies onto participants, is the researcher in fact promoting systems of control and power? Or, in the case of an overt commitment to "the positive" by a zealous appreciative inquirer, is the research in fact silencing emancipatory critique?

Bushe (2007) clarifies that positive experience is useful but not the purpose of appreciative inquiry. The purpose is to generate a new and better future, a value that is shared by both the transformative approach to research as well as critical theory. Limiting what a research participant can and cannot talk about is likely to create disconnect and a power imbalance

between the researcher and the researched. However, there are ways researchers can work within the key principles of both the transformative paradigm and appreciative inquiry. Traditionally, a researcher would respond to the sharing of a negative experience by asking the participant to elaborate on what they did not like about the experience and fully explore why they did not like it. According to appreciative inquiry, this response is not generative of change because even though these kinds of questions might lead to the collection of a significant amount of data on a person's discontent, we are no closer to generating a better future. Alternatively, appreciative inquiry researchers might ask the participant what is missing, what they want more of and what is creating the gap between what they want and what they see:

> This kind of inquiry is much more likely to be generative. Out of it can come new ideas and images that point us toward a better collective future. I think it is unwise to try and banish discussion of what people don't like during appreciative inquiry; especially if they have a lot of emotional charge around it. Instead, let's try to be thoughtful in how we make a space for inquiry into hurt, anger, injustice, despair […]. (Bushe, 2013b, p. 104)

The second tension is found between the fourth D of the 4D model of appreciative inquiry, *destiny*, which encourages research participants to consider ways in which they can actively achieve their *dream* (Cooperrider, 2012). As researchers, we must be very cautious of the expectations we place on a marginalised community to take responsibility for changing their current situation. Expecting people with disabilities to take ownership over changing their circumstances does not align with the social model of disability, which holds that impairment is what an individual has, and disability is what is created by society. The social relational model extends this by articulating the difference between impairment effects and barriers imposed by people in positions of power to exclude (Thomas, 2004b). It is likely that an individual has no or little control over the impairment they live with or the impairment effects they experience. Therefore, if disability resides in a disabling society and instigated by people in positions of power, then surely the lion's share of the responsibility for change falls on society and those in positions of power. When visualising what a better future might look like, it is important to differentiate between the responsibility of the people with disabilities and their allies, and the responsibility of society for removing disabling barriers.

Summary

Though large in size, this chapter is perhaps one of the most important of this thesis. A number of philosophies, concepts and arguments have been examined and discussed within this chapter, each being of equal importance to the one preceding it. As has been revealed,

when conducting research that seeks to confront underlying and unchallenged assumptions within academia, and research that is inclusive of marginalised populations, there are many complex issues to consider.

The chapter began by locating the disability community's experience of research within the historical context of positivist, constructivist and interpretivist research paradigms. A tense relationship between people with disabilities and academia was revealed, and the call for empowering and emancipative research paradigms was presented. The benefits of critical theory were briefly discussed, and the transformative paradigm was suggested as an overarching framework for the design of this research. Following this, the axiological, ontological, epistemological and methodological assumptions of the transformative paradigm were presented and related to the experience of disability. As a research paradigm, it was found to align with the ethos of the social, social relational and rights-based models of disability. The benefits, critiques and challenges of the transformative paradigm were then discussed before other influential research methodologies were presented, including narrative inquiry, insider research and appreciative inquiry. Finally, the benefits and challenges of these research methodologies were examined. The next chapter of this thesis discusses research design and processes, ensuring that the benefits, challenges and tensions discussed in this current chapter have been thoughtfully considered and addressed.

Chapter 5 – Research Design: "This is What I Need to Participate"

<div style="border:1px solid black; padding:1em;">

Listen

"I said- 'this is what I need to enable me to participate'
They thought they had to find out how
And they were scared and did nothing
And I said – 'This is what I need to participate'
They decided there was a better way
And they took over and I was alienated
I said – 'this is what I need to participate'
And they thought I was ungrateful and demanding
They suggested counselling and support
And I was misunderstood
I said 'this is what I need to enable me to participate'
And they listened
We talked
And together it worked
- for partnership."

(Written by an ally of the Disability Action Research Group, as cited in Boyles, 1998, p. xiii)

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Introduction

After reviewing the current literature, Chapter Three concluded with a presentation of the following key research questions:

1) What can we learn from people with disabilities about the intersectionality of disability, conflict and displacement?

2) What can we learn from people with disabilities about protecting and promoting the freedoms, rights and dignity of people with disabilities affected by conflict and displacement (as outlined in Article 11 of the CRPD)?

3) How can PACS research contribute to inclusive and accessible positive peace?

Having then explored the axiological, ontological, epistemological and methodological assumptions of various research paradigms, the next task was to develop a research design and process, which served to collect narratives and data in response to the key research questions. Importantly, the research design, methods and processes needed to be able to

problematize unchallenged assumptions and ableist ideologies in academia; de-subjugate the knowledge of people with disabilities; promote a social relational and rights-based approach to the empowerment and emancipation of minority populations; and ultimately aim to transform the social situations of people with disabilities affected by conflict and displacement.

This chapter details the specific methods and processes that were employed within this research. It begins with a brief outline of the research setting, and how Ecuador came to be the field location for the interviews. Given that key research methodologies include narrative inquiry and appreciative inquiry, I then discuss whose narratives this research sought out, as well as the mechanisms and justifications behind the selection of those narratives. Participant recruitment methods are then presented, as well as the inclusion and exclusion criteria, ethical considerations, research design and data collection processes, as well as methods of data analysis. Finally, the strengths and limitations of the selected research methods and processes are examined.

Research Setting

While there are many current conflicts that could have served as a basis for this thesis, my field research solely focused on the experiences and narratives of people with disabilities and their families who had been affected by violence and conflict in Colombia and Venezuela and who, after being displaced, were now living in Ecuador. In 2016, at the time of designing the field research of this thesis, peace negotiations between the Colombian Government and the *Fuerzas Armadas Revolucionarias de Colombia*, or the Revolutionary Armed Forces of Colombia (FARC), had progressed significantly. This evolving post-conflict environment provided a unique platform from which new concepts and discussions regarding disability, conflict and displacement could be explored.

A second reason for selecting this particular region of the world was that the ongoing peace processes provided a safe and secure environment to study issues relating to disability, conflict and displacement. Ecuador was among a small collection of low-risk countries to travel to, in comparison to high-risk communities affected by current conflicts in other parts of the world. On the 27th of February 2017, the University of Otago Ethics Committee approved my application to conduct field research in Ecuador (application 16/145).

Whose Narrative is it Anyway?

One of the first major considerations when designing this research was identifying which narratives would provide responses to the key research questions. Under the overarching framework of the transformative paradigm, appreciative inquiry and narrative inquiry are both flexible approaches to research, meaning it is possible to develop rich and diverse sets of data from various sources. Narratives can be manifested in many different forms, mediums or texts including field notes, journal records, interview transcripts, observations, storytelling, letter writing, autobiographical and biographical writing, documented plans and more (Connelly & Clandinin, 1990). Furthermore, in recognition that people with disabilities do not live in a void, but in a complex network of interpersonal and intergroup relationships, I wanted to source narratives and data from a variety of different perspectives and environments. To do this, I began by identifying mechanisms that have proven to be useful in mapping out systems of influence and development of either people with disabilities or people affected by conflict, its resolution and peacebuilding. These included:

- Urie Bronfenbrenner's Ecological Systems Theory, which considers an individual's development within different ecological environments and the evolving interactions between them (Bronfenbrenner, 1977, 1979);

- Maire Dugan's Nested Paradigm; a mechanism that considers conflicts or social issues as symptoms of broader societal structures and systems, and calls for change to be driven by the social structures that are responsible for creating and perpetuating conflict (Dugan, 1996);

- And John Paul Lederach's Peacebuilding Pyramid (Triangle of Influence), which identifies three distinct levels of influence in conflict transformation, provides insight into different actors at each level of influence, and suggests the kinds of actions that might be taken towards positive peace at each level (Lederach, 1997).

When thinking about these three mechanisms for mapping systems of development, interaction and influence in mind, I was challenged to think carefully about the types of narratives and voices this research should seek to engage with and why. Bronfenbrenner's Ecological Systems provides a framework for thinking about the different environments where relevant narratives reside, and aids understanding in how those narratives and environments interact with each other. Dugan's Nested Paradigm is suited to analysing positive and empowering responses to harmful ideologies, such as racism and disablism. Furthermore, the underlying ideologies of the Nested Paradigm reflect philosophies found within the social and social relational models of disability, particularly those that address the

social, structural and environmental aspects of disability. Finally, Lederach's pyramid helped to spur ideas about the types of actors who have the potential to positively influence the perceptions and treatment of people with disabilities who experience conflict and displacement. With these mechanisms in mind, Figure Four outlines the types of narratives and voices my field research sought to engage with, followed by an explanation of why each was selected:
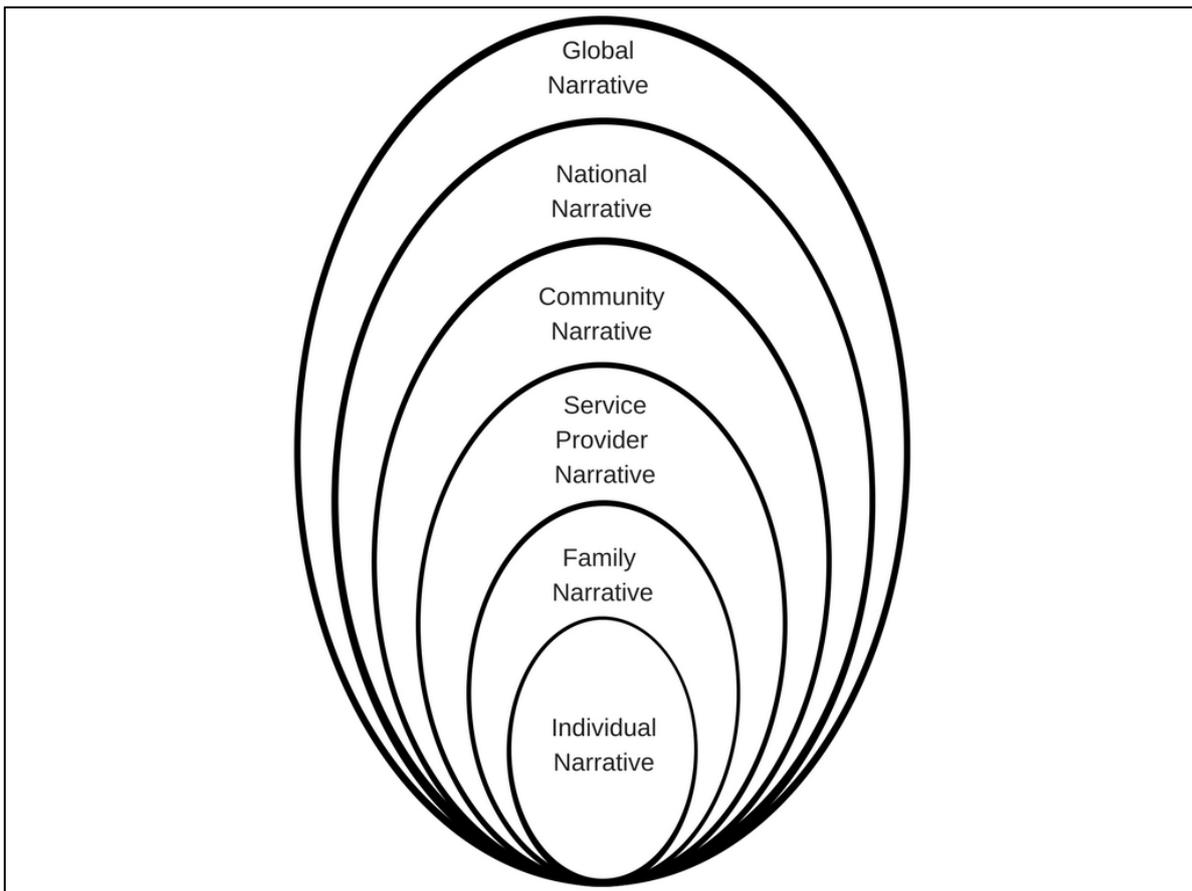
Figure 4. Nested narrative framework.

 [Image Description: Six different sized ovals sit inside each other. From the smallest oval to the largest, each level reads: Individual Narrative, Family Narrative, Service Provider Narrative, Community Narrative, National Narrative, Global Narrative.]

Individual narrative: Drawing on the disability rights mantra, "nothing about us, without us", the first and most important narrative my research sought to engage with was people with disabilities themselves. Recruiting and supporting participants with disabilities to narrate their own stories in their own way was the most crucial and defining factor of this research.

Family/Ally Narrative: According to the Ecological Systems Theory, the family narrative is located within micro- and meso- ecological systems of being (Bronfenbrenner, 1979). Family often play a significant role in the lives of people with disabilities, particularly when an individual lives with an intellectual, learning, neuro or complex disability. People with disabilities can sometimes find communicating and socialising difficult, meaning the relationships they have with family are all the more important. Moreover, families are often the decisions makers about things that affect the lives of a family member with a disability, including where they live, who supports them, who they have relationships with or how they spend their time. According to Mirfin-Veitch (2003, p. 3): "The amount of independence people have in their lives often depends on their families' views and attitudes". Other reasons for involving family in the research process is that family members are often uniquely placed to consider lines of inquiry that are relevant and likely to have a positive impact on their lives (Morris, Shilling, McHugh, & Wyatt, 2011).

Service Provider Narrative: Service providers are entities that embody certain philosophies, values, policies and practices, which directly influence practice, the provision of treatments and the way services are organised and delivered (Morris et al., 2011). As was revealed in the reviewed literature, conflict and instability can often lead to disability services being the first to be reduced as efforts are appropriated for war economies (Grove et al., 2010; Ortoleva, 2010). With regards to displaced and refugee populations, people with disabilities are often overlooked by service providers (Crock et al., 2012; Reilly, 2010) or are in competition with other disadvantaged groups for support and services. It might be noted that within Disability Studies there is tension around drawing on the knowledge of people without lived experience of disability as "experts", rather than people with disabilities themselves (Oliver, 1992). In previous chapters, I have discussed some of the critiques around expert knowledge, which has traditionally been considered superior to the knowledge of people with disabilities. While the personal narratives of people with disabilities, followed by their families and allies, remained the priority, I was also interested to see how the interactions, or what Dugan (1996) refers to as the relationships, between people with disabilities and service providers within different ecological systems influenced attitudes and decision-making processes, as well as the impact this had on people with disabilities and their narratives. Specifically, I was interested in what contributing factors (for example, attitudes, supports, services, devices or interventions) had had a positive impact on people with disabilities, their families and allies during conflict and displacement.

Community Narrative: The next targeted source of knowledge came from what Lederach (1997) refers to as grassroots and middle-range leadership. A grassroots leader refers to local leaders, community developers, local health officials or refugee camp leaders, while middle-range leaders come from respected sectors such as religious or ethnic groups, academics and intellectuals or humanitarian leaders. I kept this category broad, as I knew access could be a challenge. However, grassroots and middle-range leaders can provide insight into activities aimed at reducing disablism at subsystem and system levels, as outlined in the Nested Paradigm.

National narrative: To understand national disability narratives, ideally this research would have sought the contribution from those who Lederach (1997) refers to as top-level leaders positioned at exo- and macro- ecological system environments, in order to understand systemic perceptions of, and responses to, disability. Due to limited time and resources, national narratives relating to disability were woven throughout the findings chapter but were not pursued by means of interviews with top-level leaders.

Global narrative: The final narrative that had significant influence over research design and the analysis of findings was the models of disability presented in Chapter Two, and most importantly, the CRPD. Established in 2006, the CRPD is hailed as one of the greatest landmarks in the global struggle to reframe the needs and concerns of people with disabilities in terms of human rights. It is also regarded as one of the most significant instruments contributing to the empowerment of the world's largest minority to claim their rights, and to participate in international and national affairs on an equal basis with others (Kayess & French, 2008). In the context of this research, the CRPD was used as a framework from which all other narratives and data were analysed beside or within.

Participant Recruitment

Both Disability Studies and PACS are disciplines that at times require researchers to engage with disadvantaged or marginalised groups. Sensitive research refers to inquiries that involve the private sphere of an individual (Robertson, 2000), that have potential costs to the participant (Lee & Renzetti, 1990) or that require the disclosure of behaviours and attitudes that in other circumstances would be kept private and personal because of their potential to lead to social censure, disapproval or discomfort (Wellings, Branigan, & Mitchell, 2000). As such, it was crucial for this research to be designed in a way that was sensitive to the impact

that data collection might have on the participant, researcher, wider community and the research as a whole.

With this in mind, I chose "snowballing" as my primary method of recruitment. Snowballing is well suited to research that involves sensitive issues, private matters or when insider knowledge is necessary for locating participants. It is a process that yields participants through referrals made by people who know of or who share characteristics relative to the research questions (Biernacki & Waldorf, 1981). As such, participants were recruited by key contacts within non-governmental organisations (NGOs) working with refugees and asylum seekers in Ecuador. After being provided with a written advertisement in plain Spanish,[4] key contacts (such as, Hebrew Immigrant Aid Society (HIAS), the UN HCR (United Nations High Commissioner for Refugees) Lago Agrio, the Refugee Education Trust (RET), Volunteers Organization for International Co-operation (OVCI), and the Mennonite Church) initiated a snowballing technique to identify people with disabilities within their asylum seeking and refugee communities. Information sheets were provided to potential participants in plain Spanish, and if requested, other accessible formats were available. Participant demographics are provided in Chapter Seven.

Inclusion and Exclusion Criteria

The main priority of this project was to engage directly with people with disabilities themselves. Inclusion criteria included people affected by conflict or violence in Colombia or Venezuela who identified as living with, or having a family member who lived with, a disability. Further interviews were conducted with family members, supports, allies, service providers and community leaders, who were directly involved with asylum seekers and refugees with disabilities. Targeted streams of recruitment within these populations included people with disabilities who faced increased barriers to inclusion and representation. This included women with disabilities, people with disabilities unrelated to the conflict (for example, congenital, hereditary or acquired) and people with intellectual, learning, neuro or complex disabilities. To ensure maximum inclusion and accessibility for participants, every possible effort was made to ensure the design of this research was accessible to as many people as possible. This included the availability of:

- Written documents translated into Plain Spanish;

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[4] Plan language is a style of writing in which the wording, structure, and design of verbal or written information all work together to help the participant (Plain Language Association International, 2018).

- Written documents made available in alternative formats such as Easy Read,[5] Braille, large print (when requested);

- Accessible interview locations;

- Spanish-English translators for translating verbal communication;

- Sign language interpreters for people who were D/deaf or hard of hearing (when requested);

- Other supports when requested.

In order to take part in this research, it was necessary for participants to demonstrate that they had a general understanding of the research and what participation involved, as well as provide informed consent. If an individual could not provide informed consent, they were not permitted to participate. Participants under the age of eighteen years of age required guardian consent to take part.

Ethical Considerations

In Chapter Three, the axiological assumptions of the transformative paradigm, as outlined in the Belmont Report, were defined: respect, beneficence and justice (National Commission for the Protection of Human Subjects of Biomedical Behavioral Research, 1978). Ethics is very much at the heart of the who, what, why, where and how of this research project. Listed below are the measures that were put in place to ensure that ethical considerations specific to "vulnerable" research populations, such as people with disabilities, people affected by conflict and displacement, as well as children, were observed.

A note on "vulnerability"

Before outlining the ethical considerations of this research, I feel it is first important to discuss what is meant by the term "vulnerable"; a word that has been used throughout the reviewed literature. "Vulnerable" is a term with an array of meanings. In research, it has been applied to groups that are "more likely than others to be misled, mistreated, or otherwise taken advantage of as participants in research studies" (Levine, 2004, p. 396). In the Belmont Report, vulnerable populations refer to participants who might bear unequal burdens in research (Ferreria, Buttell, & Ferreria, 2015; Levine, 2004). In the context of disaster or conflict, it has been used to describe characteristics of an individual or group in a particular

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[5] Easy Read is a form of communication designed to support people with intellectual and learning disabilities so that they can better understand written information (People First New Zealand, n.d.).

situation that affects their capacity to anticipate, cope with, resist or recover from the impact of natural or man-made hazards (Wisner, Blaikie, Cannon, & Davis, 2005).

I have written the word "vulnerable" in inverted commas, as it is a concept that causes me discomfort. Vulnerability and its ontology have been debated within the context of disability, dependency and power, and has even been rejected by some people with disabilities who do not identify as broken, incapable or in need of protection, but as empowered and autonomous agents (Gustafson & Brunger, 2014; Scully, 2014). It is inaccurate to use vulnerable as a descriptor or characteristic of an entire group. Rather, it is a term that might be used to describe certain individual characteristics that may render individuals vulnerable in certain situations (DeBruin, as cited in Collogan, Tuma, Dolan-Sewell, Borja, & Fleischman, 2004; Mason-Bish, 2013). As Gustafson and Brunger (2014) ask, who has the authority to define a population as vulnerable and what constitutes a vulnerable population in need of special protections? They then go on to highlight that labelling an entire community as "vulnerable" assumes incorrectly that all members are similarly positioned and therefore disadvantaged, at risk, or in need of protection based on a single category of difference, such as living with a disability. Not only should this caution apply to the disability community but also for any community, including people affected by conflict. Indeed, people affected by disaster and conflict may have experienced vulnerable situations in which they have needed additional support and services. There is no evidence, however, suggesting that people who have experienced trauma or loss cannot participate knowingly and voluntarily in decision-making processes (Collogan et al., 2004). With that being said, listed below are the specific measures that were put in place to ensure that risk and harm were minimised during this research.

<div align="center">Ethical considerations: Participants with disabilities</div>

The participation of people with learning, intellectual, neuro disabilities or complex needs in research is a controversial matter. Traditionally people with such lived experiences have been perceived as vulnerable, open to coercion, inarticulate, uninformed, unable to understand or provide consent, or considered as having reduced capacity for autonomous decision making (Carlson, 2013; Iacono, 2006; McDonald & Kidney, 2012). As a result, ethics committees have become increasingly conservative in their decisions to allow people with learning, intellectual, neuro disabilities or complex needs to participate in research. When considering the controversial Willowbrook Study, which saw children with disabilities injected with viral hepatitis in search of a vaccine (Krugman, 1986), or eugenics research in 1930s and 1940s Germany (Barnes & Mercer, 2003), there is good reason to be mindful of the ethical

considerations of including participants with learning, intellectual, neuro or complex disabilities in research.

However, a fine line exists between paternalistic protectionism and discrimination (Iacono, 2006). As highlighted by Nind (2017), universities who protect their territories with obstructive ethics committees and funding formulas are institutional barriers to inclusion. This research strongly promotes the inclusion and equitable opportunity for people with disabilities (Nind, 2017). In recognition that it is also necessary to employ strategies that safeguard all individuals from harm and exploitation, outlined below are the extra steps I took towards ensuring that respect, beneficence and justice were specifically applied to "vulnerable" populations within this research project. These strategies have been strongly influenced by research conducted by the Donald Beasley Institute, a New Zealand-based research institute whose aim is to advance the health and wellbeing of people with intellectual disabilities (learning disabilities) through applied research, evaluation and education (Donald Beasley Institute, 2018).

Informed consent

There are three central aspects to informed consent: the provision of accurate and unbiased information about the research; ensuring an individual is capable of making a decision about their involvement in the research; and ensuring a choice is made freely and voluntarily (Thomson, Roberts, & Bittles, 2014). To ensure consent was informed and voluntary, all participants were provided with information sheets and consent forms in plain Spanish. Plain language is a style of writing in which the wording, structure, and design of verbal or written information all work together to help the participant. A document written in plain language is easy to read, understand, and act on after just one reading (Plain Language Association International, 2018). Plain language allows people who are illiterate, do not speak the presented language fluently, who are senior citizens, or people who live with sensory, intellectual or neuro disabilities, to participate more easily because they can understand the information presented to them. All of the documents used in this research were provided in plain Spanish. In circumstances where either the individual participant or their support networks were illiterate, plain Spanish documents were read aloud. After being provided with accessible information, if the individual or their support person expressed any doubt, research was suspended, advice sought, and a final decision was made based on the guiding principles of the Belmont Report and the CRPD.

Capacity to consent

In order to take part in this research, it was necessary for participants to show they had a general understanding of the research and participation, as well as provide informed consent. This was achieved by asking all participants to explain their understanding and expectations of the research and their participation. If an individual could not do this, they were not permitted to participate. Participants under the age of eighteen years required guardian consent to take part in this research.

Minimising coercion

A further consideration was the power imbalance that can sometimes occur between people with and without disabilities, as well as researchers and participants. This can be more pronounced for people with intellectual, learning, neuro or complex disabilities. Practical steps I took towards minimising coercion included:

- Asking participants to explain their expectations of the researcher-participant relationship;
- Regular reassurance that participation would not compromise services;
- Regular reminders that participation was voluntary;
- Requesting that participants explain their reasons for participation;
- On-going monitoring of compromised voluntariness (for example, non-verbal cues and non-participation);
- Being aware that a lack of objection did not necessarily imply consent;
- Regular reminders that participants did not have to answer questions;
- Eschewing coercive incentives;
- Encouraging participants to consult with their support networks prior to agreeing to participate, as well as during participation;
- Ensuring trusted support people were present or nearby as requested or needed (adapted from McDonald & Kidney, 2012, p. 33).

Ethical considerations: People affected by conflict and displacement

A further key ethical consideration was the trauma of conflict. Research is vital for understanding the circumstances, problems, needs and concerns of people exposed to highly stressful experiences. However, it is not a neutral exercise, especially in the context of armed conflict, civil strife and displacement. Risks of conducting research with people affected by conflict and displacement can include data being used as intelligence, identification or

conscription, negative consequences of participants sharing information and interviews may touch on sensitive issues, painful experiences leading to re-victimisation or Post Traumatic Stress Disorder (PTSD) (Boyden, 2000).

Whether unintentional acts of nature or human-made events, disaster can have a profound effect on those who experience them. Although the risks and benefits of participation in conflict-related research are not yet fully understood, most scholars agree that there is need for more research in the aftermath of conflict and disaster (Collogan et al., 2004). Such research can provide critical information on the types of mental and physical health problems likely to occur post-disaster; the risks and protective factors; side effects of post disaster interventions for first responders, survivors and victims; and the types of services victims are most likely to use and be satisfied with (Kilpatrick, 2004). While the general principles of ethics used in research unrelated to disaster are similar to those in a post-disaster environment, the unique circumstances avail themselves with the following special considerations.

Decisional capacity

The extent to which people affected by disaster or conflict are able to make capacitated and voluntary decisions to participate in research is virtually unexplored. It is, however, possible to extrapolate data from related studies which have assessed the decision-making capacity of people following a traumatic event and who have had ongoing experiences of Post-Traumatic Stress Disorder (PTSD) or acute stress disorder (ASD). According to ten years of reviewed literature, Rosenstein (2004) concludes there are no data suggesting that the experience of severe trauma renders an individual unable to make autonomous decisions. Furthermore, it is inaccurate and potentially stigmatising to assume that people affected by conflict cannot make decisions and choices for themselves. Even within the wider context of research, there is no consensus about what constitutes decisional making capacity (DMC):

> In considering this question in the context of research in the aftermath of disaster, our main conclusion ought to be the same: that most victims of a disaster would be expected to retain DCM despite expected degrees of extreme upset. Nonetheless, for certain types of studies involving victims of disaster, there may well be compelling reasons to consider the subject population under study as being vulnerable in this regard and therefore in need of additional safeguards. (Rosenstein, 2004, p. 379)

To ensure additional safeguards, Rosenstein (2004) suggests following the same protocols used in research relating to participants from other types of "vulnerable" communities.

Methodology

Conflict-related research methods should be as unobtrusive and non-invasive as possible (Ferreria et al., 2015). In the same way that disability-focused research tends to focus on discriminatory and negative experiences of the disability community, conflict-related research tends to focus on traumatic life experiences of those who experience conflict. However, my own research methodology has taken an alternative approach to PACS research by intentionally focusing on generative and positive narratives of resilience, survival, and human rights. As detailed in Chapter Four, the chosen methodologies of this research (namely, the transformative paradigm and appreciative inquiry) serve to both challenge problem-oriented approaches, while helping to minimise risk and harm to all who are involved in this research in unobtrusive and non-invasive ways.

Risks and benefits of research participation

It is expected that researchers, such as myself, will identify risks of partaking in research so that potential participants can make an informed decision about whether to participate or not. However, this can be a difficult task when participants themselves may have been exposed to vulnerable situations, and are affected by psychological, medical, economic or social difficulties secondary to a disaster or conflict. It is impossible to predict how these factors might influence a participant, and as a result, researchers often lack a reliable point of reference for making decisions about risk-benefit procedures and consent. Common sense approaches can open a researcher up to a range of decision-making errors and as a result, it is necessary to be aware of the potential negative consequences the research might have on the participants, while devising protocols to minimise potential and unforeseen risks (Newman & Kaloupek, 2004).

Research relating to instability or conflict must be in the best interests of people affected by those situations; it is generally agreed that best interests include life, safety and security (Mfutso-Bengo, Masiye, & Muula, 2008). One of the risks associated with conflict-related research is the potential for emotional distress and discomfort during interviews. Though this project utilised appreciative inquiry, there was still space for participants to report on traumatic life experiences if they chose to. Throughout the interviewing process, particular care was taken to avoid any emotional stress or psychological discomfort. If at any point a participant appeared uncomfortable or upset and I was unable to return the discussion to appreciative lines of inquiry, I was prepared to suspend the interview, and ask the participant if they wanted to continue. While this did not occur, on several occasions I did remind the

participant they could stop at any time, at no disadvantage to themselves. Furthermore, in each field location established relationships with key NGOs meant that participants could be referred to contacts equipped to deal with issues relating to displacement and conflict, if appropriate.

Informed consent

There are many reasons why a person affected by conflict might be motivated to participate in research. This can include not wanting to appear unhelpful during a time of need or as unpatriotic. It has also been found there is potential for people affected by conflict to consent to research participation because they have confused the purpose of the research (increasing knowledge) with the opportunity to access supports and services. Informed consent processes that are accessible and inclusive were used with all participants regardless of ability or disability to ensure the purposes of the research were clear and understood, and that the benefits of the research were not exaggerated (Collogan et al., 2004).

Cultural sensitivity

Disaster and conflict researchers will almost certainly encounter situations where they are faced with gender and cultural situations that could hinder inquiry (Rubin & Babbie, 2011). It was necessary for me to be able to adapt my research design to facilitate approaches that were culturally appropriate and acceptable to the local community. Consulting with local NGOs was a crucial aspect of addressing cultural differences in a sensitive manner while in the field. Another important consideration was ensuring disability supports were culturally appropriate. Even though this did not occur, it was important to prepare for implementing culturally sensitive disability supports, for example, if a D/deaf person had particular requirements about the choice of interpreter based on gender, previous experience or language repertoire.

Member checking

Qualitative research, and specifically narrative based inquiries, deal with human experience, thought, memory and interpretation, which are all subject to change and transformation (Clandinin & Connelly, 2000). As a researcher, I brought my own values to the writing process, and as a result, the participant's story becomes an articulation of my values, communicated through content and form (McNiff, 2007). In recognition that narratives are not static or single representations of reality, but transforming, fluid thoughts that change over time, this project aimed to draw on a credibility technique referred to as "member checking"

to ensure collected data represented what the participant valued and wanted to communicate as accurately as possible (Lincoln & Guba, 1985). During member checking, participants were invited to review their interview transcript (in Spanish), and asked to check that it was consistent with their views and opinions.

Ethical considerations: Children

Children are not simply small adults and research results provided by adult participants are not necessarily valid or transferable to younger populations (Helseth & Slettebø, 2004). Under the United Nations Convention on the Rights of the Child (CRC), children are considered active agents with a right to express themselves on all matters that affect them (for example, see Articles 12 and 13) (UNHCR, 1989). Reflecting on childhood studies, Smith (2015) states that, "Children are considered to be people who can make a difference and contribute to creating their own futures, to sustaining their communities and to coping with difficulties, rather than being totally dependent on others" (pp. 10-11). However, research committees also accept that for research to involve children there must be minimal risk (Helseth & Slettebø, 2004). The most fundamental consideration in undertaking research involving children is deciding whether the research actually needs to be done, if children need to be involved, and in what capacity (Ethical Research Involving Children, 2013). It is generally agreed children and young people are considered "vulnerable" participants and research should only be conducted where their participation is indispensable, the study method is appropriate, and the circumstances in which the research is conducted provide for the physical, emotional and psychological safety of the child or young person (Ethical Research Involving Children, 2013). While this research did not actively seek the input of children as solo contributors, it was important to allow for the option of a child to participate along with their family, particularly if it was the child who was affected by disability. Steps taken to minimise risk to child participants followed the same guidelines listed above for the other "vulnerable" populations taking part in this research. This included developing an information sheet and consent form specifically designed for children, ensuring consent by both the child and guardian was voluntary and informed, ensuring the presence of a support person or family member, taking particular care to avoid discomfort or psychological harm, being aware of the power imbalance between children and adults, using appropriate terminology, using sensitive lines of questioning, as well as the availability of professional support if needed.

Compensation

The practice of providing research participants with cash or vouchers has become increasingly common within social science. Compensation can provide an important incentive for individuals to consider research participation (Head, 2009). For some researchers, omitting to pay participants is considered unethical, and payment can be a means of recognising and beginning to equalise power relations between researchers and participants (Thompson, 1996).

However, there is also potential for compensation to have unintended implications in terms of the ethical requirements for consent that can impact on recruitment and data collection (Head, 2009). Take, for example, undue inducement. Although minimal, there could have been risks and burdens associated with participation in this research. Concerns have been raised within academia that potential participants will feel pressured to participate because they are in financial need. When the inducement is so big it leads to individuals taking excessive risks, it is considered an undue inducement (Emanuel, Abdoler, & Stunkel, 2016). These ethical implications are particularly pertinent in the discussion of the participation of people with disabilities and people affected by conflict who may be in a position of economic disadvantage.

When considering these arguments and preparing to conduct the research, several points came to mind, the first was the level of risk associated with this research. At all stages, every effort was made to ensure participants were informed, consenting and aware of the risks and benefits of the research. Risks were minimised by careful planning, consultation and collaboration with the local NGOs. After speaking with representatives from these NGOs, it was agreed that their instigation of snowballing recruitment or association with the research could not be associated with financial payments. After careful consideration and further consultation, it was decided that participants would be reimbursed for any costs associated with the research, such as travel, and provided with refreshments.

Research Design and Data Collection

Interviews

This research project required participants to take part in a face-to-face semi-structured qualitative interview in an accessible location of their choice, such as their home or in a local cafeteria. Each interview took between one and two hours depending on the level of support

needed to participate. Participants were initially asked for their basic demographic information, such as age, nationality, time living in Ecuador and type of disability. Research questions were then presented in a semi-structured way, following the basic framework of the 4D principles of appreciative inquiry: discovery, dream, design and destiny (Cooperrider, 2012). For a full list of interview questions in English, please see Appendix A. While the tone of the questions very much focused on generative dialogue, the semi-structured design meant that participants were able to determine and narrate whatever issues, challenges, successes and suggestions they valued and wanted to communicate (Mertens et al., 2011). While I had initially intended to meet with participants on multiple occasions, logistical challenges relating to disability, poverty and security, prevented this from happing.

All of the interviews were recorded using a digital recording device. While in the field, data containing participants' names, contact details and any other personal information was kept in a different physical location from audio recordings taken during the interviews. All data and information were kept on password-protected devices (external hard drive and laptop). Access to these devices was limited to myself, research supervisors, and when necessary a translator or transcriber (recruited using a snowballing method).

Creative activity

During the interviews, all participants were invited to take part in a creative activity in which they could draw an image relating to key research themes. Participants were provided with necessary resources such as paper and colouring pencils. The purpose of this activity was to provide participants with the opportunity to express themselves in a way that may have felt more natural and comfortable than face-to-face interviews. While no adult participants chose to partake in this activity, several children enjoyed drawing pictures while their family members participated in the interviews.

Member checking

To ensure participants felt they had been accurately represented, when possible they were invited to go through a summary of the interview notes and transcripts. The purpose of this task was to provide participants with an opportunity to review and amend responses if necessary. Member checking in the context of disability and displacement is reflected upon and discussed in greater depth in the following findings chapters.

Data analysis

After returning to New Zealand, interviews were directly transcribed into verbatim transcripts by contracted transcribers, which included over eighteen hours of Spanish and English audio. Following this, transcripts were translated into English. This two-stage process was important when considering the authenticity of the translation and interpretation of different languages, regional colloquialisms, words and meanings. Transcripts were then loaded into NVivo, a computer software programme that supports qualitative research by helping to organise, analyse and code insights in semi- or unstructured qualitative data (NVivo, n.d.). The analysis process itself employed thematic analysis, Polkinghorne's (1995) analysis of narratives technique, and the narrative inquiry technique of storytelling as lived experience (Chase, 2011).

The first two research questions (What can we learn from people with disabilities about the intersectionality of disability, conflict and displacement? And what can we learn from people with disabilities about protecting and promoting the freedoms, rights and dignity of people with disabilities affected by conflict and displacement?) primarily drew on the narratives of people with disabilities, their family and allies, as well as service providers. As such, thematic analysis was used to understand and analyse themes and patterns within the narratives in a systemic way. Thematic analysis is a method of identifying, analysing and reporting themes within data, in relation to key research questions (Braun & Clarke, 2006). Within this research, this meant initially identifying a broad range of appreciative inquiry themes before beginning to analyse the transcripts. Based on the 4D principles of appreciative inquiry, themes included what participants appreciated about living in Ecuador, what is currently working well, what is not working well (challenges), suggestions and recommendations, and what a future looks like where the participants' rights, freedoms and dignity are being upheld. Within these broad appreciative inquiry themes, sub-themes or nodes were generated and grouped as they emerged across the transcripts. This is known as the analysis of narratives approach, whereby I moved from stories to common elements, collecting storied data, which was then analysed through paradigmatic processes (Polkinghorne, 1995). In this way, although broad appreciative inquiry themes had been predetermined, participant transcripts generated the specific issues, challenges, successes, suggestions and recommendations that were most valued and commonly communicated by the participants (Mertens et al., 2011).

The third key research question, which focuses on promoting inclusive and accessible positive peace through the process of PACS research and activities, drew on the narrative inquiry

technique of storytelling as lived experience (Chase, 2011). Similar to thematic analysis in that common themes and patterns were generated, identified and examined, the narrative inquiry technique of storytelling as lived experience was used to focus on the actual interview process and the engagement of participants in the methodology, which had drawn on the transformative paradigm and appreciative inquiry. This included reflecting on how participants responded to the appreciative inquiry questioning technique, the types of stories that were told, words that were used, body language, and how these developed over the course of the interview. Further analysis also included drawing on my own observations, field notes, interview transcripts and informal de-briefing conversations with field translators. This final stage of analysis provided the basis for the applied aspects of this research.

Limitations and Strengths

Throughout this thesis, I have discussed the limitations and strengths of knowledge, power, research and academia, and the impact these might have on the participants, community, discourse, academic research and myself as a researcher. Listed below is a summary of these discussions.

Limitations

The first limitation to this research is my own inexperience with conflict-related trauma. There are two key aspects to this, the first being my limited experience in responding to the disclosure of traumatic life experiences, and the potentially negative effects that such disclosure might have on a participant's wellbeing. As discussed earlier in the chapter, this limitation brings a certain element of risk to the research. The second aspect of this limitation is the potential impact this research might have on me as an individual. When exploring sensitive research topics such as disability or conflict, it is not uncommon for researchers to experience vicarious trauma:

> This may leave researchers feeling methodologically vulnerable, verging on the distressingly incapable, because of emotional and anxiety challenges, and thus ill-equipped to deal with some of the issues that may arise in this context. On the other hand, it can be distressing for participants to talk about such events and they are rendered vulnerable by being asked to do so. (Melrose, 2002, p. 338)

For example, before entering the field it was important to consider how I might respond to the discloser of abuse or details relating to a topic I did not have the time or expertise to cope with effectively. In these circumstances, I was prepared to listen and empathise, however, I would not have probed or asked further questions (Shakespeare, 1997). Instead, I would have acknowledged their experiences and asked whether I had their permission to

refer them to a trusted local NGO, or someone else of their choosing. In the circumstance the participant declined, I would have reassured them of the anonymity of the research and asked whether they would like to include or omit the disclosed information in the data. Although this situation did not occur, it was important for me to prepare my response ahead of time, and respect and trust the participant's autonomy of choice or supported decision-making in these circumstances.

The second major limitation of this research relates to power and representation. As earlier discussed, there are concerns within the field of qualitative research about the role of the researcher in the context of the researched. Qualitative research entails much more than simply observing the lives of others, but calls on researchers to listen, collect, and participate in the polyphonic way participant narratives are either resisted or reproduced (West, 1993). While every measure was taken to remain unbiased and to represent the participants fairly and accurately, it is impossible to claim absolute objectivity. As highlighted by Fine (2009, p. 189), "Objectivity is an illusion – an illusion snuggled in the comforting blanket of positivism – that the world is ultimately knowable and secure."

I have no doubt that as an outsider (New Zealander) and partial-insider (person with a disability), my own life experiences have influenced the research process, in particular, the stages of data collection, analysis and interpretation. With this in mind, I employed a number of techniques to ensure I remained aware of these biases, while doing what I could to minimise their impact or, when appropriate, deliberately draw on them. This has included writing in first-person perspective to distinguish my own voice from the voice of the participants, regular reviews with my supervisors, consultation and collaboration with key NGOs, employing methodologies that privilege participant voices and member check-ins to ensure participants feel accurately represented.

The final major limitation to this research is time and resources. My attempt to begin to de-subjugate the knowledge and experiences of a small collection of people with disabilities affected by conflict, while challenging widespread ableist ideologies embedded in academia and society, is but a small drop in a vast ocean of critical approaches to tradition, hegemony and harmful discourses. This research would have benefitted significantly from a larger, more experienced research team, data collected from varying places of conflict, and a larger scope of participants over a longer period of time.

Strengths

One of the core strengths of this research has been the de-subjugation of subjugated voices (Foucault, 1980) and the problematizing of underlying assumptions that have remained unchallenged in existing literature within PACS (Alvesson & Sandberg, 2011). This research appears to be one of the first PACS academic inquiries into the disability narrative during conflict and displacement. While countless studies on disability and conflict have been conducted, I have not found any evidence of these two specific fields coming together to recognise the protection and promotion of the rights and dignity of the largest minority in the world.

The second key strength are the employed methodologies, methods and processes. As an emerging methodology, the transformative paradigm and use of appreciative inquiry distinguishes this research from other research in the field. It is both pure and applied. The aim has been to collate a rich and varied data set derived from in-depth interviews with various participants in different ecological environments. Each of the methodological approaches that have been discussed were carefully selected for their potential to have a positive impact on the rights of people with disabilities. With transformation as the goal, these methodologies, methods and processes have the potential to challenge intentional and unintentional subjugation of the narratives of people with disabilities in academia and beyond, by focusing on factors that have contributed to ensuring the fundamental freedoms, rights and protection of people with disabilities affected by conflict and displacement. Admittedly, it is a unique approach to take; that is, starting with research questions that prompt positive reporting rather than a traditional problem-oriented approach. However, this approach also has the potential to open up a range of positive research possibilities that align with values found in critical theory, the transformative paradigm and narrative inquiry. By taking this approach, I was also able to mitigate some of the negative effects that my lack of experience in post-disaster research might have had on the participants or myself.

The final key strength, I believe, is my own lived experience of disability. It is not often that I get to describe what is considered a deficit or weakness, as an asset. In Chapter Four, I outlined the challenges of insider research. The benefits of being a researcher with a disability who is conducting disability-related research, however, includes normalising the role of researchers with disabilities in academia (Brown & Leigh, 2018; Kitchin, 2000); that disability can serve as a "passport" of legitimacy (Seymour, 2007, p. 1193) or a "badge of authenticity and a marker of shared identity" (Brown & Boardman, 2011, p. 25); and that

disability can be a rapport-building experience, which breaks down unseen barriers of communication (Andrews, 2005). As summarised by (Brown & Boardman, 2011, p. 25):

> A disabled identity can help bridge the gulf between the worlds of the researcher and participant, offering a point of connection. Thus, while being attributed a disabled identity can sometimes be experienced as invalidating, during interviews it can unify, facilitate rapport and challenge traditional barriers of power and status.

Summary

In summary, Chapter Five has provided an introduction to the methods and processes that were employed within my research design. The chapter began by recapping the three key research questions, before my reasons for selecting Ecuador as a field location were presented. Bronfenbrenner's Ecological Systems Theory, Dugan's Nested Paradigm and Lederach's Peacebuilding Pyramid (Triangle of Influence) were then examined as mechanisms that influenced my framework for understanding the types of narratives my research sought to engage with. Next, participant recruitment, inclusion and exclusion criteria were presented, followed by an in-depth discussion on the ethical considerations of this research. Given that my chosen methodology sought the engagement of three research groups that academia has traditionally considered as "vulnerable", a significant amount of attention was allocated to ensuring the research methods and processes were ethical and suited to the participation of people with disabilities, people affected by conflict, and children. The chapter then outlined data collection methods, including the semi-structured appreciative inquiry participant interviews, a creative activity, member checking, and data analysis. Finally, the limitations and strengths of this research were discussed.

Chapter Five has provided a thorough overview of the methods and processes that were employed while documenting the narratives of people with disabilities and their families affected by violence and conflict in Colombia and Venezuela and who, after being displaced, are now living in Ecuador. The next chapter of this thesis introduces the findings of the field research by first outlining the historical, social, geographical and political contexts that set the scene for the narratives that were shared.

Chapter 6 – Context: Setting the Scene

> *"La discapacidad no es incapacidad sino parte de la maravillosa diversidad en la que vivimos."*
>
> "Disability is not incapacity, but a part of the wonderful diversity in which we live."
>
> - President Lenín Moreno (President of Ecuador, 2017)

Introduction

This chapter helps to establish the context of the interviews that will follow. As outlined in Bronfenbrenner's Ecological Systems Theory (1979), the key chronosystem milestones around the context of research interviews can help establish normative and non-normative life occurrences and transitions. Establishing context around the narratives that unfold in the following chapters helps bring richness and depth to understanding what it is like for people with disabilities who are seeking asylum and refuge from conflict and displacement. More specifically, it helps differentiate between the experiences of Colombian and Venezuelan asylum seekers with disabilities, as well as from those who experience conflict and displacement around the world where the political, geographical and social contexts are very different. The chapter begins with a description of the geographical context of the research and a brief history of the Colombian armed conflict and Venezuelan crisis. It then discusses figures and reports around Colombian and Venezuelan asylum seekers and refugees, before briefly addressing disability rights within the context of Ecuador.

From Where We've Come

The field aspect of this research took place in the South American country of Ecuador, with most interview participants coming from the three South American countries indicated in Figure Five: Venezuela, Colombia and Ecuador. Venezuela is one of four South American countries located entirely in the Northern Hemisphere, while Colombia and Ecuador are both traversed by the equator line, meaning part of each country is located in the Northern and part in the Southern Hemisphere. All three countries are coastal, mountainous (the Andean mountains) and include areas of Amazon Rainforest.

As depicted in Figure Five, interviews were conducted in and around three key locations:

1) Quito, the capital of Ecuador, which is located in the Guayllabamba river basin on the eastern slopes of Pichincha, an active volcano in the Andean mountains. At an elevation of 2,850 metres, Quito is the second highest capital in the world.

2) Lago Agrio, also known as Nueva Loja, is the capital of the Sucumbíos Province. It is a small town located in the Ecuadorian Amazon, close to the Ecuador-Colombia border. Lago Agrio is home to Ecuador's controversial Amazonian oil fields.

3) Esmeraldas is the north-western coastal capital of the Esmeraldas Province. Esmeraldas is the principal trading hub for the region's agricultural and lumber resources, and is the terminus to the Trans-Ecuadorian Pipeline that connects to the north-eastern oil fields.
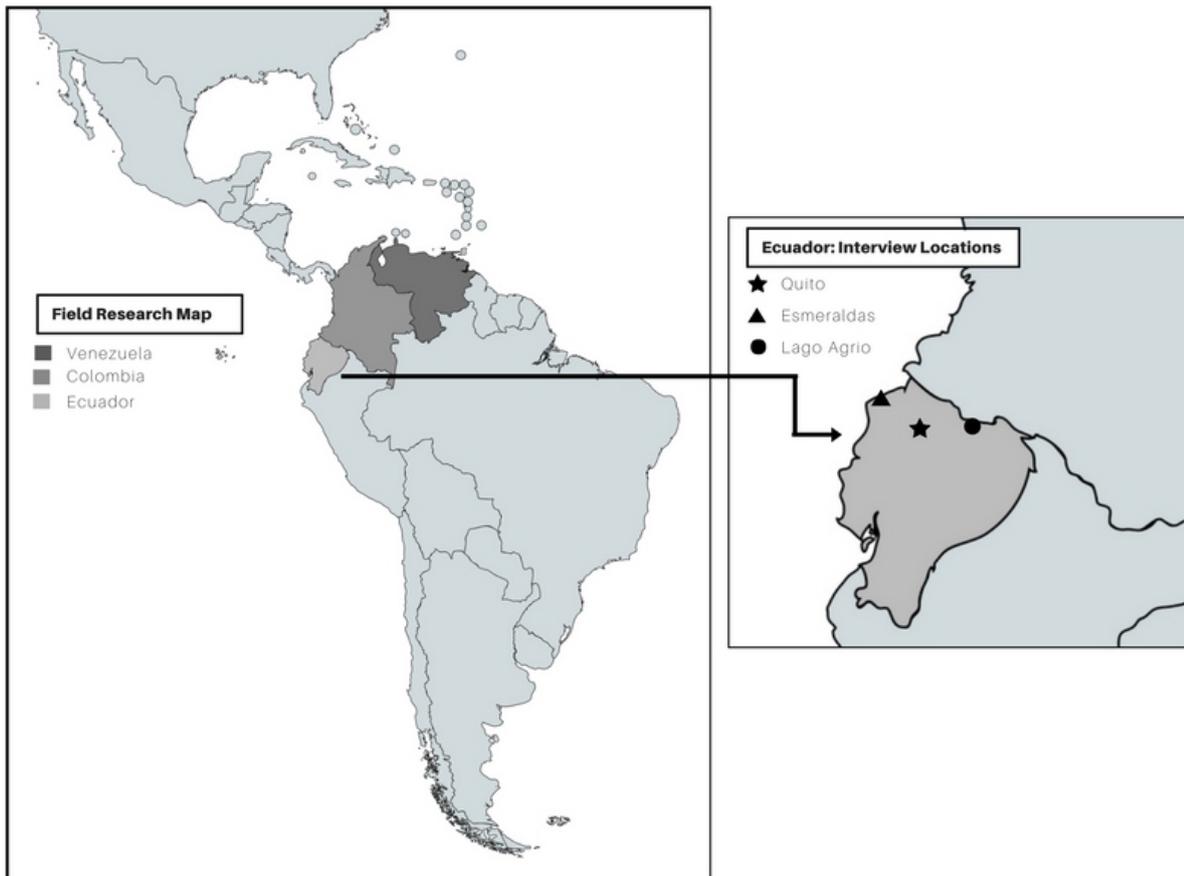
Figure 5. Field research maps.

[Image Description: Two images. The first map on the left is of Latin America. The top three north-western countries are shaded, and the legend shows the top shaded country is Venezuela, the next shaded country below Venezuela is Colombia, and the third country below Colombia is Ecuador. The second image is a close up map of Ecuador. The legend

indicates three field locations. The first is Quito in the northern central part of Ecuador, Lago Agrio is to the right of Quito on the border with Colombia and the third location, Esmeraldas, is on the north-western coast.]

The Colombian armed conflict

The Colombian armed conflict is a protracted conflict that has spanned over half a century, one of the longest and most hidden of recent history (Eboe-Osuji, 2012). The conflict is known for its complexity and multitude of stakeholders, which makes writing a complete, yet brief, historical summary a challenge. Outlined below is an attempt to do just that, an overview of key events beginning in the early 1900s until the landmark peace agreement of 2016.

The origins of the current Colombian conflict can be traced back to independence in the early nineteenth century (Ospina, 2016). More notably, however, is the period of violence and civil unrest that began to emerge from the Conservative and Liberal battle for political power during the 1900s. From 1930 to 1948 the two parties fell in and out of power, sparking fierce debate over land reforms and ancestral privileges. In 1948, following the assassination of a popular Liberal leader, violence broke out across the country. What ensued was a decade long period known as *La Violencia* or "Era of Violence", which claimed the lives of an estimated 200,000 people. In 1958, a truce was brokered between the two warring parties, bringing *La Violencia* to an end. This lead to the formation of a Conservative-Liberal coalition called the National Front, whereby the leaders agreed to rotate power (Molano, 2000). However, new and unforeseen substructures of violence emerged, with many Colombians in impoverished rural areas feeling excluded from the agreement. Convinced the Colombian political system was in need of a radical overhaul, many rural communities rejected the legitimacy of the National Front and refused to surrender their arms, instead forming leftist guerrilla insurgencies (LaRosa & Mejía, 2017).

What began as an ideological dispute quickly evolved into an intense conflict, driven by economic interests and territorial control. Key stakeholders in the conflict included the leftist guerrilla insurgencies, the Revolutionary Armed Forces of Colombia (FARC) and the National Liberation Army (ELN), amongst others. With the complicity of public officials, right-wing paramilitary counter-groups began to form (International Center for Transitional Justice, 2009). By the late 1970s, the FARC, who for the most part had spent their first fifteen years defending territory, building membership and increasing military capacity, opted to

switch to a more proactive and aggressive strategy, including strategic kidnappings, extortion and narco trafficking. Initially, the Colombian State attempted to negotiate peace with the leftist guerrilla groups by providing incentives – such as prisoner release, amnesty and a reduction of state action against guerrilla groups – to give up their struggle and to halt the growing collaboration between guerrilla insurgencies and drug traders. However, not only did the reduction in State action lead to an increase in violence, but it also caused significant backlash from those who were directly affected by the violence inflicted by drug traders and guerrilla groups. Paramilitary and self-defence groups grew in strength and number and unofficial ties with the military were forged, as weapons, ammunition and intelligence were shared. It was not long before paramilitary groups also turned to drug trafficking and extortion in order to fund their efforts (Latin Travel Guide, 2018).

By the late 1990s, an increase in guerrilla group operations prompted an upsurge of paramilitary activity. In 1997 a collective of small right-wing paramilitary factions came together under the name of Autodefensas Unidas de Colombia (AUC), proclaiming the necessity of armed self-defence due to the State's inability to provide protection for its citizens. With a membership of nearly 30,000 fighters, more than seventy per cent of AUC's funding came from the drug trade (Trent, 2012). The conflict between paramilitaries and guerrilla groups intensified, leading to the massacres of civilians accused of collaborating with guerrilla groups. Between 1997 and 2006, tens of thousands of cases of kidnappings, rape, massacres, extortion, drug trafficking and displacement were attributed to the AUC (Trent, 2012). On the other side of the conflict, the FARC, who had been displaced from strategic areas of drug trade and income by the AUC, responded by carrying out more roadblocks, mass kidnappings and extortion (Ospina, 2016).

In 1999 the USA and Colombian governments devised "Plan Colombia", a six-year aid package to end Colombia's conflict and eliminate drug trafficking, while promoting economic and social development within Colombia. Negotiated under President Bill Clinton's administration, the Plan linked economic development to the immobilization of guerrilla insurgencies and peace through militarism. The theory behind the Plan was that drug money sustained guerrilla group activities, whose violence justified the existence of self-defence and paramilitary groups, which perpetuated the conflict. As such, if drug money was eradicated, then the guerrilla groups would no longer be able to fund their violent operations, leading to a reduction of threats and violence. The paramilitaries, who existed to fill the security void, would then have little reason to exist (Marcella, 2001).

In the early 2000s, the Colombian Government, supported by the US government and military, entered into negotiations with the AUC, launched a counter-offensive against leftist guerrilla groups, and began aerial fumigation of large coca growing areas in the south of Colombia. The outcomes of Plan Colombia, however, were mixed. While the Colombian and US governments boasted the demobilisation of paramilitary groups, reclaimed territory, a reduction in violence, an end to mass kidnappings, as well as a reduction in coca cultivation, the actual effects on the trade of cocaine, social outcomes and human rights were highly controversial (Korovkin, 2008). Critics of Plan Colombia claim that even though the Plan was promoted as a drug eradication programme, its main intent was to, in fact, eradicate leftist guerrilla groups and sectors of society who advocated for social reform and who were hindering international plans to exploit Colombia's resources, such as oil (Stokes, 2005). While Plan Colombia is believed to have successfully reduced coca cultivation from 160,000 hectares to 48,000 hectares between 2000 to 2013, methods of eradication have been particularly harmful on the health of rural populations, and the environment, and alternative livelihood programmes for coca-producing regions have been poorly implemented (Mejía, 2016). Furthermore, contradictory reports by the Washington Office on Latin America (WOLA) and the UN have suggested that, in fact, land used to cultivate coca has increased, as has the production of cocaine within Colombia (Cosoy, 2016).

The human impact of the Colombian Armed Conflict

Characterised by widespread violence, political instability and blatant disregard for international law, a report released by the Centro Nacional de Memoria Histórica in 2013[6] revealed how widespread the atrocities of the Colombian armed conflict actually were. Between 1958 and 2013, approximately 220,000 people were killed as a direct result of the Colombian Armed Conflict, 80% of whom were unarmed civilians (Historical Memory Group, 2016). Over 7.7 million civilians have been forcibly displaced since 1985, generating the world's second largest population of internally displaced persons (IDPs) (Human Rights Watch, 2018). Evidence reveals there were more than 25,000 forced disappearances, although this number is believed to be much higher, and more than 27,000 kidnappings committed by guerrilla groups (25,482) and paramilitary groups (2,541) (Haugaard, 2014). One third of the 7.6 million registered war victims are children, and since 1985 a further 8,000 minors have been reported missing (United Nations Children's Fund, 2016). Between 1980 and 2012,

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[6] English translation: *BASTA YA! Colombia: Memories of War and Dignity* (2016).

1,982 massacres took place, the majority of which were committed by paramilitary groups, but also by guerrilla groups and the national military. Between 2001 and 2009, over 489,000 women were victims of gender-based violence, although again, the limitations of the research suggests that this number is probably a lot higher (Haugaard, 2014; Historical Memory Group, 2016).

A further consequence of the conflict was an increase in extreme poverty and socio-economic inequalities. Poverty and crime are inextricably linked with the Colombian armed conflict. Together with the impact of narco trafficking, at its peak the conflict increased both the socio-economic divide between Colombia's rich and poor, as well as a geographical divide between urban and rural populations (Gordon, 2016). With much of the violence occurring in rural areas of Colombia, many of those who were directly affected by the violence were forced to abandon their land and other assets. Internal displacement is one of the main causes of poverty in Colombia (Hinteregger, 2017). Alternatively, by remaining in rural communities and being exposed to crime, insecurity and violence, the risk of being exploited by paramilitary and guerrilla groups increased significantly (Gordon, 2016). While Colombia saw a significant decrease in extreme poverty rates between 2002 and 2014 (World Bank, 2016), they then began to increase again between 2015 and 2016. This is believed to be a consequence of displaced rural populations moving to larger cities where the poverty level is concentrated in specific urban areas. As most IDPs in rural centres are undocumented and have no assets or income, they have less access to public services such as health benefits or free education, and are at a higher risk of being trafficked (Hinteregger, 2017).

There is no doubt that the Colombian armed conflict has also had a significant impact on the lives of people with disabilities, as well as causing widespread physical, neurological and psychosocial disabilities. Even so, the number of people with disabilities who have been reported as victims of the conflict is unclear (Biel Portero & Bolaños Enríquez, 2018). According to the Registry of Victims, only 2.5% of victims identify as disabled, even though the actual number is expected to easily exceed 200,000 (Biel Portero & Bolaños Enríquez, 2018).

It should be noted that in a more general political context, Colombian jurisprudence has traditionally taken a very active role in protecting the rights of persons with disabilities, referring to disability rights in multiple laws (Correa-Montoya & Castro-Martínez, 2016). In particular, Colombia's Constitution of 1991 recognises that people with disabilities, who are

at increased risk of vulnerability and social exclusion, are the subject of special consideration. This includes a series of State obligations to adopt measures that provide special considerations for persons with disabilities in order to protect them against discrimination. It has generally been agreed that Colombia has made great progress in updating and harmonising its legal system in light of the CRPD (Correa-Montoya & Castro-Martínez, 2016).

In terms of public perceptions of disability, the social relational and rights-based models have led to significant advancements in recent decades, and disability is understood from a human rights perspective, rather than a matter of public health or rehabilitation (Correa-Montoya & Castro-Martínez, 2016). However, as in most countries, there are still many barriers to inclusion and access for the disability community. For example, travel blogs for people with disabilities praise efforts to ensure access within major cities, while cautioning that outside of the main cities, access to buildings, pedestrian paths and transportation is difficult, with many cafes, restaurants, hotels and residential buildings lacking step-free access. Local buses and taxis are not accessible for people with disabilities, further limiting movement and independence (Insight Guides, 2017; Woods & McColl, 2015). Given that many people who identify as disabled are also amongst the poorest in the country, a lack of access to medical services, rehabilitation and employment, means that they often do not benefit from state-funded welfare (Renoud-Lyat, 2015). According to the Administrative Department for National Statistics (DANE), an estimated sixty-one per cent of people with disabilities in Colombia have no income and only 15.5 per cent of people with disabilities who are of working age have some kind of occupation or income (Swedish International Development Cooperation Agency, 2014). Only 2.5 per cent of people with disabilities in Colombia receive the legal minimum wage or higher. Women and afro-Colombian minorities face increased barriers to economic and social inclusion. Illiteracy is three times higher than the rest of the population (22.5 per cent), with children and young people with disabilities being underrepresented at all levels of education (Swedish International Development Cooperation Agency, 2014):

> Even when there are great advancements in internal regulations which promote a social approach based on rights, it is clear that, in Colombia, the handout mentality and a medical rehabilitation approach are the predominant views. In practice, there is a close relationship between the concepts of disease and disability underlying the existing and implemented programs and actions across the country. These still have the intention of "normalizing" disabled people, instead of developing a set of specific adjustments to the environment which are necessary for people with disabilities to be included and have actual participation. This is also evidenced through practices such as Teletón and other similar actions carried out across the country, which stick to the classic approach based

on charity that seeks to obtain resources, out of pity, to be used for health, rehabilitation, and habilitation purposes exclusively. (Disability Rights Promotion International, 2014 section 2.2)

The Colombian peace process

In 2010, Juan Manuel Santos was elected as the President of Colombia. Having previously served as the Defence Minister in Álvaro Uribe's Government, Santos had been accused of directly carrying out controversial military operations. This included being linked to the *Escándalo de los Falsos Positivos* or "False Positives Scandal" in which members of the military lured poor and often disabled civilians to remote parts of the country with offers of work, killed them, and then presented their bodies to authorities as guerrilla combat kills, in an effort to inflate body counts and receive promotions or other benefits (Eleanor, 2017; Human Rights Watch, 2016). After being elected, however, President Santos took an alternative approach to the political challenges facing Colombia by actively seeking solutions to the conflict and bringing together the Government and FARC for dialogue. Negotiations between the two parties began in September 2012 in Havana, Cuba, with negotiators announcing a final agreement to end the conflict on August 24, 2016. However, in November 2016 a referendum to ratify the agreement was rejected by a plebiscite, with 50.2% votes against and 49.8% votes in favour (British Broadcasting Corporation, 2016).

Following the rejection, adjustments were made to the agreement and on November 30, 2016 Congress endorsed a "Final Agreement to End the Armed Conflict and Build a Stable and Lasting Peace". Even though the Agreement gives special consideration to women and indigenous populations, it has been criticised for excluding the disability community from both the negotiation process and for a lack of individualized attention within the final Agreement (Biel Portero & Bolaños Enríquez, 2018). At the time of my field research in 2017, the Colombian Government were in ongoing peace negotiations with the ELN.

The Venezuelan crisis

The second country from which participants came was Venezuela. While the Venezuelan crisis was not a context or perspective I had expected to include within this thesis, upon arriving in Ecuador it was clear that the recent influx of Venezuelan asylum seekers provided a unique opportunity to explore a more diverse scope of participants. Venezuela's economic, political, and constitutional crisis has a much shorter history than the Colombian armed conflict, and although it shares a major border with neighbouring Colombia, the crisis has emerged from a very different political and social context. While extensive research has been

conducted on the rise of Chavez and the oil economy of Venezuela, there is much less academic research on the human impact of the crisis or civil resistance. This is in part due to the censorship of media, with Venezuela being rated 143 out of 180 countries in the 2018 World Press Freedom Index (Reporters Without Borders, 2018).

Once Latin America's wealthiest nation, Venezuela holds the world's largest proven reserves of oil. In the space of just one decade, however, it has plunged into crisis: the national currency, the Bolívar, has completely collapsed and an extreme shortage of food and medical supplies has prompted a mass exodus of its citizens into neighbouring countries. Many who remain in Venezuela are afflicted by poverty, malnutrition, instability and violence (Venezuela's Deepening Crisis, 2017).

In 1999, Hugo Chavez, a populist socialist leader, began his Presidency with the promise of addressing the growing gap between the country's rich and poor. Having benefitted greatly from a prosperous oil industry, Chavez used the money from oil sales to fund social systems and services for Venezuela's most impoverished citizens. In 2013, Chavez passed away, and leadership of the country was passed to his handpicked successor, Nicolas Maduro, who continued to heavily invest in socialist policies. However, in 2014, following a plunge in oil prices, the Venezuelan economy took a significant hit and the country spiralled into economic and social unrest. Power outages and food shortages became common, and inflation increased at an alarming rate (Mitchell, 2016; Venezuela's Deepening Crisis, 2017).

Venezuela, having solely relied on oil export revenue to generate a healthy Gross Domestic Product (GDP), was now at a loss. With very few alternative exports or products, and no money to import basic necessities, the Bolívar lost 99% of its value in just five years. By the end of 2017, oil prices had dropped to their lowest in three decades. In January 2018, Stefano Pozzebon, a journalist in Caracas, reported being unable to withdraw even 191,000 Bolívar (the equivalent of one US dollar according to the black-market exchange rate) from an automated teller machine (ATM). It took the journalist four hours to withdraw 10,000 Bolívars (US 6 cents), which he then used to pay for a 35,000 Bolívar cappuccino. In response to the deepening crisis, in 2017 Venezuelans took to the streets of Caracas for more than ninety days, in protest of changes to the constitution and to demand elections and humanitarian aid. The Government responded to the protests violently, with more than 120 people losing their lives, according to State-run media (Pozzebon, 2018).

In particular, a drain in doctors and medical staff has had a significant impact on the disability community, with an estimated 16,000 physicians having left the country in the past twelve years (Venezuela's Deepening Crisis, 2017). Extreme food shortages have resulted in what locals refer to as the "Maduro Diet", with almost three quarters of Venezuelans losing an average of 8.7 kilograms in 2016 (Mitchell, 2016; Venezuela's Deepening Crisis, 2017). Many children suffer from malnutrition related illnesses. Infant and maternal mortality have both increased significantly, as have cases of malaria, diphtheria and other illnesses due to shortages in insect repellent and vaccinations. Since 2014, it is estimated that the number of people in poverty has increased from 48% to between 75-82%. The Government's response has been to militarise supply distribution. However, many of those who need food the most are not receiving it, in part due to corruption within the military, whereby food is diverted to military personnel and their families (Venezuela's Deepening Crisis, 2017).

Disability in Venezuela

From a disability rights perspective, Venezuela ratified the CRPD in 2013 and has since implemented important policies regarding the rights of people with disabilities (Global Accessibility News, 2016). When reporting on their progress to the CRPD Committee in 2015, the Venezuelan government highlighted the focus they had put on realising the rights of vulnerable groups, such as people with disabilities, since Chávez's assumed presidency in 1999 (Bolivarian Republic of Venezuela, 2015). For example, in 2014 the Venezuelan Government established a Council for People with Disabilities, for the purpose of reducing stigma around disability, strengthening the participation of people with disabilities in state and societal affairs, increasing awareness of disability and eliminating discrimination. According to Telesur (a multi-State funded television network including the Venezuelan Government), in addition to the Council, Venezuela has also instituted health programmes focusing on the needs of people with disabilities and has increased access to education (Telesur, 2014).

However, contradictory reports emphasise the significant impact that the economic crisis, which has caused major shortages of food and medical supplies, has had on people with disabilities. For example, in 2016 *New York Times* reporters visited six state-run psychiatric hospitals throughout Venezuela (Kohut & Casey, 2016). They found a lack of running water, food scarcity that was causing patients to rapidly lose weight, a total absence of soap, toothpaste, toilet paper and hygiene products, and dwindling supplies of important medicines. With few other options, staff were forced to physically restrain otherwise mentally well

patients in solitary confinement, in breach of the CRPD. The Venezuelan government, however, denies that public services are suffering from shortages and continues to refuse offers of international medical aid (Kohut & Casey, 2016).

Seeking Asylum in Ecuador

Ecuador has been a popular destination for asylum seekers and immigrants for much of the last century, beginning with an influx of Jewish immigrants in the 1930s and 1940s (Converti, 2015). In particular, its commitment to asylum seeking populations has been internationally recognized as an example of best practice regarding the human rights of refugees (Ortega, 2013). In 2008, a reform to its Constitution ensured that refugees have access to the same rights and responsibilities as those afforded to Ecuadorian citizens, and that refugees can apply for Ecuadorian citizenship after just three years. However, the revision also altered the original definition of "refugee" and imposed a fifteen-day window for asylum seekers to apply for status after entering Ecuador (Converti, 2015). This has been problematic for asylum seekers, particularly those who recently fled violence and life threatening situations, who do not have the emotional, physical or financial capacity to apply within such a short window of time, who cannot prove when they entered the country and/or who experience feelings of deep mistrust towards law enforcement authorities where application processes take place (Arevalo-Carpenter, 2013). As will be discussed in the next chapter, challenges relating to physical access and accessible information in relation to the application process also provided further complications for asylum seekers with disabilities.

It is also interesting to note that in 2008 former populist leader, Rafael Correa, unilaterally lifted all visa requirements to enter Ecuador for a ninety-day tourist stay. Other than a partial reintroduction of visas for ten African and Asian countries in 2010 (Freier, 2017), most nationalities are able to enter Ecuador on a tourist Visa, including Colombian and Venezuelan asylum seekers. However, while many asylum seekers enter Ecuador on the ninety-day tourist stay, many do not complete the necessary applications for refugee status within the fifteen-day time frame. It is now estimated that 250,000 refugees live in Ecuador, the largest refugee population in Latin America. Of these, 60,500 are officially registered as refugees, with another 175,000 seeking asylum (Asylum Access, 2014). 87.5% of recognised refugees are Colombian citizens, while 12.5% are from other countries (Hebrew Immigrant Aid Society, n.d.). Unlike other host countries, asylum seekers and refugees in Ecuador do not live in

camps but settle and integrate into urban settings. It is estimated that 60% of the refugee population live in urban areas, and 40% in rural zones (Feinstein International Center, 2012).

Colombian asylum seekers

During the 1990s, as Colombia's protracted armed conflict spread throughout the country, Ecuador became the most frequent country of refuge for displaced Colombians (Shedlin, Decena, Noboa, & Betancourt, 2014). Spanning over 200 nautical miles of sea and 586 kilometres of land, the Colombia-Ecuador border is largely made up of remote hard-to-reach farming communities nestled amongst dense Amazonian rainforest. Border populations are often impoverished and lack access to basic infrastructures such as sewage, electricity and clean water. It is estimated that Ecuador's northern border is home to 85% of all Colombian refugees, asylum seekers and populations in need of protection (Poe & Isacson, 2009).

Initially, all Colombians seeking asylum in Ecuador were granted refugee status. Reasons for fleeing Colombia include pressure to join paramilitary forces, threats against family members, violent disputes or threats from armed forces relating to property ownership, the possession of money, witnessing violence or for refusing to participate in one of the armed groups (Shedlin et al., 2014). According to the UNHCR, only 709 Colombian refugees were registered in Ecuador between 1996 and 2000 (Poe & Isacson, 2009). However, by 2001 the number of applications for asylum increased exponentially. As the number of applications rose, rejection became common, and approval rates for asylum applicants dropped from 87% in 2000 to only 30% in 2004 (Women's Commission for Refugee Women and Children, 2006). Neighbouring destination countries began to actively limit the spill-over effects by adopting deterrent measures, military operations, and border control systems to stem the increasing flow of Colombian refugees and, in many cases, systematic deportations. In doing so, neighbouring countries breached their commitments owed to refugees under the 1951 United Nations Convention Relating to the Status of Refugees, the 1967 Protocol Relating to the Status of Refugees, the 1969 American Convention on Human Rights, and the 1984 Cartagena Declaration on Refugees (Gottwald, 2004).

Using a narrow and selective definition of "refugee" taken from the Cartagena Agreement, asylum seekers are only considered eligible for refugee status if they can prove they have been victims of large-scale, well-documented massacres or if they can provide undeniable evidence of individual persecution (Korovkin, 2008). Other reasons for being refused asylum include:

- The requirement to produce evidence of immediate danger such as a death threat letter or another document justifying fear of persecution (Korovkin, 2008);

- The complexity of the conflict and its stakeholders, making it difficult for an individual to explain why they are seeking asylum;

- The perception that asylum seekers are members of armed groups, often because they were forced to provide supplies for them;

- The perceived association with coca cultivation and the international drug trade;

- The requirement to produce a *pasado judicial* or a clean criminal record, "…as most asylum seekers come from rural areas where stopping by a police station to get a certified criminal record is impossible or even dangerous" (Poe & Isacson, 2009, p. 5).

When considering these challenges and reasons for refusal through the lens of disability, asylum seekers with disabilities face significant barriers to safe passage and asylum. For example, there are added challenges of collecting proper legal documentation when you have a physical, sensory or intellectual disability, or the difficulties a non-verbal individual might have when asked to explain why they are seeking asylum.

By circumventing the application for refugee status, not only do asylum seekers avoid the complexities of the registration process, but also discovery by, or reprisal from, Colombian guerrilla and paramilitary members located within the Ecuadorian side of the border (Women's Commission for Refugee Women and Children, 2006). However, without papers, asylum seekers regularly become the target of police abuse, unemployment, human trafficking, discrimination in access to food, housing, education, employment and healthcare, and negative stereotypes (for example, Colombians are violent, criminals, gang members, thieves, guerrillas, and promiscuous), leading to increased isolation, hardship and targeted violence (Shedlin et al., 2014).

While much of the hardship experienced by asylum seekers has occurred as a result of misunderstanding and misinformation, it must be considered within the larger context of the challenges faced by Ecuador as a host country (Shedlin et al., 2014). The Ecuadorian government and society is grappling with its own complicated humanitarian issues and economic limitations. In 2000, as the influx of Colombian refugees sky-rocketed, 60% of Ecuadorians were already living below the poverty line. Even though communities welcomed their Colombian neighbours, the already strained public resources and services were put under even more pressure, resulting in Ecuador having to "share their poverty with

displaced Colombians" (Korovkin, 2008, p. 326). Over the past decade, poverty levels within Ecuador have declined significantly, owing to high oil prices and external financing. Between 2006 and 2014, GDP growth averaged 4.3% and poverty declined from 37.6% to 22.5% (World Bank, 2017). However, this does not take into account the circumstances of unregistered asylum seekers and the recent influx of Venezuelans seeking asylum.

Venezuelan asylum seekers

It is estimated two million Venezuelans have fled their country since Chavez came to power in 1999 (Venezuela's Deepening Crisis, 2017). According to a recent press briefing by UNHCR spokesperson, William Spindler, in 2016 there were some 27,000 Venezuelan asylum seekers world-wide, although it is believed that this figure only represents a small fraction of Venezuelans who "may be in need of international protection, as many do not register as asylum seekers, despite the fact that many have indicated that they fled because of violence and insecurity, as well as an inability to meet daily subsistence needs" (Spindler, 2017 para. 3). Some of the challenges posed by the large influx of Venezuelans in neighbouring countries include international protection and physical security, lack of documentation, sexual and gender-based violence, exploitation and abuse, lack of basic rights and services, as well as being exploited by local host populations.

Ecuador is both a destination and a transit country for Venezuelans on their way to Peru and Chile. As of October 2017, Government data on arrivals and asylum claims estimated that 62,000 Venezuelans were living in Ecuador, 40% of whom had obtained temporary residence permits. A further 500 Venezuelan asylum seekers were crossing the Colombian border into Ecuador every day (UNHCR, 2017). Even though there appears to be very little information, research or literature on the experiences of asylum seekers from Venezuela, particularly in relation to disability or Ecuador as a host country, my personal experience was that the presence of Venezuelan asylum seekers seemed to be, anecdotally, felt strongly by both Colombians and Ecuadorians.

Many Venezuelans I spoke to informally had come to Ecuador on a ninety-day Tourist Visa in search of money, food and medical supplies. While I was waiting to catch a bus following an interview, a young man approached me selling donuts. Using a mix of Spanish and English he told me that he was a medical student from Caracas, the capital of Venezuela, and that he had arrived in Quito only a week before. He had abandoned his studies because he could not afford to eat, let alone pay for university. He said there was a curfew in his

neighbourhood, and if you were caught outside after dark, you were likely to be shot. He had come to Quito to make money so he could eat, but did not know whether he would apply for refugee status or not because he did not have the proper paperwork. Further conversations with Venezuelan nationals in Ecuador hinted at the difficulties they faced when trying to obtain refugee status in countries that actively support the Venezuelan socialist government, and who might not consider the Venezuelan context as a legitimate reason for refugee status. Certainly, the Ecuadorian government identifies as an ally of the Venezuelan government, and together with Cuba and Bolivia, openly declared their support for Maduro in 2017, while attacking US sanctions against Venezuela as "imperialist interference" (Phillips, Brodzinsky, Agren, Collyns, & Goñi, 2017 para. 20).

On an interesting side note, in September 2015, President Maduro of Venezuela pledged to resettle 20,000 Syrian refugees while reiterating his support for the al-Assad regime. The number is close to the estimates of Colombian nationals who fled Venezuela following the 2015 crackdowns in the border region (Esthimer, 2016).

Disability Rights in Ecuador

Over the past decade, Ecuador has seen major improvements to the rights of people with disabilities, who have historically faced a life of abandonment, exclusion and extreme poverty (Garcés, 2012). An investigation launched by then Vice-President, Lenin Moreno Garcés, in the mid to late 2000s, began to challenge and address negative perceptions of disability. Moreno, who was himself paralysed by gun violence in 1998, became the Vice-President of Ecuador in 2006. He immediately launched the *Ecuador sin Barreras* (Ecuador without Borders) programme, which then became legislation in adherence with the CRPD. From this legislation came two historic programmes addressing the rights of people with disabilities in Ecuador. The first was *Manuela Espejo*, an investigation conducted between 2009 and 2011, which documented the needs and incidence of disability in Ecuador. This was followed by *Joaquín Gallegos Lara,* which responded to the results of *Manuela Espejo* by delivering technical, housing, financial and training assistance to people with disabilities. Furthermore, it brought together fourteen ministries and institutions to sign an agreement with the Vice President's office to develop further policies (Garcés, 2012). From 2013 to 2016, Moreno served as a United Nations Special Envoy on Disability and Accessibility, and in April 2017, he was elected as the President of Ecuador – the first elected world leader to openly identify as disabled (Ulmer, 2017).

From my own observations, while the Ecuadorian disability community was visible and prioritised in theory and in policy (for example, state run television news bulletins had a sign language interpreter), research participants indicated that there was still a long way to go until disability rights were realised in practice, particularly in provincial regions. This reflects research from around the world detailing the disparities between access to disability and health services in urban and rural settings (Iezzoni, Killeen, & Day, 2006).

Summary

This chapter has set the scene for the ensuing findings chapters. It began with a brief overview of the three South American countries most relevant to this research, as well as key Ecuadorian locations where the research interviews took place. A short history of the Colombian armed conflict and the Venezuelan crisis was provided, which helped differentiate between the two conflicts and their root causes. Geographical and political contexts provided a framework, within which the different experiences of research participants can be understood. Finally, a brief overview of disability within the context of Ecuador itself was given. This chapter is important as it provides context around the narratives that will be presented, discussed and analysed in the following chapters. The next chapter is the first of five that will engage intimately with the responses of interview participants who have lived experience of disability and displacement. This chapter serves to bring a depth of understanding to the context from which the participants have come, and the personal experience of conflict and displacement in this particular region of the world.

Chapter 7 – Findings: Meet the Participants

> "We are the people, we have less chance of running, we have less chance of hiding, we have less chances to hear. We are the people... because of disability, we are the people... the first ones that could fall. […] Suddenly it's, "Save whoever you can!" And the person who uses a chair or a person with prosthesis, will not have the same ability to escape the problem, like a normal person."
>
> - Participant #2 (PwD, 2017)

Introduction

This chapter is the first of five that will draw on participant narratives, as well as my own observations, to explore the three key research questions of this thesis. It begins by introducing the participants as experts, and details the journeys that brought us together to meet in that particular time and place. In the context of disability research, one of the cornerstones of interpretive inquiry and emancipatory epistemology is that people with disabilities themselves, and not health professionals, social workers or researchers, are the true experts and "knowers" within an inquiry (Stone & Priestley, 1996, p. 715). As outlined in earlier chapters, the knowledge of people with disabilities has traditionally been subjugated for reasons that stem from structural and cultural violence. According to the Merriam-Webster online dictionary, the term "expert" refers to "having, involving, or displaying special skill or knowledge derived from training or experience" (Merriam-Webster, 2018). My hope is that these next chapters will convincingly argue that the special skills and knowledge of people with disabilities and their families, derived from the unique and intersectional experience of disability, conflict and displacement, is a knowledge worth de-subjugating.

This chapter also strives to appreciate and respect the journeys that have been endured by participants, and the challenges they continue to face. Although a core aspect of appreciative inquiry is appreciating the "best of what is" (Cooperrider, 2012), there is also danger in ignoring the shadows of human experience (Reason, 2000). This was articulated by many of the participants and summarised by a recently displaced Colombian asylum seeker with a physical disability which he had acquired as a result of an injury: "I am always sad, always

sad. I don't know what to do, I'm desperate and don't know what to do now. My day anymore, my day isn't happy or anything" (Participant #22, PwD). Indeed, most, if not all of the participants, faced unfathomable trials and tribulations relating to the intersectional experience of disability, conflict and displacement, and to only acknowledge and appreciate the "best of what is" would be unethical and do them a disservice. As a researcher, and fellow person with a disability, I feel obliged to designate this chapter to getting to know the participants; providing a safe space for the shadow of human experience to be expressed. Subsequent chapters will address appreciative inquiry, generative dialogue, solutions, recommendations and "the best of what is" in greater depth, including my own personal reflections on the methodology and process.

Let us first become familiar with the participants. In doing so, we, the academic community, acknowledge that those who have contributed to this research are much more than simply participants, refugees or asylum seekers, but are also human beings with pasts, presents and futures. They are human beings with hopes and dreams, as well as value, knowledge and expertise. This chapter begins with a demographic overview of the participants who contributed to this research. Next, the chapter follows the geographical journey of displacement by first outlining life in the participants' home communities and their reasons for leaving, their journeys towards displacement, and their lives in Ecuador. The chapter then concludes by addressing the first key research question regarding the intersectional experience of disability, conflict and displacement.

Participant Overview

Over the course of five weeks, twenty-five interviews were conducted with nine people with disabilities, eleven family members of people with disabilities and five service providers. Of those who identified as disabled, or as a family member of someone with a disability, some had refugee status, while others were seeking asylum from conflict and violence in Colombia (seventeen participants) and Venezuela (three participants). Interview locations included Lago Agrio (provincial border town in the Ecuadorian Amazon), Esmeraldas (provincial border town on the Pacific Coast) and Quito, the high-altitude capital of Ecuador.

Of the participants with disabilities, eight of the nine were male. All had acquired physical disabilities (four of these were a direct result of the conflict) and one participant also had a traumatic brain injury (TBI). The single female participant with a disability was blind. Quotes by participants with disabilities are indicated by the acronym "PwD", which has traditionally

stood for "people with disabilities". However, in the context of these chapters I have altered this to mean "participant with a disability". Of the eleven family members I spoke with, all were parents and siblings of a family member with an intellectual or neuro disability such as autism[7] or a type of Global Development Delay (GDD). Ages of people with disabilities and their family members ranged from two years old to thirty-nine years of age and also included an interview with a family member who was caring for four elderly refugees, one of whom was ninety-seven years old. Of the family member interviews, there were eight who were female and six males. In some circumstances, the family member who lived with a disability was present at the interview and was able to provide informed consent to participate. At other times, I only spoke to the parents and siblings about their own unique experiences as relatives. I have indicated family member quotes by writing "Family" after stating which interview the quote came from. It is important to note that while participants were given the option to use their name openly, many chose to remain anonymous – a choice that reflects the serious, delicate and sensitive nature of preserving the safety and security of themselves and their families.

Service providers contributed secondary information, which helped to contextualise primary data contributed by people with disabilities and their families. The five interviews with service providers included representatives from the United Nations High Commissioner for Refugees (UNHCR), Asylum Access, Refugee Education Trust (RET), the Mennonite Church, and the Sucumbíos Women's Federation.

Leaving Everything Behind

There are many reasons why an individual or family might leave their home community for a new country. For the participants from Colombia, reasons for leaving were mostly related to violence and threats of violence:

> Our lives in Colombia, we had a lot of violence and slaughtering […] We were there but we didn't die, the bullets passed near us. It made us feel fear, but thank God, all my family are alive […] Because God saved our lives during this conflict and also the plane over us, which was dropping fire. The plane was above us, we were below in the middle of the confrontations. (Participant #5, Family)

> They tortured my dad, the government tortured my father and killed my eldest son, two uncles and a cousin… (Participant #8, PwD)

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[7] For discussions on the autism paradox, see Evans (2018).

We left because of the violence, because of the armed groups, we had to leave our land, leave our land [abandoned] and we came here [...]. (Participant #16, PwD)

Yes, we had to pay a… oh, what's that called? To the ones that… they said they were from the FARC. I don't know, from the guerrillas. I don't know what the guerrillas wanted. The point is that they got us and since they saw that the store was going well and everything, we had to pay them every eight days. The store started going bankrupt. So, they started threatening us. The house, there were bullets, they lit our house on fire, they lit up bottles on fire and threw them at the house. They told [my husband] that if we didn't pay them that they would kill him and me. (Participant #23, Family)

And they killed my [colleagues], and they shot me. (Participant #24, PwD)

We worked on the streets and the reason why we are here is because of the violence. We came here because of the violence from the youngster gangs. They threatened us repeatedly and they robbed us repeatedly. Therefore, we denounced those who had harmed us several times and then we received death threats, therefore we left and came here. (Participant #25, PwD)

Further reasons for leaving their communities included family members being recruited for conflict related activities and in one case, the kidnapping and sexual abuse of a minor with an intellectual disability:

[…] because my partner… she has a seventeen-year-old son. From the age of thirteen, they started to persecute him. To chase him, to recruit him for the paramilitaries… he was followed up and according to what he said, if he didn't get recruited, if he didn't go with them, they would kill him. (Participant #15, PwD)

Why I left? […] In my neighbourhood new guys arrived, I mean the paramilitaries. I don't know how it happened, I sent her [my daughter] one morning to collect the money for something I sold. I realised that a paramilitary had kidnapped her all day. And I felt bad. I never met the guy. So, I was asking who he was, who was this guy? And I couldn't get an answer. So, the owner of the neighbourhood [leader of another armed group] told me that I shouldn't send her [my daughter] there because he had punished him because he didn't like what he did with her. I didn't report that to the police, but I felt outraged because she was only fifteen years old. (Participant #4, Family)

For the participants from Venezuela, reasons for leaving went beyond violence and threats, and also included the scarcity of food, medical supplies and health services:

For instance, I get to a supermarket... at least in my country there is no food. There is no food right now, you don't know why there is no food. (Participant #2, PwD)

Food was a particular concern for Participant Family #3, a family of five from Venezuela. The second son lives with autism and relies on a strict diet to remain physically and mentally well:

Father: One of the main reasons, apart from the insecurity… So number one safety. Number two his condition. They told me that he should follow a strict diet in a place

that I can't find anything to eat. What do I give him to eat? There's no maize flour any more. There's no rice. Rice, pasta, all of them had gluten but you can't even buy those! So I tell myself, 'What am I going to do, starve my child?' What do I give him? I have nothing to give him. Apart from that, he also has a digestive issue. (Participant #3, Family)

Participant #2 had suffered a spinal injury in his late teens and had left Venezuela because of the lack of medical support for people with disabilities. Now twenty-eight years old, he is a wheelchair user and travelled alone by taxi and bus from Venezuela, through Colombia and into Ecuador, in a desperate attempt to seek lifesaving medical treatment for a serious infection that had developed in his bones.

Participant: The situation is not only difficult at the level of... for feeding. At the hospital level as well. There is no gauze, there is no catheter, and there is no fever medicine. There are no supplies. So, if you go there... I have an infection in the bone called Osteomyelitis. I need to take medication and stuff to control it while I have surgery. And there are no medicines. There are people who suffer from hypertension, are diabetic, and don't get medications. They have been dying, they have been passing away.
Interviewer: Is it a result of the conflict?
Participant: Yeah, well... who knows if it's the conflict or the economy. But, there [are] no resources in the hospital. [talking a doctors voice] 'He needs some medicine for his pain and for some infections he has. And, he needs the medicine until he can get a surgery.' But, they don't have it in the hospitals and he says people […] for example… they die. There are normal people dying in hospitals […]. (Participant #2, PwD)

For other participants, sharing their reasons for leaving their home communities were simply too painful to talk about.

On the Road - Seeking Asylum

For many of the participants, travelling from their home countries to Ecuador was a reasonably simple journey. Time of travel ranged from hours to weeks, with most participants arriving by bus, taxi or by walking across the border between southern Colombia and northern Ecuador. Two participants came by boat through the Amazon and one of the families from Venezuela flew directly into Quito, the capital of Ecuador. As was discussed in the previous chapter, Ecuador is one of the only countries in the world that accepts all visitors on a three-month tourist Visa, regardless of where they come from, why they came, or how they got there. This made the experiences of the participants unique to this particular context, an experience that is not shared by people seeking asylum in other countries such as New Zealand, where refugee status must be granted prior to arriving in a resettlement country (New Zealand Immigration, 2018). However, this is not say the journeys of the participants were without difficulties or challenges. For many of the participants travelling from

Colombia, it was imperative to leave in secrecy, without warning, preparation, possessions or support, in order to preserve their safety. This meant that it was almost impossible to ensure family members with disabilities and health conditions were able to carry necessary devices and supplies with them:

> If we talk about leaving Colombia, in a situation of threat, in a situation where the integrity of my life is being affected, it is safest to leave without giving notice to the authorities. Go out on your own… without any warning. (Participant #17, PwD)

> I left in Venezuela everything I have built. I worked since I was around eighteen. I finished my high school. I went to university, but I worked as well. During all that time the little or a lot that I built in Venezuela; an apartment, a car and a truck, everything that I built in my life I simply gave it up. What I didn't give away, I sold, what I didn't sell I gave away. (Participant #3, Family)

For those who travelled long distances on public transport, for example by bus, a key challenge was being able to afford either the cost of transport or supplies during the journey:

> No, it was hard because I didn't have money for transportation and I had to beg to let me travel for less money because I had no resources and I was with my little baby, and by myself, and with a vision impairment, indeed, it was difficult. (Participant #25, PwD)

> Because sometimes the bus stopped, and we didn't have money to buy the food everyone else was buying. (Participant #3, Family)

These challenges were often exacerbated by inaccessible modes of transport. One participant who suffered a machete wound to the arm, described carrying his luggage as "cumbersome" (Participant #6, PwD), while another spoke of the risk of falling down and bumping into things when getting on and off the bus (Participant #5, Family). Participant #15, who had recently arrived in Ecuador by boat, spoke of the discomfort and pain of travelling with a disability on the water:

> Well, for me it was, yes, the most difficult thing was the transport, because my transportation was very difficult because I could not go down a step, because I was just beginning to [use crutches]… To use them, it generates a lot of difficulty. Because, little by little, I was going down the steps, the boy [step-son] was holding me to get off and then I got on the boat. That's the hardest thing… I had my lifejacket… when those boats jump, I felt the blow here in the foot [points to foot]. (Participant #15, PwD)

Further challenges included untrustworthy guides, criminal activity and cross border security: "Yes, you learn that you should not trust almost anyone" (Participant #9, Family).

Life in Ecuador

The amount of time each participant had been in Ecuador differed greatly, with some only arriving several months before and others having lived in Ecuador more than twenty years. Given the nature of the Colombian armed conflict, Colombian refugees and asylum seekers had generally lived in Ecuador longer than the three families and participants from Venezuela, who had all arrived within twelve months of our interview. There were many aspects of life in Ecuador the participants enjoyed, which will be discussed in greater depth in Chapter Seven. However, the most commonly appreciated aspect of Ecuadorian life was the *tranquilidad* and *seguridad* – the tranquillity and security. As highlighted by a UNHCR Field Director:

> It's interesting because when you ask people that come here, you ask them 'How are you feeling?', 'Oh, I am feeling peace. I feel this is really calm.' Even if you live in a very difficult environment with nothing, 'Oh no, this is nice.' It is for them. Because they feel they don't have that, that pressure even when you live in border communities where the presence of the conflict is still important, they don't feel the same pressure as they felt there. (Service Provider #11, UNHCR)

However, given that this chapter is dedicated to the reality of life for refugees and asylum seekers with disabilities and their families, it might be noted that many participants expressed deep frustrations with their lives in Ecuador. Keeping in line with Galtung's violence triangle (1990), I have categorised these challenges into direct, structural and cultural violences. In some instances the frustrations appeared to be born out of confusion and a lack of information. In these circumstances it is important to acknowledge that some of the frustrations may not have been legislatively or legally accurate, but a result of misunderstanding and misinformation. However, for the participants, they were a reality at the time of the interview and, therefore, a legitimate source of concern. Other challenges and difficulties were blatant violations of human rights, including the CRPD.

Cultural violence

I begin with cultural violence, which comes in the form of religion, law, language, art, science, or cosmology, and is enabled and perpetuated by institutions such as schools, universities and the media. It is the type of violence that makes structural and direct violence acceptable (Galtung, 1990, 1996). In their study on Syrian refugee experiences of cultural and structural violence, Schneider and colleagues (2017) suggest that the roots of structural and direct violence are often derived from cultural biases or prejudices, as well as from thoughtlessness, inefficiencies, incompetence or greed. This certainly appear to be applicable when considering both the rhetoric and language around the global "refugee crisis" (Diedring

& Dorber, 2015), as well as the experiences of people with disabilities. When considering the intersectionality of disability, conflict and displacement, the respective cultural violences manifest into particularly destructive instances of structural and direct violence. Outlined below are three examples of key cultural violences that emerged from the interviews with participants and service providers.

Nationalism and xenophobia

While "nationalism", "xenophobia" and other related terms were not directly referred to within the interviews, the experiences of participants with disabilities and their families indicated the presence of anti-refugee discourses. As highlighted by the service provider from Asylum Access, there tends to be a dichotomy of discourses rooted in cultural violence:

> The dichotomy of discourse that we hear about refugees is really interesting […] we have 'refugees are dangerous people that come to change our culture and steal our jobs and hurt us'. And 'refugees are poor people that need our help'. Both are violent. Both of these discourses generate violence. (Service Provider #21, Asylum Access)

Many of the participants and family members referred to their inability to find work in relation to their Colombian and Venezuelan identities:

> I have asked for a job and no because I have the arm [disability] and the attacks and because I am Colombian too. (Participant #22, PwD)

> My husband is unemployed. He's a locksmith, but it's hard for him to get a job because we're Colombian. (Participant #23, Family)

> But there's still a lot of discrimination. Especially against Colombian refugees. Especially against Colombian populations in general, there's a lot of stereotypes against [them]. (Service Provider #21, Asylum Access)

> Mother: The first day we arrived I was looking for the Ministry of Human Mobility and I went into another office. And I came in and I asked, 'Excuse me lady can you show me where this Ministry is?' She replied, 'Where are you from?' I said, 'From Venezuela.' And she said, 'Why don't you go starve in your own country?' (Participant #3, Family)

Patriarchy

When discussing the root causes of structural and direct violence, all of the interviewed service providers suggested that patriarchy and traditional perspectives on gender were key legitimisers of violence, particularly against refugee and asylum-seeking women, girls and anyone who is perceived as different. Patriarchy refers to social systems where males hold primary power and predominate in roles of political leadership, moral authority, social privilege and control of property; and in the domain of the family, father or father-figures

hold authority over women and children (Walby, 1990). It is directly linked to *machismo*; a Latin American cultural parallel of patriarchy that refers to a set of hyper-masculine characteristics and their value in traditional Latin American society (Kumar, 2014):

> The origin of gender violence is a patriarchal origin. This is common for women in a situation of refuge. And women in a situation of refuge suffer physical, psychological, social, I mean, sexual, sorry, patrimonial or economic violence just like Ecuadorian women, because they aren't in a context of violence. What it does is that women in a refugee situation suffer this type of gender violence in their place of origin and it is aggravated by the social violence that they are bringing, say, and when they arrive here it is a double vulnerability. It is a situation much more complex because they don't only have the weight of intra-family, sexual, and gender violence, committed in the family environment, but they also have all that weight of social violence that has forced them to leave their place of origin looking for survival. Then, they are double survivors of the violence of their own family environment and the social violence of their country. And let's say that for women in a refugee situation, it's much more difficult, because they don't have that support network. Because you are in another place that isn't your community, sometimes you have separated from your family of origin. And perhaps here she is the victim of discrimination, of xenophobia. So, it's a lot more complex. (Service Provider #14, Women's Federation)

> It's really complicated and if we think about this province and this context you have the very traditional mind-set in a way. So, you have general officials, the institutions. This traditional mind-set implies that you have the regular family, the traditional family. Umm, the traditional life. Everything is traditional in a way, so change and innovation is difficult. (Service Provider #11, UNHCR)

> […] if they [women with disabilities] live inside a place of conflict, their vulnerability is very strong because in many cases, if they had a disability before, they don't have much space in their community. […] The incidence of sexual abuse is very high, but also this situation of poverty becomes extreme poverty because they can't find a way to work. So for example many of them, some of them, are abandoned by their family, then they don't find that they have support in their family or that they can receive some protection and they also find that the government, the government, doesn't provide them with any kind of health for this […] they have much more limited access to health, but in general it is sexual violence, lack of work spaces, lack of study opportunities too. So they generally haven't done all their schooling, they haven't finished school then if there is a lack of opportunities in the social issues of health, of education and a lack of protection in everything that is security for their own lives. (PwD and Service Provider #20, Mennonite Church)

> There are a lot of double, triple, quadruple discriminations that refugees face. You can face discrimination for being foreign, for being a refugee, for being of a specific nationality, because specific nationalities carry their own connotations and stereotypes, as well as for being a woman, having a different sexual or gender identity, for having a disability, for having a different skin tone. All these factors add up to these multiple levels of discrimination that people, including refugees, face. (Service Provider #21, Asylum Access)

Ableism

Examples of ableism at an ideological level were less evident. This does not mean that ableism was absent, but rather, I believe an indication of how deeply embedded and accepted it is. Indeed, I am yet to come across a community, anywhere in the world, which is not culpable in excluding people with disabilities, simply by promoting and valuing "able bodies" and "sound minds" as the human ideal. However, my analysis proposes that examples of structural and direct violence relating to disability were almost always upheld by culturally violent ableist ideologies such as the medical and charitable models of disability.

What I did observe were the by-products of ableism. Take, for example, the high levels of confusion and misinformation surrounding refugee/disability legislation, Refugee Status Determination processes (RSD), Cedula (Ecuadorian National Resident identification), Conadis (Government issued disability identification card) and other systems and structures. I understand this to be a clear indication that crucial information was designed and presented in a way that targeted people *without* disabilities. As a result, information was not available or accessible for refugees and asylum seekers with disabilities, specifically those who live in the provinces, and who have lower levels of literacy and/or sensory, learning, neuro and intellectual disabilities.

A further indication of ableism related to my own difficulties in accessing the towns, cities and services where the interviews took place. This included access to public transport, public spaces, and the buildings of organisations whose purpose it is to support and promote the rights of marginalised communities (a point also noted by Bombi, 2010). On multiple occasions, either myself or the participants were unable to meet due to difficulties in finding accessible transport or spaces.

Many of the participants spoke of receiving official charity and handouts from NGOs, as well as unofficial aid from private citizens, including leniency on rent payments. This was vital given the vulnerable circumstances many of them found themselves in when they first arrived in Ecuador. However, charitable giving was limited and only a temporary measure to address immediate issues such as hunger and homelessness. Such support soon expired, often leaving participants in an even more vulnerable situation than when they first arrived. When the participants tried to access more sustainable support as rights bearers, it was extremely difficult, especially for participants who had no family support. Challenges included a lack of finances to travel to meetings or to even ensure they had enough credit and battery on their

mobile phones, inaccessible buildings and resources, and for those who were homeless it often came down to a choice between begging or peddling to pay for shelter each night or spend the money on travelling across the city to meet with officials (again, often navigating inaccessible transport to attend meetings in inaccessible buildings). Take, for example, Participant #25 who lives with blindness:

> Yes, so the lady from [NGO] she was doing all the paperwork trying to get me some financial support. But the challenge is because I am Colombian, therefore she couldn't do anything. Then she asked me to renew my Conadis card and then I got my mobile phone stolen and that's the phone number she had for my appointments… because we were getting psychological help. My daughter and I were seeing psychologists, and then… but I haven't been back, because I don't have an appointment, I have not attended the appointment… (Participant #25, PwD)

Another participant with a traumatic brain injury (TBI) and physical disability caused by guerrilla gunshot wounds, was one of at least four participants who feared imminent eviction because he could not find work and he did not earn enough money from peddling to pay rent:

> The lady I am paying the rent to, but, it's been six months that I haven't paid the rent because I can't work or anything, and I am selling candies every day [in the park]… the lady told me that if I didn't give her money in the next few days she'll kick me out, to not live there and she's very noble. She gives me food, I sometimes clean for her, wash her clothes, and I am very sad. (Participant, #22 PwD)

As highlighted by the UNHCR Field Director, even though there are often programmes and systems in place to support marginalised populations, they are yet to integrate refugees and they are not yet inclusive or accessible to people with disabilities:

> So, you could have a disability and say it's 30%. However, this is mixed with other factors related to poverty. […] So this is probably what you need to define, and that implies an open attention to the complexity of the situation of the families. I mean, in general, for the refugee populations the thing is that there are, in many cases we are pushing and trying to help the state to integrate this population into their programmes, and in their specific assistance programmes for people in vulnerable situations. However, they are still not there. So refugees they are not in those programmes for the moment. So they are still vulnerable among the vulnerable population and it's quite difficult because I may imagine, which are the consequences of suffering disability, or living with a disability after an injury is suffered, in the context of a conflict. (Service Provider #11, UNHCR)

While I am starting to move into examples of structural violence, the purpose is to highlight the presence of anti-refugee discourses, patriarchy and ableism – that is, culturally violent ideologies, which play a significant role in preventing refugees and asylum seekers with disabilities from fully and equally enjoying their human rights as outlined in the CRPD and other human rights instruments. Furthermore, as proposed by Galtung (1990), cultural

violence legitimises structural and direct violence against people with disabilities who have been displaced by conflict.

<div align="center">Structural violence</div>

Structural violence (ways in which social systems harm or disadvantage individuals or groups), on the other hand, was widespread and present within many different environments, including the participants' home communities in Venezuela and Colombia, resettlement communities, schools, businesses and even within the families themselves. While the participants reported many challenges relating to structural violence, listed below are a small selection of common examples that emerged during the interviews.

Education

Education was a key issue for most, if not all of the families. While the integration of students with disabilities in mainstream schools is encouraged and even written into law, a lack of resources in the provincial locations (Lago Agrio and Esmeraldas) meant that neither mainstream or special education schools were equipped to receive students with disabilities. In mainstream schools, teachers lacked training and resources to ensure their teaching methods and curriculum were accessible and inclusive:

> […] for example, say, is the education law that promotes the integration of children with disabilities into the standard spaces of education, in a formal community school, and there really would be no problem in enrolling, in enrolling the child, the girl. The problem is that this child in the classroom, there are many children and there is only one teacher, and this teacher is not specialised in meeting the needs of the boy with, or the girl with intellectual disability. (Service Provider #14, Sucumbíos Women's Federation)

> Regular and fiscal institutions, they have the obligation to receive people with disabilities. The role of the educational institutions is that curriculum should be adapted, depending on the person's disability. But that in practice does not occur either, because clearly there is a deficiency in terms of human resources, there are no professionals that should be in those educational institutions, and therefore there are situations, where evidently, the educational permanence of those people are put at risk. (Service Provider #13.1, RET)

In Lago Agrio, there were at least two special education schools for students with disabilities. However, these schools were located far away from the city centre, in a dangerous area of town and often sent students home because the teachers believed "they really can't learn" (Service Provider #13.2, RET):

> Because having this type of mentality, the [teachers] say, 'Ok there are kids with a disability, so the education level is lower,' and these kinds of things. 'It's not really important that they come every day because they really can't learn,' or something like that. So, you see there is a huge difference. And also, they [parents] don't like that their

kids have to go to separate schools. Because the parents feel that their kids are discriminated [against] because of that. So, they feel really bad. Imagine for a refugee that you already feel discriminated here because you are a refugee, and afterwards you see that your kid that has a disability is discriminated [against]. Because refugees are, because he or she is a refugee, or because they have a disability. (Service Provider #13.2, RET)

Furthermore, according to participants, special education schools do not receive the government funding that is given to mainstream schools:

[…] the normal schools receive uniforms and books, and the special school doesn't, just uniforms, and, why doesn't it receive books? They're students too! (Participant #10, Family)

They don't have academic material for the schools for children with disability. So I was talking to the professors, which are saying to me, 'We have a lot of work. We are really few professors doing this job.' Most of what you imagine here in Lago Agrio. Few people know how to do that and can do that. And so, they have a lot of work and they also have to adapt the book they receive into some material that can be accessible for their kids. So it's just a really great task... And also with some kind of disability it's really difficult because, for example, they don't have books for people who cannot see. Like Braille. They don't have it. And this you cannot do it at home, you know. So that's a problem… They didn't really think about people with disabilities. Because as [my colleague] said before, here it wasn't common that a person with disability goes to school and learns and looks for a job. Like, a lot of people still think that if you are with disability, then you just stay at home and that you are a burden for your family and you cannot do anything with your life. (Service Provider #13.2, RET)

And then another problem is the fact that these two schools are in Lago Agrio. But here in a place where a lot of people live in the rural area. So, if you have a disability you have to come to the city in order to study because you cannot access a rural area school. And maybe there are people coming from two hours of distance walking in order to go to school. So imagine the problems they can have. Most of what they have if they have a disability like a physical one, like, walking two hours, think with this heat… It's terrible and a part of that is the problem of the fact that the schools don't offer, for example, lunch. So maybe these people that come from the rural area are, aren't, they don't have a lot of money. So having to walk two hours, going back, you need to eat something when you're here in Lago Agrio because otherwise you will not eat for ten hours. And so having to buy food here it's so expensive. (Service Provider #13.2, RET)

As a consequence of the inequity between the mainstream and special education systems, many parents kept their children at home. Children with disabilities remain uneducated, perpetuating the cycle of illiteracy, dependency, and poverty.

Disability services

Another key challenge was the inability to access disability services and aids. It was unclear what the exact reasons for this were, but it seemed to be related to cost, the lack of resources

and services in provincial communities, together with the difficulty of obtaining legal status or the Conadis disability ID card and the associated services and benefits. For example, Participant #17 is a Colombian national who arrived in Ecuador four years ago. He suffered a spinal cord injury after being shot in the back, resulting in a T10 fracture and paralysis. Now, he is a respected community leader and supports a wide range of local people with disabilities and refugees living in impoverished neighbourhoods. He also volunteers for OVCI (Italian NGO), a charity that provides Community Based Rehabilitation (CBR) and orthopaedic aids to local people who cannot afford to pay for it themselves. As a Colombian asylum seeker, his choice was between waiting for a State-funded wheelchair that was not adapted to his needs (further limiting his functionality and independence) or to pay for his own wheelchair:

> […] the difficulties that I have personally had is that, if I want a wheelchair, I have to buy it or make it as I like, in my own way. But I have to get the money out, okay? Because the state cannot give it. (Participant #17, PwD)

In a second meeting with Participant #17, he mentioned that his own wheelchair tyres last three months in a developed city like Quito, but only one month in underdeveloped provincial communities, such as Esmeraldas and other communities situated along the Frontier (Ecuadorian-Colombian border), which is where most refugees and asylum seekers settle.

Unemployment and poverty

As was discussed in the section on cultural violence, participants found it difficult to find employment due to factors relating to disability, prejudice and racism. All of the participants spoke about the financial stress they were under, and many alluded to being unable to pay for basic needs. I did not ask how much each participant earned, and as such, cannot compare it to the official World Bank measures for poverty and extreme poverty. However, the UNHCR Field Director reported that in Lago Agrio, 80% of the population were unable to meet their basic needs:

> They also have in the country [Ecuador], they measure also people under the poverty line and the extreme poverty line. So… under the poverty line you earn less than eighty-two dollars a month in capital [US$], which is the basic salary more or less for a family… extreme poverty is less than forty-two dollars a month [US$]. So, in general in the country, it's about seven per cent of the population in extreme poverty and fourteen in poverty. For refugees, this average is doubled. (Service provider #11, UNHCR)

For many of the participants, poverty not only affected their physical wellbeing, but their mental health as well. Many participants became emotional when sharing stories about being unable to feed themselves and their families, pay for medication or medical services, of being homeless or being unable to pay rent and the risk of eviction:

[…] sincerely I have been suffering a lot with my kid [adult son with an intellectual disability], with him because I have hardly had anything to eat. Look, I don't even have enough for medicine. I don't have anything. He ran out and I have to get some money in order to get his pills. I don't even know now to get my hands on some pills because this is his last one… I don't know what I'm going to do, but I have to go pawn something so I can go buy it. Of course, it's not expensive, it's about two dollars. (Participant #23, Family)

Well, it's hard progress in life with family. At the beginning you have to rent a house and buy the food. Who provides it? No one. This is why I am suffering. (Participant #5, Family)

It has always been hard, very hard because you know about poverty, right? Where the little you do know how to do, there is nothing. (Participant #5, Family)

A further challenge was not being able to receive respite care for their family member with a disability, in order to work:

[…] the landlady, she sees and she has told me, 'It's so difficult what you're going through. I know you're struggling and everything.' And she gives me some food for my son sometimes. Even the neighbours give me food and everything, but sometimes we don't have any food at all or anything. And my son needs to eat and since here [NGO] they told me that they couldn't provide me with any more food, that they couldn't help us anymore because they've already helped me, but I tell them, 'What do I do if I don't have a job or anything?' I can't work because of him, because I have to be taking care of him. (Participant # 23, Family)

Even though she is 14 years old, she is like a baby. What you always find is that it's difficult, because when you work you have to seek help [to take care of her]. (Participant #9, Family)

Direct violence

The third and final type of violence, direct violence, is the most obvious and where there is a usually single or identifiable perpetrator (Galtung, 1969). Listed below are examples provided by three participants which exemplify experiences of direct violence relating to their disability, their status as a refugee or asylum seeker, or both.

Sexual abuse

According to the staff member from the Sucumbíos Women's Federation, sexual and domestic abuse is common amongst refugee and asylum-seeking populations:

The context of armed conflict, let's say, is an aggravating circumstance. But in itself, what we attend are situations of gender violence committed against women, [which] can be in the context of armed conflict or intra-familiar, or community. And, obviously, the situation of women survivors of violence, sexual or intra-familial, who have lived and who are also victims of conflict… they are doubly victims… apart from being victims of the social conflict of their country, they bring back intra-family violence. That is a

more complete and a more serious situation. (Service Provider #22, Sucumbíos Women's Federation)

In relation to disability, this was something experienced by Participant Family #4. As outlined in a previous quote, at just fifteen years of age the daughter had been kidnapped and raped by paramilitaries in Colombia. Having escaped Colombia with her mother, she was then seduced by a married man and became pregnant at the age of seventeen, while living as a refugee in Ecuador. Even though the family had made a complaint to the police, the pregnancy was considered consensual, irrespective of being a minor and her intellectual disability:

> Mother: When he [my son] realised that she was pregnant he got mad, because no one told me [my daughter] could be pregnant, because of her disability. Then my son took some documents to him [father of the baby] but he denied it. So, I asked him, because when the baby was born they must be registered, but he denied recognising the girl. This is why we submitted a claim…
> Interviewer: Did you present a claim to prosecute him for rape?
> Mother: I went to the prosecutor and he told me it is not rape.
> Interviewer: Who told you it wasn't rape?
> Mother: The attorney. He doesn't consider that it was rape. I showed him the card [Conadis disability ID].
> Interviewer: What happened with your claim?
> Mother: We came here with protection. I have the number of the policeman here in case of an emergency. Also, they are investigating the guy, and the guy who works for the UN knows who it is. Because one day someone threw tear gas through my window. Then I went to the prosecutor's office and he told me that it wasn't a crime. I said, 'How is this not a crime?!' (Participant #4, Family)

Assault

While many participants and family members had experienced direct violence during conflict, (either because of their disability or violence that resulted in disability), two participants also reported being directly assaulted while living as a refugee or asylum seeker in Ecuador. The first was a participant from Colombia who had come to Ecuador with his wife sixteen years ago and who lived with no disabilities or health conditions. However, on Christmas Day 2016, five months before our interview took place, an intoxicated neighbour had attacked him and caused grievous bodily harm:

> I saw him putting his hand up… I looked and noticed he had a machete (inaudible). In that moment, I bent because I tried to run, but while I was bending he hit me with the machete. When he hit me with the machete, like I said, I wanted to run, but I couldn't, I was deranged with the smack he gave me. So, I was in this position, and then I saw him putting his hand up again and he tried to hit me again with the machete. If I had stayed still, he would have cut my head in two parts. (Participant #7, PwD)

As a result of the attack, the machete had cut the participant's hand clean from his arm, and also led to the removal of his eyeball. As a refugee, the participant voiced distress at what his newly acquired disability would mean for his refugee status and financial security:

> […] before I used to have very happy times. I worked, I didn't reach out [for help], I didn't go for money or anything. But the only thing I used to do was renew my Visa, and I wanted to get the Cedula [Ecuadorian National Resident ID] (inaudible). But now it's different, it is now very hard for me to get a job. Therefore, now I'm seeing what I can do, how can I make sure I can stay in Ecuador. Of course, I have a place to live, that's all sorted out. But regarding the financial support, I don't know (inaudible), I don't understand a thing. They told me I have to get the Cedula, but I still don't know how to get it, where I can get it. [I need] someone who knows these things well, to help me and show me and explain to me exactly how can I stay [in Ecuador]. (Participant #7, PwD)

Another example of direct violence was recalled by participant #22, who lives with a TBI and physical disability. Just four months after arriving in Ecuador, he was assaulted and robbed of all his documents, including his passport and Colombian ID while selling candies in the street. Without documentation, it is now almost impossible for him to receive support, status, legal or refugee services.

Research Question #1: Intersectionality

This chapter has introduced the participants and their journeys, while also responding to the first key research question, which asked: what can we learn from people with disabilities about the intersectionality of disability, conflict and displacement? The responses documented within this chapter have demonstrated the compounding nature of intersectionality. In addition to this, all participants alluded to poverty as being both a product of, and an influencing factor on, the intersectionality of disability, conflict and displacement. While the reviewed literature in Chapter Three, and anecdotal evidence, predicted this would be a key finding, it has been important to provide a dedicated space both within the interviews and this thesis, where these experiences can be shared and documented. By openly acknowledging such experiences within this PACS research thesis, it will become increasingly difficult to subjugate and exclude those who have lived it from research and practice.

Summary

This chapter is the first of five that present the findings of this research. Breaking away from the traditional principles of appreciative inquiry, the purpose of this chapter has been to acknowledge, appreciate and respect the shadow of human experience. In the case of the participants, this meant giving space to the issues that they valued and wanted to talk about,

that is, the challenges they face as human beings, living with disability, and being displaced by conflict and violence from their home communities.

The chapter began by providing a demographic overview of the participants. To ensure that anonymity was maintained, and participant identities were kept concealed for their own safety and security, demographic data was disaggregated in a very simple way that included gender, age, nationality, type of participant, type of disability and time in Ecuador. The chapter then followed the geographical journey of displacement, starting with life in their home communities, reasons for leaving and life in Ecuador. Challenges and difficulties relating to the intersectionality of disability, conflict, displacement and poverty were then categorised as cultural, structural and direct violences.

Upon reflection, this chapter appears to have painted an incredibly bleak picture. The goal of making the rights of people with disabilities affected by conflict and displacement real, seems further away than ever before, little more than a well-meaning, but impossible dream. Indeed, the barriers, challenges and difficulties that have been presented in this chapter would appear to some as being too big and too hard to overcome. However, to succumb to this conclusion would be to openly accept ongoing cultural, structural and direct violence against the largest minority in the world, which is quite the opposite of pursuing positive and sustainable peace.

Even so, these are only some of the experiences shared by participants. As will be revealed in the next chapter, from the shadow of human experience came great wisdom and insight into the "best of what is", as well as innovative solutions, suggestions and recommendations for promoting, protecting, and respecting the rights, freedoms, and dignity of people affected by the intersectionality of disability, conflict and displacement.

Chapter 8 – Findings: Discovering the "Best of What Is"

> "Well, here in Ecuador, for me in Ecuador, there are many more challenges. Therefore, the achievements are more visible. Because when there are more difficulties, the achievements are noticeable. What is achieved is much more remarkable."
>
> - Participant #17 (PwD, 2017)

Introduction

As noted in Chapter Four, appreciative inquiry is based on four principles: *discovering* the best of what is, *dreaming* of the future, *designing* that future, and actioning *destiny* (Cooperrider, 2012). Even though the interview questions were designed in a semi-structured way that allowed space for the participant to talk about whatever they wanted, the structure loosely followed these basic 4D principles. As was discussed in the previous chapter, this meant that the shadow of human experience could be expressed, regardless of whether the question related to discovery, dreams, design or destiny. However, the interviews mostly began with a conversation about what the participant appreciated about living in Ecuador, their journey from Colombia or Venezuela and what had helped them get to where they are today (*discovery*). Participants dreamed about what a future looked like in which they, or their family member with a disability, are leading full and meaningful lives and where they feel safe, equal, included and respected within their community (*dreaming*). We also discussed what steps need to be put in place, or what needs to change, for these dreams to become a reality (*design*). Based on the discovery, dream and design questions, the participants then started to provide suggestions on how to action *destiny*. This included practical advice on how to promote, protect and uphold the human rights, freedoms and dignity of people with disabilities during conflict and displacement (as outlined in the CRPD and the second key research question).

Much like the structure of the interview questions, the next two chapters will also follow the 4D principles of appreciative inquiry. In Chapter Seven, the challenges and trauma that people with disabilities often face during conflict and displacement were presented. In this chapter, however, the attention is turned to discovering the "best of what is" (Whitney & Trosten-Bloom, 2010). That is, it turns to an exploration of factors, events and moments that

helped or aided survival and wellbeing during what was for most participants, an extremely difficult and traumatic experience of conflict and displacement.

Life in Ecuador – Discovering the "Best of What Is"

The core task of the discovery phase is to identify and appreciate the "best of what is" (Cooperrider, 2012). As part of this process, participants were encouraged to openly share discoveries and possibilities relating to their current life in Ecuador, the aim being to set the tone for the rest of the interview, while creating context for generative dialogue (Cooperrider et al., 2008). Following initial introductions and an overview of the research, the interviews began with a simple question that was designed to break down any discomfort or awkwardness: what do you like about living here in Ecuador? By looking at what the participants appreciated about their life and peak experiences, amidst the hardships, I began to gain insight into what is working well, what is valued, and based on this feedback, possible areas for further growth and investment. For many of the participants, the most common responses related to basic human needs such as shelter, food, financial security, personal security, health and wellbeing. If we were to contextualise these within Maslow's hierarchy of needs (1943), a psychology theory that describes stages of human growth using a pyramid, almost all of the discoveries related to physiological and safety needs, the two levels at the base of Maslow's pyramid. Listed below are four of the most common responses to the first question of the interview.

Tranquillity and security

When asked "What do you like about living in Ecuador?", the first and most common response was the *tranquilidad y seguridad* – the tranquillity and security:

> The sensation that you will not be killed. (Participant #1, Family)

> Violence is not easy. Well, I come from a difficult situation. Let's say, I've come looking for something calmer, some calm. And I decided to go to Ecuador. And automatically, the atmosphere looks a little softer, quieter. (Participant #2, PwD)

> Mother: Yes, yes. The security one feels. To be sitting here is peaceful. Because we don't have that peace in our country Venezuela. But that's what gives us more peace – to go out and be safe. To walk or move around without fear. That gives us a lot of peace.
> Father: Yes. I want to tell you, I was a policeman for twelve years so I know what insecurity looks like. I know what danger looks like. So I know a lot about security. Here I have been surprised because, well, at least in the capital, which is what I know, you see cameras on every corner and I've even noticed that they have infrared cameras. Yes to be honest, I've been very surprised. […] In addition to that you see on the street that generally there are no mishaps. You don't even see arguments. And when you do

see an argument, the same people don't need the police to be there with a whip telling them, 'Be good.' It's the people themselves saying, 'Hey, hey, calm down. Behave.' People help the security. Something that, at least in Venezuela, you can see someone being punched on the street or being mugged and people will not move, they will not even look. Because they know getting involved will create a problem for themselves. (Participant #3, Family)

Well, I like it here because it is calm, the tranquillity is good. (Participant #5, Family)

My enjoyment… Umm, I feel the tranquillity, it is beautiful. Wherever I go I feel happy, content, there are no problems, nothing. That is why I feel happy here. (Participant #7, PwD)

The truth is that here in Ecuador it is calmer than in Colombia. Right now it is a bit bad for work. But, thank God, there is something to eat. But I feel calmer here because in Colombia it is harder. (Participant #12, PwD)

Here you don't see the violence. We don't feel threatened for doing nothing. (Participant #19, Family)

When considering the circumstances that initiated the exodus to Ecuador, it is no surprise that safety is the first thought that comes to participants' minds when thinking about their new home. When these responses are contextualised within Galtung's violence triangle (1990), however, along with the evidence of direct, structural and cultural violence presented in Chapter Seven, it is clear that the participants' concepts of tranquillity, security, safety and calm refers to negative peace (the absence of conflict), rather than positive peace (absence of all types of violence and the presence of social justice).

Aid

The second most common response was the provision of basic physiological needs such as food and shelter. These were mostly provided by local and international aid agencies for a limited period of time following the participants' initial arrival in Ecuador:

Interviewer: Have you received help from NGOs?
Mother: Yes, they have been helping me with the baby and with her diapers. HIAS[8] helped me. (Participant # 4, Family)

Interviewer: So from your experience, what support is really important?
Participant: Just the food and nothing more. They gave it to me, but it was only for six months. (Participant #12, PwD)

Participant: Yes, we came around the 20th. On the 20th we left, and on the 22nd we arrived here, we arrived at Tumaco, from Tumaco we came to San Lorenzo, and from San Lorenzo they gave us, from there HIAS, they took us to a hotel. From there they

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[8] HIAS, formerly known as the Hebrew Immigrant Aid Society.

gave us food, then the next day, at eleven o'clock in the morning, they sent us on a bus to here [Esmeraldas].
Interviewer: Has HIAS been very helpful?
Participant: Well, they helped me sure! In the accommodation. Because, for the stay they sent us here. Here they gave us shelter eleven days. From there they paid us a month of rent. (Participant #15, PwD)

HIAS gives us food. They give us $50 a month for food. (Participant #16, Family)

It was unclear whether all organisations provided extra or specialised assistance for asylum seekers and refugees with disabilities. However, the Mennonite Church staff member indicated that their programme gives special attention to people in urgent need, which often includes people with disabilities. For example, Participant #2, whose paralysis impacted his function, was able to receive personal products on a daily basis through the Mennonite Church:

So, we have interviews on Tuesdays and Wednesdays, in which we serve attending refugees and see why they are in Ecuador, what their fundamental needs are, although they are always all of them! The needs, and the church, then have a program to help. We select the most urgent and priority cases, which have to do with families that have many children or have elderly people, and now we say people who have some kind of disability. But this was not our parameter either. And then we give certain urgent help. For example, a stove and a cylinder, a mat, a blanket, an amount of food that can be distributed for up to six months, depending on the need. People donate clothes to us, and we also donate these clothes, we have put together a hygiene kit, and then... We don't give everything at one time because among so many people, we are distributing what we have to people who may have urgent needs. (PwD and Service Provider #22, Mennonite Church)

Father: Changing all of that [life in Venezuela] to come here to live in a room!? My two children on one mattress and me and my wife on another mattress. And even then, we still feel happy. To change everything, everything that I had, the much fortune or little fortune, however you see it, should change everything for nothing. Here we don't have anything, but we have a little kitchenette that was given to us by the Mennonite Church.
Mother: The first day we arrived they gave us a kitchenette. We used it to make coffee using one of those cotton tee-shirts. We cut off the sleeve and then use that as a filter.
Father: To make the coffee. We laughed so much about it, we don't drink instant coffee! (Participant #3, Family)

Given that contact with most of the participants was arranged using a snowballing method (Biernacki & Waldorf, 1981) initiated by Asylum Access, most, if not all, of the participants were seeking help in legal matters such as Refugee Status Determination (RSD). Take, for example, Participant #2 who I met while visiting staff at the Asylum Access office in Quito. It was the participant's first day visiting Asylum Access, and he was there to seek help with obtaining a passport so that he could apply for legal documentation. In a later interview, the participant also mentioned that Asylum Access was helping him get a work permit:

[…] I went there asking for a permit to work in the street and they told me that they couldn't help me with that. But they are helping me with a position in a market. The San Francisco market, a popular market… I went to see the position and everything and they handed me the documents that had to be filled out so I could start. But, I need documentation. I entered [Ecuador] without a passport with nothing and I don't know how to fill it out. But I'm already here running errands in the interior [Ministry]. And they gave me an appointment! I already had the first date on the 23rd or something like that to see if they can provide me shelter there [at the market]. If not, to see what I can do to process the passport here to be able to fill that paperwork… (Participant #2, PwD)

A staff member explained that Asylum Access is a family of global organisations, whose vision is to make refugee rights a reality in the world. This includes employment and educational rights, amongst others. As well as supporting asylum seekers and refugees to realise their rights, they also work with provincial and national governance on policy advocacy. For example, they had recently successfully advocated for a change in policy that helped asylum seekers and refugees work in a popular tourist market:

[… the] informal economy in Ecuador is generally important. But in Otavalo it is especially important because it's a street market. So people are selling artisanal products, but they're also selling food and electronics, all kinds of things. And the permit to sell things on the street was not available to asylum seekers and refugees. And so we worked with the provincial government and the council of rights protection to change that local ordinance so that refugees can now sell things on the street. (Service Provider #21, Asylum Access)

A further interesting aid initiative was mentioned in brief by a participant who had received financial support to start his own business. This relates to a growing body of research around the role of self-employment for people with disabilities, which has been identified as an important source of non-standard work and income (Blanck, Sandler, Schmeling, & Schartz, 2000; Jones & Latreille, 2011; Schur, 2002). Research from the USA and Europe has shown that people with disabilities are more likely to engage in non-standard work (such as self-employment) than people without disabilities (Pagán, 2009; Schur, 2002). This is in part believed to be the result of employer and workplace discrimination against people with disabilities and because of the flexibility of self-employment, especially when health issues and accessibility make standard full-time work difficult. The down side, as was experienced by many of the participants, is that self-employment tends to pay less and provide fewer benefits than traditional full-time jobs (Schur, 2002).

For a person with a disability, having a business of his own would be a very big advantage, more than employment, not because he has to work in his own business, you have to work a lot more in your own business, but [because of] your earnings. If I work more, I will win more in my own business, than in a job […] So, it is very, very advantageous. What's more, a person with disability, their expenses are more. So, that way it is important. I always tell my friends, that instead of becoming weary and

seeking employment, we should find a way to each create a small business. Because that is the only way to be able to become more independent every day, to be able to have facilities to solve your economic situation. In itself, in Ecuador, mainly in Esmeraldas, the economic situation is hard. (Participant #17, PwD)

The importance of self-reliance through entrepreneurship has also become a focus of organisations such as HIAS and the UNHCR who developed the Graduation Model for Refugees (Cahn, 2018). The Model is a multi-faceted mechanism that provides material support, training, asset transfers, access to saving and coaching to help transition refugees out of severe poverty. Often this includes seed funding for refugees and asylum seekers to develop their own enterprises and businesses. According to the HIAS website, HIAS Ecuador has reached 2,300 families since 2015, with data showing that graduates of the Model become "more food-secure and economically stable, better integrated into their communities and increasingly well-positioned for future plans" (Cahn, 2018 para. 18). One of the participants appeared to have participated in the Graduation Model (or a similar programme) and spoke very highly of the impact it had had on his life:

> My dream is to be a noble person, humble, earn my food only with the will… And my dream is to have a business for myself to survive. And have my house where I live, nothing else. A small store I have, but home I do not have. I have a small ranch, but with some old roofs that were already chopped. I made it strong myself but there are already leaks. So, I want to start a small business because I have a freezer, and thanks to the organization HIAS, they helped me solve that. And that money, because I have it while I set up the ranch and already stock again… No, thank God that HIAS has helped me. Yes, with $300 HIAS helped me. So then, that's what I want, stock the business and move on. Because that's what they told me, that with that energy I should work, according to how they look at me working, that is why they helped me with that money, to help me set up a business... (Participant #12, PwD)

Interestingly, eight out of the nine participants with disabilities and three of the ten family members indicated they were in some sort of non-standard work such as self-employment. The term that was most commonly used to describe this type of work was "peddling", referring to the on-selling of products such as biscuits, candies and basic necessities. Participants indicated that this work was extremely hard, inconsistent, dangerous and did not earn them enough income. Take, for example, Participant #22 who had been gifted shoes and candies by the Mennonite Church for selling in the streets. However, as was reported in Chapter Seven, this had led to problems with the police and meant he had become a target for robbery and assault. Even so, this type of work was necessary for his survival, given the difficulties he faced as an asylum seeker with a physical disability and TBI. Another example is Participant Family #1. The father is Ecuadorian but grew up in Venezuela, while the mother is Venezuelan, as is the daughter, who lives with autism. The father, who lives with

significant physical disabilities, reported that he had had great difficulties in trying to find work in Ecuador, even though he had Ecuadorian documents. He believed this was a result of discriminatory attitudes towards people with disabilities in the workforce.

> Mother: He is Venezuelan-Ecuadorian. He was born here but since he was four he has lived in Venezuela.
> Father: So I am tired of sending my resumes to jobs websites… And nothing… it's like I don't exist… No, there were a few places I found, but they never said, 'Yes please come for an interview.' No. Only one time they called me for an interview and I was close to getting the job, but I didn't get the job. Another time I participated in a contest for a job with another 500 candidates, I came in seventeenth position, but there were only six places.
> Mother: No, only the first is qualified for the jobs, so they said, 'Well you got very close, seventeen is good!' Yes, but still he didn't get a job! Then another person told us, 'Well the truth is that those jobs they call for recruitment, but they already have the people they want to hire.' So, he has only been called twice for an interview, but it has not gone past the interview stage. In one year, since we arrived here he has been sending CVs, he is doing all he can. He is an accountant, he has a university degree, he has studied for this…
> Father: What I need is an opportunity in the right place. But no one, no one is willing to give me that opportunity. (Participant #1, Family)

The mother (Venezuelan) had been able to find employment but said that she was exploited within her work because of her nationality and undocumented status.

> Mother: Here, unfortunately since we arrived, because my husband has a disability, and even if the law says so, he cannot get a job. He has never had a job. This is the first time [working as a hostel receptionist] and he got it thanks to God. Because we were… me, so far this year… look, January, February, by February I have already had five jobs and each of them was worse than the previous one.
> Father: That was exploitation.
> Mother: Exploitation to the highest, grossest level.
> Father: It was gross, so to speak. I mean it was very explicit the exploitation.
> Mother: Because they know that I need the job because I have a child and I have him [both with disabilities]. Then they hire me as a health specialist, they ask for my resume, certificates, all the paperwork, and they say I'm going to work as a specialist, as a therapist, you'll be a nurse, ok. But when I get there, then they ask me to clean this and that, to clean seven toilets, and they say you're going to do the laundry, you have to wash by hand, you will cook…

Being unable to provide for themselves and family members due to barriers to financial security rooted in disablism and racism was one of the greatest concerns for many of the participants. However, these challenges also led to reports of local people working together with the participants to break down those barriers to ensure their physiological and safety needs were met, when support from other sources fell short.

Working together: Support from locals

For many of the participants, support from local Ecuadorian people had a significant impact on their wellbeing. What often started out as a formal relationship between a participant and a stranger (such as a land or business owner), then developed into a source of basic provisions and sometimes even a life-line. These relationships were forged in shared spaces such as apartment buildings or neighbourhoods.

> Mother: I love Ecuador, it's been great, I mean the tranquillity Ecuador has given me is incredible, despite the small details. I can't say that some small details will shadow the good things. No, the woman from this hostel [owner/boss] is Ecuadorian and she's an angel… The man from the hostel where we were before is Ecuadorian as well and this man was really a prince, he was too nice to us. I didn't have money for my daughter's uniform and a woman that sells ice cream across from there told me the girl isn't going to go with clothes that aren't from there [the school]. She bought her the entire uniform, and she didn't know me! She had seen me three days, two days seeing me and she came and said that the girl isn't going to go to school looking like a mess. And I was there and I don't know how to sew but I told her I'd get the fabric, I am going to make the skirt and she said, 'You're crazy,' and went and bought the entire uniform. I mean there are wonderful people, I know that they're not prepared for such a violent immigration like the one we're having, but neither are we. (Participant #1, Family)

> [When I first arrived in Ecuador] I was on the street. As I said, I didn't know anyone. When I arrived, the first thing I did was to stop at a traffic light. I stopped at a traffic light and asked the people to help me. With that help, I paid for a hotel that night and slept, ate and spent several days like this. I was a week like that, more or less. Fifteen days, a whole month. (Participant #2, PwD)

> Here, thank God people have been helping me. The lady whose name is Maria. She is a teacher near here. And her husband. She gave me food and she visits me. The people here are good, thank God. (Participant #5, Family)

And for Participant Family #23, who was the mother of an adult son with an intellectual disability, support from her landlady went a long way at a very difficult time. This included the ability to pay the tenancy bond in small instalments over time, leniency on rent payments, food for her malnourished son and keeping an eye on her son so that she could make a small living from selling food:

> As soon as I sell some empanadas I give her [the landlady] any little amount, any amount of money, whatever I have left. Look, last night, you're not going to believe this. Last night I made twenty empanadas and I was left with thirteen, and all the coffee over there… And the landlady, she sees, and she tells me, 'It's so difficult what you're going through. I know you're struggling and everything.' And she gives me some food for my son sometimes. Even the neighbours give me food and everything, but sometimes we don't have any food at all or anything. And my son needs to eat and since [NGO], they told me they couldn't provide me with anymore food, that they couldn't help us anymore because they've already helped me. But I tell them, 'What do I do if I don't have a job or anything?' I can't work because of him [adult son with disability], because I have to take care of him. Look, I spend the whole day making empanadas and

I go out and sell them by night and I come back to where he is. But, I tell the landlady, 'Do me the favour of taking care of him. If anything happens, call me.' (Participant #23, Family)

As summarised by the Asylum Access staff member:

I think there are a lot of people in Ecuador that are very open and receptive to foreigners, to Colombians and Venezuelans, and are excited to have those people in their places of work, in their schools. (Service Provider #21, Asylum Access)

Leadership

As discussed in Chapter Five, Lederach (1997) uses a pyramid to outline three levels of leadership, while identifying the distinct levels of influence each has on conflict transformation and peacebuilding. In this context, I use the term peacebuilding to refer to the pursuit of inclusive and accessible positive peace and the elimination of all types of violence against all people, including the disability community. I also refer to these three levels of leadership in the context of the "best of what is" – both through what I was told, as well as what I observed. I was particularly interested in learning about leadership roles within Ecuador, specifically in relation to asylum seekers and refugees with disabilities. Throughout the interviews, the leadership of President Lenin Moreno was identified as something positive for the disability community, because of his experience and passion for disability rights. However, I also observed the importance of what Lederach (1997) refers to as grassroots and middle-range leadership in promoting the rights of people affected by disability, conflict and displacement.

Grassroots leadership

Grassroots leadership refers to leaders who represent citizens that form the base of the society they are part of. In general, grassroots leaders face different challenges than middle-range and top-level leaders. In situations of protracted conflicts, these issues often relate to basic physiological and safety needs. While grassroots leaders are well connected within their communities, they can sometimes find it difficult to implement comprehensive and well-resourced programmes of change. However, it is important for peacebuilding strategies to be employed at the grassroots level. This can include integration programmes, as well as trainings and workshops aimed at reducing prejudices (Lederach, 1997; Maiese, 2003).

Before arriving in Esmeraldas, I was recommended by more than one person to make contact with a particular respected grassroots community leader. During my time in Esmeraldas, I was fortunate enough to meet with this community leader, Participant #17, on several

occasions, as well as accompany him on a visit to his community. This man is an asylum seeker from Colombia with a Bachelor's Degree in Community Management and Development. Twenty-three years ago he was shot in the back during conflict-related violence, resulting in a T10 spinal injury. He described the first few years of recovery and adjusting to life using a wheelchair as difficult. As he learned to control his body and mind, he gained confidence and started to work again. Then, eight years after his injury, he married and had four children. He soon became connected with a wide network of people with disabilities within Colombia and found purpose in serving the disability population:

> I have had difficulties, but I have also had great achievements. I am satisfied with life, and I still want to continue, to continue, not only to work for myself, also working for others. And, I always see the need of my partner. I always see the needs of another person with disabilities and I don't like the issue of a person with disabilities having to ask for alms when they can work, when they can do things. So it's important to teach them if one knows how to teach them. If one looks at a possibility that he has not seen, show him. That way we stay afloat. (Participant #17, PwD)

Participant #17 arrived in Ecuador four years ago, after fleeing the Colombian armed conflict. He had been working in Colombia for ten years with a foundation that supported over 400 at risk people, including youth, people with disabilities and senior citizens. After the foundation's financial accounts were seized by an armed group, he moved away and started a small sports club for children with disabilities. However, the club was in an area of narco trafficking and after the treasurer of the club was killed, he and his wife went into hiding for a week before deciding to flee to Ecuador. Participant #17 currently describes himself as a community promoter and small business owner. His work involves regularly visiting more than fifty people in his neighbourhood (most of whom are refugees) and establishing self-help groups, while organising Independent Living and Community Based Rehabilitation (CBR) workshops for people with disabilities, their families and the wider community. Participant #17 spoke about the difficulties he had faced as an asylum seeker with a disability without proper documentation. His ability to join organisations, set up organisations and earn an income were limited, and he was unable to get the support and devices needed for his mobility and independence:

> With the mere fact of being a foreigner, not having an ID card, […] you could not be part of an organisation. I can't [officially establish] an organisation, so I have to work with... putting together non-formal groups, self-help groups that are not recognised by a ministry but who, however, are recognised by a community and supported by these people. (Participant #17, PwD)

Participant #17 spoke passionately about his work and the impact it was having on local people with disabilities and refugees living in poverty. He offered great insight and

suggestions on how to promote the rights of asylum seekers with disabilities during conflict and displacement, which will be discussed in the next chapter. However, at this point in the thesis, I want to acknowledge the importance of his grassroots leadership as an asylum seeker with a disability. On one occasion, he invited me to visit his community, which had a reputation for being on the rough side of town. Situated on a river bank, the community is densely populated with fragile infrastructures, high rates of crime and extreme poverty. Even the local translator was surprised and hesitated when I asked if he would join us on the visit. However, Participant #17 assured us of our safety and said that this would be the best way to meet the people most affected by the intersectionality of disability, conflict, displacement and poverty. As he wheeled his way through the crumbling potholed streets, with the translator and me in tow, people came to the doors of their houses to greet him and shake his hand. Many called him over to discuss issues they were having or to update him on something he had helped them with. When we visited people in their homes, there was always a helping hand to get him and his wheelchair inside the house, despite the neighbourhood being totally inaccessible. He knew all of the children and babies by name, some of whom lived with disabilities.

I recall this experience because the grassroots leadership of Participant # 17 struck me as something that is working well, the best of what is. As a self-advocate, an advocate of the people in his community and as a gatekeeper to the community, he was using his knowledge and experience to empower other people with disabilities to know their rights and to advocate for themselves. Take, for example, the informal conversation we had with two Ecuadorian mothers of children with disabilities. These conversations were informed and insightful. Although both families lived in poverty and had few resources, they had knowledge about disability rights and CBR. This was a stark difference to other conversations I had had where there appeared to be no grassroots leaders with lived experience of disability, conflict and displacement:

> Participant: And, it seems to me, I think we can't rest. For example, I have sold the idea, Esmeraldas is divided into two sectors, the sector of the riverside, the river, which is from here to below, where I told them, the south side, and all the rest. The riverbank is marked as the most marginalised sector, the sector where everyone goes to sell the drugs, where everyone goes and smokes, where everyone goes and violates the rights, where everyone does what they want. Then, from that perspective, I live on the riverside... In the Ribera there are more than one hundred and fifty people [with disabilities]. There are four, five, six… we are seven neighbourhoods in the Ribera where more than one dwell, about 250 people with disabilities. So what are we looking for? I am pitching the idea and I have been working on the subject, to which we count, we create an organisation here in the Ribera for people with disabilities. I mean, I'm one of the people who thinks that if we set up a foundation and create a foundation here on

the riverbank, that foundation will begin to help a lot, not only for people with disabilities but it will help a lot for the sector.

Interviewer: Is it important for people with disabilities to also fight for the rights of other people, not just their own rights?

Participant: If I only fight for myself, happiness itself, I will have part of happiness, but my happiness is not going to be complete. Because when there are other rights affected around me, circulation is stopped. Rights are circulated. Rights have to circulate everywhere, in all directions. It cannot be that I fight only for my rights when I see that there is child abuse, when I see that there are girls being raped, when I see that there is an older adult abandoned, yes? It is more, it is more, even us, having the disability, was created here below the self-help group […] where we met fifty people with disabilities. This self-help group has had to work with elderly people who have a disabling situation but cannot get documentation and cannot get a wheelchair from the state because they do not have a disability card. Then, they either have to buy their chairs, or relatives, or they stay on the floor. So, what have we done? We make these people also participate in our meetings. We have done activities like raffles, and things like that that we do, to be able to buy canes, support canes, batons for the blind and wheelchairs and walkers so that these people can have them. And we have donated them to them. There is one thing, there is one thing in all the work we do, and it is if you talk to a hundred people of any social group and you go with a hundred people, that is, one hundred people from each social group, at least in the nineties, if not more, at least ninety [of them] are always going to complain about the economic situation, always, yes? Because people do not see options, people do not see that there are things to do, people have not discovered their potential, their strengths. (Participant #17, PwD)

Interestingly, this final comment strongly reflects and promotes the ethos of appreciative inquiry. From my various encounters with Participant #17, it is clear that grassroots leadership is an important element of promoting the rights of asylum seekers and refugees with disabilities, especially when state support is lacking. However, as predicted, challenges included limited resources and the lack of legal status, which was a hindrance to growth and impact. From my own observations, the respect he was afforded as a grassroots leader was for the most part due to his life's experiences as an asylum seeker and as someone with a disability, as well as his passion for serving others. In summary, effective grassroots leadership must be rooted in lived experience and self-advocacy, where minority populations can see their own life's experiences reflected in those who are actively working towards claiming their rights (Goodley, 1997; Powers, Ward, Ferris, Nelis, Ward, Wieck, & Heller, 2002).

Middle-range leadership

The second level of actors that Lederach refers to is middle-range leaders, who occupy leadership positions in sectors such as education, business, agriculture, and include ethnic and religious leaders, academics and leaders of NGOs. Middle-range leaders play an important role in peacebuilding due to their proximity to key top-level decision-makers, as well as

grassroots leaders (Lederach, 1997). During my field research, I conducted five interviews with middle-range leaders, including representatives from Asylum Access, the UNHCR, Sucumbíos Women's Federation, RET and the Mennonite Church. Each of these representatives were doing significant and important work in their respective capacities to promote the rights of asylum seekers and refugees.

However, I would like to focus on the middle-range leadership of Participant #20, who is the Refugee Project Coordinator for the Mennonite Church in Quito, Ecuador. Participant #20 herself is Ecuadorian and like me, was born with a congenital disability. She said she never paid much attention to her disability until she was a teenager, when she noticed that society perceived her as different from everyone else. As a result, she too started to see herself differently. Within her church life, she felt that people saw her disability as a punishment from God and she thought that God could heal her and make her perfect (moral model of disability, see Olkin, 1999). After a long period of coming to terms with herself and her disability, she decided to start working with other people with disabilities. She began working in the Latin American Council of Churches and linked into a network of indigenous people with disabilities and the Cuban Baptist church. At that time, Ecuador was going through its own changes as the Government began to focus on addressing disability rights:

> However, in earlier times people with disabilities were sometimes hidden. They were forgotten and had no access to school or anything. They didn't even have minimal technical resources. So, at that moment I worked. I needed besides all that to feel like a person […] we were 'the disabled', 'the blind', 'the deaf' but the dignity and courage of being 'people' didn't exist. Then we started working with people with disabilities on this sense of dignity valuation, of fullness, of being complete. But later on, we understood that if the whole society doesn't make a transformation and a change, it's much more difficult to move forward. Because society can put a lot of architectural, verbal, psychological limits on a child with a disability and the little friends don't want to get together with him or her, no. So, we realised that society as well needed to be sensitized, aware and we started. I started working in schools giving workshops about what disability is and about how society has been making assumptions and then we also said that our churches didn't have any knowledge about disability either […]. (Service Provider #20, Mennonite Church)

Participant #20 is currently the coordinator of the Mennonite Colombian Refugee Project. When talking about her work with refugees with disabilities, it was clear her own lived experiences gave her insight and empathy for those she was working with:

> Participant: I believe that the fundamental problem of all social inequality are social structures. The social structures of our countries are totally unfair; a few have many opportunities and most have few opportunities. I think one of the fundamental things is how to modify [this]? How to transform a social structure that is oppressive? Because in Colombia the conflict, the violence is maintained there. But in Ecuador, well, it's the

same. Because the structure remains the same. Then they change one country to another. But if we have a country with a social structure of inequality that excludes, that discriminates against people, their situation is the same. All over the world, that is the problem. That is why what we do advances so slowly, because you have to face such complicated situations in Ecuador. Laws had to be made so that school teachers learn how to work with children, children with disabilities, then force them to meet their work obligation. But it isn't what they want to do as a vocation. Employers are forced to hire people with disabilities. Because for me, this doesn't work. I spent some time without work. I am a psychologist and I think I have academic qualifications. But when I was looking for a job, I was offered a job of lower academic quality than mine because I have a disability. The issue is very difficult and challenging and I think that what you do is important, it's to make the situation visible, to question society, but also to give strategies for society to sensitize. […] but also of course to see, to get in contact with social organizations, with political entities to relate to that level that is where transformations really take place. Because they are the ones who have the power. But then, begin to knock on those doors, to take our rights, our possibilities, our real value, our dignity as human beings, then from there begin to have the space. I need to know that they are not giving me anything, they are not giving me alms. I don't want that. To be aware also of our being, right? […]

Interviewer: Do you do any work with the United Nations Convention on the Rights of Persons with Disabilities?

Participant: We have, I know it, we have read it and we have tried to socialize it, so that it is like, like a tool for knowledge, that there are universal laws and rights that states are committed to comply with. Ecuador signed this statement and I think it has done a lot […] Perhaps what we [people with disabilities] also need, is to see ourselves from that possibility, right? That society itself has been thinking of people with disabilities as recipients of aid but then it's necessary that we move or not just stay there but that let's say we are the promoters, we are the ones who promote... those who are now asking for things, thinking, analysing, acting, having influence, having thought processes, of proposing other possibilities to society. (Service Provider #20, Mennonite Church)

The personal experience and knowledge that Participant #20 had of the different models of disability provide the foundation for her passion for promoting the rights of all people, regardless of disability, ability or any other identity. As a middle-range leader, her lived experience enables her to engage with asylum seekers with disabilities on a deeper level, while also advocating for the rights of people with disabilities at higher levels of leadership, both within the church and the wider Quito community. This is not to say the middle-range leaders from the other organisations were not effective in their leadership roles. However, Participant #20 was the only middle-range leader who had an intimate knowledge of the CRPD and the impact that the various models of disability can have on the disability community. In this way, it is important to appreciate the best of what is by highlighting the strength of those in middle-range leadership positions who have lived experiences that reflect the experiences of those people whose rights they are fighting for.

Top-level leadership

The third level of leadership is top-level. This refers to leaders with high visibility, whose focus is on high-level negotiations, policies, mediations, agreements, and so on. Despite my best efforts to make contact with the newly inaugurated President Lenin Moreno, he did not respond to my invitation to participate in this research. However, as the world's only Head of State who is a wheelchair user, high hopes have been placed on his top-level leadership appointment both in Ecuador and around the world. Many of the participants saw his leadership as something positive for the disability community, regardless of how they felt about his politics:

> Yes, we hope now that the other one [Moreno] won, that it also brings benefits to the disabled. Yes, he said he was going to work a lot with the disabled. (Participant #9, Family)

> I, as a mother, think that now with the President, there might be more opportunities for them [people with disabilities]. Because there are laws, articles, for people with disabilities, but the problem is who follows those articles and laws for people with disabilities? […] we're hopeful that with this new government, with Moreno at the lead, things can improve for people with disabilities, to have new opportunities. Because right now there aren't any. However, there are rights, there are laws, and so many things, but there aren't the opportunities they need so much. (Participant #10, Family)

> So having this Presidential programme in the moment and now having the President, it's like the people are aware of that. And it's like, this [disability rights] is in the speech, and this is in the policy, everywhere in your day to day activities. So this is really important. Because it's a way to tackle to those kinds of difficulties you have, in general, to promote anything, to change the situation. (Service Provider #11, UNHCR)

As demonstrated by these three examples of leadership, different approaches to peacebuilding must be taken at each level. High-level initiatives championed by elites, such as President Lenin Moreno, play an important role in advancing inclusive and accessible positive peace. As a top-level leader with a disability, he had successfully raised the profile of disability and the visibility of disability issues in Ecuador. Likewise, the work of middle-range leaders, such as Participant #20, help to establish relationships and the necessary infrastructures to sustain high-level endeavours. Grassroots leaders, such as Participant #17, bring together people both with and without disabilities, and refugees with local populations, to translate top-level initiatives into grassroots change. In this way, when there is lived experience at each level of leadership, that is, leaders who intimately understand the consequences of direct, structural and cultural violence, there is potential to develop a comprehensive framework for inclusive positive peace (Maiese, 2003).

Though my research did not investigate whether all three levels of leaders were actually working together to form said framework, I do believe it is important to begin by acknowledging and celebrating these leaders. Furthermore, all three leaders rejected the charitable approaches to disability, and promoted a rights-based ethos within their respective communities. This in itself is a strong foundation for progressing the CRPD and advancing the rights of asylum seekers and refugees. As highlighted by Powers et al. (2002), supporting individual leaders with disabilities, building the capacity of organisations led by people with disabilities and encouraging cross-disability partnerships, lead to more positive and satisfactory outcomes. Further research in this area might investigate how leaders with disabilities from communities affected by conflict and displacement are developed, how to ensure different levels of leadership are working together towards shared goals, and how to ensure people with lived experience are present, participating and determining the agenda on issues that affect them both within their own communities, as well as in the mainstream or dominant culture.

The "Best of What Was": The Journey from There to Here

Having established rapport and explored the best of what currently is, we then discussed the best of what *was* in reference to the participants' journeys into Ecuador. This was when many of the participants took the opportunity to recall the trauma discussed in Chapter Seven. However, this then gave way to conversations about what had aided their journeys. Some participants indicated that nothing had aided them; that they were completely on their own with no one to help and there was no "best of what was" to recall or discover. For me, this was a strong indication of extreme resilience amidst extreme challenges. Other participants identified specific events, circumstances and moments that had made their journey that little bit easier.

For many of the participants, given the nature of their departure – in secrecy, only with what they could carry and with very little financial security – help from others along the journey was important for their survival and wellbeing. For example, allocated seating for people with mobility issues meant that Participant #2 was able to get on and off the bus more easily. When the bus stopped, strangers brought food to him, so he could avoid unpacking his wheelchair. Both Participant #2 and Participant #25, who is blind, encountered bus drivers who allowed them to travel at a cheaper price, and in some circumstances, strangers helped cover the cost of tickets. However, one of the most compelling stories was told by Family #1, the family

from Venezuela in which the father lives with significant physical disabilities and the daughter with autism:

> Mother: Well, see, in Venezuela, like here, they [people with disabilities] have the privilege of not waiting for too long. They can go VIP and stuff. In our trip I travelled with food. Which I should not have done, not only because it's illegal to travel internationally with food but because in Venezuela it is illegal to take food out [of the country]. It is considered extraction of national goods, because there is no food in Venezuela. I only took a little bit, but of course I was very scared. I had to pay some bribes, so they would not look into my bags. I paid quite a lot, so they would not look into my bags. So, we left. We left by airplane because my husband would not have survived the trip otherwise, he was not doing well at that time. And the girl was emotionally destroyed. She had a lot of crises. She cried a lot. We had travelled before, we travelled a lot. But nothing like this trip. She knew this was travel without return. From the night before, the girl was feeling unwell. She was unwell in her stomach, she would not breath well. We had to ask for a miracle so they (people at the airport) would not notice that she was sick. Because if they see that you are very sick they won't let you travel. So, we had to do everything we could so that she would feel a little better and she could get on the airplane. Once we were on the airplane we did everything we could, so we could get her to 'fall in love' talking about the landscapes, beautiful landscapes. Colombia is a beautiful country, from air and land. It is very beautiful with all the mountains. When we were on Ecuadorian land, it looked very similar. The two countries are very similar. But when we landed [she] got very sick. She had very high fever for about two days. She didn't want to eat. Very high fever.
> Father: Now she eats more.
> Mother: Yes, so there was a lot of crying too. We knew we would come to Ecuador at some point, but to visit family, not to move here permanently. We never thought about leaving our country. We thought we would be able to survive like the many people who are fighting there now. But we really never, ever, ever thought… we actually got married legally but we never got the paperwork (the married ID). That is why it has been so complicated for me to get my documents in order. So, the girl only has my last names. I did it so that she could travel easily with me… Well, the service in the airplane was very good. We had economy tickets, but the airline staff saw how long we had waited and they upgraded us to first class. When the girl started having the panic attack the airline staff were nice enough to let her go without the belt. They even stayed next to us the whole time and kept asking if we needed anything. They also took her into the cockpit and she met the pilot and they gave her their autographs. They asked if she wanted a photo, but she said no. [My husband's] family in Guayaquil was also very nice when we arrived. That also helped a lot. (Participant #1, Family)

As recalled by the mother, the attitudes, adaptability and flexibility of the airline staff in this story clearly alleviated the pressure of an extremely stressful situation. For people with disabilities who are attempting to flee violence, especially when modes of transport and information are designed for people without disabilities, the risks are magnified. In this circumstance, the willingness of the airline staff to adapt to the needs of the child meant that they were able to leave Venezuela safely, even amidst the daughter's distress. Although it was not discussed, it appears that the stewardess in this story may have had training on how to respond to passengers with disabilities. In this way, the airline staff member was actively

promoting the rights of asylum seekers with disabilities as outlined in the CRPD. In many other circumstances, this story would have ended very differently, most likely with the family being removed from the plane, or the girl being physically restrained, causing more distress.

Summary

This chapter has been an exploration of *discovery,* the first D of the 4D principals of appreciative inquiry. This was achieved by focusing on peak experiences, discovered amidst the challenges of conflict and displacement. Four of the most common responses, together with my own observations, were presented: tranquillity and security, aid, support from local people, and lived experience of disability at different levels of leadership. After discussing life in Ecuador and the best of what *is*, the chapter then presented the participants' recollections of the best of what *was*, specifically in relation to the journey from their home countries to Ecuador. It might be noted that many of the examples presented in this chapter relate to the goodwill of others, an idea that might be interpreted as relating to dependency and the rejected charity model of disability, but often seemed to be manifestations of empathy. However, what these examples show are the values and circumstances that can aid survival and wellbeing, as well as the importance of collaboration. These discoveries will now provide the foundation from which we start to look forward, as the participants share their advice and recommendations for realising a future where their rights are upheld.

The next chapter begins with a summary of what life might look like when the rights of people affected by disability conflict and displacement are being promoted and upheld (dream), followed by what needs to change and the steps that need to be taken to achieve such a future (design and destiny).

Chapter 9 – Findings: Peace that is Married to Justice

> "Peace is creating a community where we are all responsible for one another. Where, if I have well-being, I can't have well-being while the other doesn't have well-being. That is peace and that is why it is a process that has nothing to do with only with peace. Because peace is… it's married to justice. Then if there is no justice, there is no peace."
>
> - Participant #20 (PwD and Service Provider, 2017)

Introduction

Having discussed the best of what currently *is*, as well as the best of what *was* during the journey from Colombia and Venezuela into Ecuador, the conversations with the participants then moved to the next three Ds of appreciative inquiry's 4D principles (Cooperrider, 2012). This involved *dreaming* about a future in which the participants' human rights, freedoms and dignity were being upheld, as well as pathways towards achieving that future (*design* and *destiny*). It was during these discussions that the value of lived experience became particularly evident, as participants expressed what rights and values are important to them and what they want for their own lives.

This chapter begins with a glimpse into what participants dreamed life might look like in five years' time, followed by my own reflection on these conversations, specifically in relation to basic needs theories, human rights and positive peace. The chapter then explores what needs to change in order to achieve those envisaged futures. This includes the participants' advice and recommendations for future asylum seekers with disabilities, as well as NGOs' and Governments'. The challenges of enacting participant recommendations are then discussed. To conclude the chapter, I then reflect on the second key research question and what was learnt from participants about protecting the rights of people affected by disability, conflict and displacement.

Dreaming: "What Might Be"

According to appreciative inquiry, the dream phase is where participants dream about, or envision, what might be in the future. Having already recalled the best of what is, the theory proposes that the human brain naturally begins to search further to envision new possibilities

(Cooperrider et al., 2008). Anticipating this, during the interviews participants were asked, "Thinking about the future in five years' time, imagine that you (or your family member with a disability) are living a dignified life. A life where you (they) feel safe, equal and included in society. What does that future look like?" For many of the participants, this was a difficult question to comprehend, given the fragile and uncertain nature of their current lives in Ecuador. However, the responses of those who did answer could be loosely grouped into three types of dreams. The first type of dream related to the participants' own personal wellbeing. For example, the most common response was the dream of having not only paid work and financial security, but work that is meaningful and dignified:

> God willing, I'll get a little money and just put myself in one place, and start selling something. (Participant #12, PwD)

> Well, I wish, hopefully, [to] have money to set up a coffee shop or a quick snack [place], because I like fast food. (Participant #15, PwD)

> I would at least want to get some kind of job, like a messenger or something like that. I move well on the street. (Participant #2, PwD)

> To live well, to have a job, for my boy to be doing well in Colombia. I had everything necessary there. I worked there and everything. But not here [Ecuador]. […] But, wealthy enough to survive. I don't want riches, but something to get by. (Participant #23, Family)

> Interviewer: And what do you want to do in five years? […]
> Daughter: Be a Mum.
> Mother: What else?
> Daughter: And work.
> Mother: What else?
> Daughter: Learn to write and read. (Participant #4, Family)

> I need economical help, maybe a job, maybe a benefit. (Participant #6, PwD)

> I am sure that one day I am going to get ahead in any little job. I just have in my mind that I have to get a better job than what I have. (Participant #7, PwD)

> Well, I would like the job now, not in five years. (Participant #9, Family)

The second type of dream was *where* they envisaged living in five years' time. Most of the participants spoke fondly of their home countries but saw themselves remaining in Ecuador. A few expressed the desire to return to their home countries and two participants wanted to move to a third country. It was unclear what their motivations for staying, returning or leaving were:

> Mother: […] but I'd like to go back home. I love Ecuador, it's been very nice. They've been very good to us really, but Venezuela is my home. (Participant #1, Family)

I hadn't seen him [my son] for more than twelve years, and until now a friend told me, 'Your son is now here on the border as a prisoner.' How can I know how he is and how can we get him out? […] if my country is truly going to beg, and if God gives me life I want to return to my country again. (Participant #8, PwD)

Father: I would leave here from Ecuador, I would go to another country. (Participant #16, Family)

Interviewer: Thinking a little about the future, where would you like to see yourself in five years? What is the most important thing for your health, work, house… where would you like to see yourself in the future?
Participant: In another country. (Participant #22, PwD)

The third type of dream related to the wellbeing of others and service to the wider community:

Father: We know our situation is different to everyone else's and we don't want to go back. We know Venezuela is going through its own process. There's a lot that Venezuela needs to grow, as humans and in politics. We know we have to help Venezuela, all the people that are in need in Venezuela, once we are stable. We want to be able to help people that were in the same conditions as we were before leaving. Maybe we don't help them to leave, but we could help them with money, help them start a business. We can help Venezuelans from here. (Participant #3, Family)

It depends a lot on people, on politics. I insist, I insist, and I always go with that ideal, that if there is a way to unify us more, to come together, to think together, to debate, to make debates among us, for those ideas to improve situations, each day would be better. (Participant #17, PwD)

So maybe we need to get together and form networks that strengthen us, that make us stronger. Get together among many people who are working on the issue of disability and create teams, multidisciplinary work teams where, from all parts of the world, we begin to generate ideas, to generate projects and do that. Networks that are interwoven to make visible the issue of disability. Perhaps to have a support from there. Another, so basically it would be how can I support you? That is, what we need to do to make this change, how do we put together economic resources? How do we gather humanitarian resources to help? How do we open this, ideas, possibilities? Networks that are woven for a joint work, a teamwork. (Service Provider #20, Mennonite Church).

To help elaborate on these responses and understand what values are important to a safe, secure and dignified future, I also asked each participant what they thought are the most important human rights. Responses included the right to life (Article 3 of the United Nations Universal Declaration of Human Rights, or UDHR), housing (Article 25, UDHR), health and wellbeing (Article 25, UDHR), food (Article 25, UDHR) and financial security (Articles 22, 23 and 25, UDHR) (United Nations, 1948):

Mother: Life security.
Father: Life. (Participant #1, Family)

Between the rights is education, health, and to be respected and accepted as we are. (Participant #10, Family)

All are important, but the fact of being with health is very important. (Participant #17, PwD)

Well, I think that what is happening in my country [Venezuela]... I think for a human being, the fundamental right should be the right to food. The right to feed, and the right to health. (Participant #2, PwD)

Well, the economic part and work. […] Health and education. (Participant #4, Family)

Well, in order to survive we must have health, and also have financial aid for us because we can do nothing. We were living in a little hut and we left all our possessions. We couldn't bring anything. (Participant #5, Family)

Yeah life. The health […]. To have a roof over my head, to have food, medicine, work… (Participant #6, PwD)

Reflection: Moving Beyond Basic Needs

I would like to take a moment to reflect on participant responses, particularly in relation to disability rights and the importance of moving beyond basic needs. When considering participant responses, the future that was envisaged was simple; it was a future where the participants' physiological and safety needs were being consistently met. In this sense, the future that participants dreamed of was no different to what all humans strive for, or in many circumstances, take for granted. At the most basic level, this shows that we, people with disabilities, are no different from anyone else. However, as a disability rights advocate, there is something unsettling about the hesitancy, or perhaps inability, to imagine what life might be like beyond the meeting of basic needs.

If we look to Maslow's (1943) other levels of need, for example, he includes emotional needs such as love and belonging (friendship, family, intimacy and sense of connection), mental and intellectual needs such as the need to have self-esteem (confidence, achievement, respect of others and uniqueness) and the need of self-actualization (morality, creativity, spontaneity, acceptance, purpose, meaning and inner potential). Other philosophers have added to and debated these needs over time (for example, see Kenrick, Griskevicius, Neuberg, & Schaller, 2010; Wahba & Bridwell, 1976). Basic need theories have also contributed a great deal to PACS and discussions on positive peace. Peace scholar, John Burton (1990), argued that the universal needs of human beings must be fulfilled in order to prevent or resolve conflict, and

scholar Edward Azar (1980), who developed the protracted social conflict theory,[9] associated conflicts with needs such as security, identity, recognition and participation. Johan Galtung (2012) identified four basic needs of humanity:

- Survival needs: Protection from violence, safety.

- Wellbeing needs: Food, water, nutrition, movement, protection from illness.

- Identity needs: belongingness, happiness, affection, actualization, self-expression.

- Freedom needs: Freedom from fear, freedom to choose occupation, way of living.

Galtung maintains that no one need is more important than the other, and that some needs can be sacrificed for others. For example, survival can be sacrificed for identity or freedom. However, if all basic needs remain unmet, then violence may ensue.

According to TRANSCEND,[10] for there to be sustainable solutions to conflict, all human needs must be fulfilled – including social, spiritual and psychological needs (as well as basic physiological and safety needs) (Graf, Kramer, & Nicolescou, 2007). This point is widely accepted amongst peace scholars and practitioners within a variety of disciplines and fields (for examples, see Coleridge, 1993; Galtung, 2012; Nyamu-Musembi & Cornwall, 2004). Positive peace is both the elimination of overt forms of violence (negative peace), *as well as* the creation of a more equitable social order that meets all human needs (as listed above) and all human rights (Christie, Tint, Wagner, Winter, & Anderson, 2008).

It is also important to acknowledge that an unwavering focus on basic needs as a peak experience and future goal does not align with the rights-based model of disability. As outlined in Chapter Two, the rights-based model of disability encompasses both civil and political human rights, as well as the economic, social and cultural rights of a person (Degener, 2016). It is also based on empowerment (referring to the participation of people with disabilities as active stakeholders) and accountability (the duty of society to implement rights and to justify the quality and quantity of their implementation) (Miller & Ziegler, 2006). As such, my analysis has led me to conclude that research and practice targeted at fulfilling *only* the basic needs of people with disabilities fails to promote or uphold the other key aspects of the rights-based model (such as social and cultural rights) and also fails to advance positive peace.

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[9] In relation to hostile interactions between communal groups that are based in deep-seated racial, ethnic, religious and cultural hatreds, and that persist over long periods of time with sporadic outbreaks of violence.

[10] TRANSCEND is an organisation co-founded by Johan Galtung in 1993 that focuses on conflict transformation by peaceful means (Fischer, 2013).

Of course, this discussion is not only limited to the disability community. It applies to all people and all groups affected by any type of violence. However, while many of the interviewed service providers indicated they had moved beyond basic needs approaches in theory, principle and practice, participant responses suggested these approaches were yet to trickle down to asylum seekers and refugees with disabilities. For example, organisations that provided services for refugee and asylum seeking populations also facilitated support groups for women, youth groups for young people, language classes, art classes, as well as other initiatives aimed at fulfilling needs beyond the basic ones. Within the interviews there was little indication of these initiatives being attended by, consciously being made accessible to, or even mentioned by the disability community. However, further research in this area is needed to determine more substantial evidence and analysis. While I do not believe the exclusion of refugees and asylum seekers with disabilities from activities aimed at fulfilling a wider range of needs was intentional, it may be indicative of underlying ableist ideologies. That is, the subtle, and often overlooked, preferential treatment of people who attain to certain corporeal standards and abilities (Campbell, 2001). Even so, the difference in attention afforded to the needs of people affected by disability, conflict and displacement, when compared to those without disabilities, is not surprising and reflects the findings of the literature review (for examples, see Crock et al., 2012; Grove et al., 2010; Ortoleva, 2010; Reilly, 2008; Reilly, 2010; Shivji, 2010).

The question remains: whose responsibility is it to raise the standard of expectations to more than just the meeting of basic physiological needs of people with disabilities during conflict and displacement? If we are working from the social-relational model of disability, which holds that disabilities are the limitations imposed by people in positions of power to exclude (Thomas, 2004a), then I would suggest that in conflict and displacement it is the responsibility of people in positions of power to exclude to think beyond initiatives that simply fulfil the basic physiological needs of minority groups. This might include peacebuilders, academics, humanitarian groups, NGOs, government officials and other key stakeholders in conflict management. Furthermore, it is only by collaborating with the disability community as equal partners that people's needs can really begin to be identified and understood (Powers et al., 2002).

Our Future

This brings us to the pinnacle of the interview questions, which looked at practical steps that might be taken in order to achieve a future where the rights, freedoms and dignity of people

with disabilities affected by conflict and displacement are promoted and upheld. According to appreciative inquiry, the design and destiny stages of an interview are where participants co-construct the future by helping to turn future dreams into everyday realities. More than a vision, the design stage sets out intent, based on what has worked in the past or the best of what is. The fourth stage, destiny, relates to innovation and action. Participants help move key stakeholders towards the ideal future: "This is important because it is precisely through the juxtaposition of visionary content with grounded examples of the extraordinary that appreciative inquiry opens the status quo to transformations in collective action" (Cooperrider et al., 2008, p. 7). Due to limitations in time and resources, we were unable to fully realise these two final stages of appreciative inquiry. Instead, I asked participants what steps need to be taken to achieve the dreams they had envisaged and what needs to change before that can happen. To help make this concept easier to understand and relate to, I also asked them to provide practical advice to a hypothetical person with a disability, or family, living in a place of conflict, such as their home town or somewhere else (for example, Syria), who is considering seeking asylum in another country. To do this, I encouraged participants to think about what had helped them get to where they are today, the peak experiences that had been revealed during discovery, and what they wished someone had told them before they sought asylum in Ecuador. Listed below are the participants' responses, which I have categorised into the following three types of advice: 1) recommendations for a particular course of action; 2) recommendations against a particular course of action; and 3) recommendations about how to make a decision (as summarised by Dalal & Bonaccio, 2010).

Recommending a particular course of action

By this stage of the interview the participants were practising appreciative inquiry and generative dialogue that was solution-based, rather than problem focused. As such, most of the advice and suggestions were recommended courses of action rather than advice against doing something particular. Suggestions were either for the benefit of future asylum seekers with disabilities and their families, or other key stakeholders such as NGOs and governments. The first recommendation most participants made was for people thinking about seeking asylum in another country:

> Well, if you have the situation of insecurity, the first thing is that, personally, I would advise you to do what I did. If I see that my life is in danger, yes? It's getting away from the danger. (Participant #17, PwD)

> The truth is that I don't know. But I would advise to come over here. There are many more opportunities, both for people with disabilities as well as for work, I think life is easier over here. (Participant #19, Family)

I'd tell him to come. Sure! Because here it is quieter than there. (Participant #12, Family)

I don't know. In my case I would tell him to leave, as I did, it was very simple. Cornered, and I left my country. In that case, if he decides to stay, well, let him hold on to God and fight for him and his family in the best way. (Participant #2, PwD)

Father: The advice I will give to Syrians, for example, or any family in conflict is to get out […] Yes. As hard as life can be here they can survive, they can live here. If services for people with disabilities are difficult before conflict, they are not existing during conflict. So it's worth to take all the risk and get out. […] Here there is always the chance to survive, to eat, to have a life. Here there are helping organisations, and there is always the chance […] That's why I told you may help people who can; people in the conflict environment are needed to take them out.
Interviewer: If we were thinking on a big scale… financial support for organisations to get…?
Father: Here it could be the case that the country should help, should allow a big scale operation. But that couldn't be… people like them don't see, they can't… (Participant #1, Family)

A challenge that many of the families faced prior to leaving their home communities was the lack of accessible information on what to expect during the journey into Ecuador, and what Ecuador would be like when they arrived. This was particularly difficult when considering the needs of family members with disabilities and health conditions. Although it helped that the participants spoke the same language as the local population, there were no instructions on how to integrate into Ecuadorian society as asylum seekers with disabilities. When discussing the logistics of providing accessible information for people with disabilities who are seeking asylum, a possible suggestion was that NGOs might be able to provide resources and information for families before they leave their home communities. However, as several participants highlighted, this could be risky because you cannot trust anyone during conflict. As such, they recommended that future asylum seekers with disabilities should not tell anyone they are leaving, including NGOs:

Participant: If we talk about leaving Colombia, in a situation of threat, in a situation where the integrity of my life is being affected, it is safest to leave without giving notice to the authorities. Go out on your own and in secret, that is, without making so many warnings. […] What happens is that in countries like my dear Colombia, the situation is so complicated. Because if you are being threatened, because if you are in danger of death, if you go first to the authorities to help you out or to protect you, there's no security, no security. (Participant #17, PwD)

Yes, you learn that you should not trust almost anyone. (Participant #9, Family)

These discussions made me wonder about the possibility of utilising mobile technology, which is already being used globally to connect isolated and often impoverished rural

communities (for example, see The World Bank, 2012), for the purpose of information sharing. As of 2018, more than half of the global population has access to the internet (53%), and there are 5.135 billion unique mobile users worldwide, which is over 67% of the global population (Kemp, 2018). Given that the majority of the world's population already has access to basic mobile technology and that accessible technology has had a significant impact on the disability community and people with different access needs (Raja, 2016), could mobile technology also be used to establish networks of people affected by disability, conflict and displacement? While I did not get a chance to discuss this further with the participants – particularly in relation to significant barriers and challenges such as security, anonymity, cost, practicalities and technological literacy – the need for accessible, safe, secure and anonymous information sharing tools is a potential area for future research.

These conversations then led to generative dialogue about the importance of lived experience and word-of-mouth information. Several participants suggested that they would have benefitted from a peer support network as a means of sharing information and experiences, as well as resources, opportunities and funding.

> Mother: Let's say, for example, you have a child with special needs. You have money, you have possibilities. So, I say, 'Well, I'm going to find a woman who also has a special needs child to help take care of mine.' What do you think?
> Interviewer: It's an interesting idea.
> Mother: Yeah, sure. There are a lot of wealthy people who pay normal people. Why not pay someone who needs to take their little boy [with them]? It's like doing charity and also helping someone out. 'Hey, I have an apartment, come and help me take care of my little girl that also has special needs.' And, you can feed her and all that. If I had money, I would do that, I would. If I had money, I would find other special need kids and tell their mothers to come and watch their kids and watch mine and we could help each other out.
> Interviewer: Yeah. So, it's families with a shared experience allowing each other the opportunity, through helping each other.
> Mother: Yeah. Let's say, if you are able and I am not, you would be giving me charity and I would be helping you, because I don't have the resources.
> Interviewer: Yeah, so the first step… and that would be creating a network between parents […]
> Mother: That would be good. (Participant #23, Family)

> Mother: If I had had the resources, I would have bought a big house where I could bring kids with disabilities and the elderly where I can look after them […] because there are a lot of people who seem to act like children, even though they are adults or older people. If I could, I would have had a big house, which one part is for elderly people and another part for children. And sometimes I would like to run a restaurant, because I've seen that some people throw out food and I would like to run a restaurant and hire other women, and work together in the restaurant making sugar water and do you know if you can help me? (Participant #4, Family)

The importance of peer support networks was simply and eloquently summarised by the mother of a girl with an intellectual disability. When asked what she would say to someone in Colombia who is in the same situation as she was, she replied:

> Mother: I would tell them that when they come to call me. They trust me, no one else.
> Interviewer: That's really important, people with a shared experience helping each other…?
> Mother: Yes, to see how I could help her. (Participant #9, Family)

Other participants recommended the establishment of an impartial NGO, whose sole purpose is to provide disability information and support once asylum seekers had arrived in the host country:

> Participant: I am sure that if we have a foundation, if there is a foundation here, a foundation that has no qualms, that has no limits as to who it will help and who not to help, okay? Then, ah no, there comes a foreigner from Colombia or any country that is, with a disability, to seek our benefit, to seek our help, why not provide [it]? (Participant #17, PwD)

> […] It will be necessary to find an organisation and support people with disabilities. The only way if they can do it... An organisation that specifically helps people with disabilities. It's the only way. (Participant #12, PwD)

> Father: In fact, I've been talking to Asylum Access, that I'm interested in starting a foundation, so we can start helping in a little way. This is why when you asked for our time I thought sure. Anything that can help another person, sure. We don't want anyone else in Venezuela or Colombia or anywhere else in the world that lives the same situation. We're all human beings. We all have a heart and at some point in life we will be hurt. And I don't think pain was what humanity was made for. I don't think man came to the world to feel pain. We came to the world to achieve, to grow, to help each other to be happy. So, I really don't understand why there is so much suffering. (Participant #3, Family)

Humanity and Inclusion (HI, formerly known as Handicap International) is an international NGO that already works with people with disabilities affected by conflict and displacement around the world. According to their website, HI has had a presence in Ecuador since the 2016 Esmeraldas earthquake (Humanity & Inclusion, n.d.). However, they did not appear to be active in the participants' communities at the time of the interviews. Further research would be needed to understand the differences in the experiences of asylum seekers and refugees with disabilities who received specialised services from organisations such as HI, and the experiences of asylum seekers and refugees with disabilities who do not have access to those disability specific services.

Another practical suggestion was derived from the airplane story reported by Participant Family #1 in Chapter Eight, in which the airline staff's attitudes and sensitivity towards

disability helped to provide comfort, reassurance and safety during the flight between Venezuela and Ecuador. During informal follow up conversations with both the family and the translator of this interview, we discussed the benefits of an NGO that could assist with accessible safe passage specifically designed for people with disabilities and their families. An alternative option would be to work with an existing airline or transport agency on inclusion and access training and sensitivity, and then arrange sponsorship for the safe passage and travel of people in vulnerable circumstances on a semi-regular basis. This would align directly with Article 13.2 of the UNDHR, which states that all people have a right to leave any country, including their own, as well as the following CRPD articles:

> States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters. (Article 11, United Nations, 2006a)

> 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. (Article 18, United Nations, 2006a)

Other general recommendations were aimed at NGOs already working with asylum seekers and refugees and the Governments of host countries:

- More job and work opportunities for asylum seekers and refugees with disabilities (Participant #6, PwD, Participant #22, PwD).
- Priority for people with disabilities within the refugee status determination (RSD) processes and current support systems (Participant #12, PwD, Participant #18, Family).
- Accessible housing for people with disabilities (Participant #6, PwD, Participant #16, Family).
- Integrated services (that is, services that are inclusive of everyone rather than separate services for people with disabilities) (Participant #17, PwD).
- Protection for refugee women with disabilities (Participant #4, Family, Service Provider #14).

- Work with the parents to change attitudes within the family towards disability (Service Provider #13).

- Psychological support for asylum seekers and refugee children with disabilities (Participant #16, Family).

Recommendations against a particular course of action

Recommendations against a particular course of action was the most uncommon type of advice. I believe this to be the result of the appreciative inquiry methodology, which encouraged participants to focus on solutions rather than problems. However, one participant did recommend against a particular course of action, and that was for asylum seekers with disabilities to avoid travelling by boat between the Colombian and Ecuadorian border:

> Participant: Well, I say, if some of these things, it is better by road.
> Interviewer: Would you have done it by road?
> Participant: Yes, I would have come by road. [Now] I know how it is around here, I came [from] above, I didn't know. So, they didn't tell me to come over there. A lot of work is done, because, there you have to go... Take a small boat to get passed, and then take a car that brings you here […] and from there the boat that brings you to San Lorenzo. So, that was a very hard tragedy for me, a very hard race.
> Interviewer: So, if he did it again…
> Translator: Yes he would do it by road.
> Participant: […] If he's going to come then I'll tell him not to come around that way. It is better by road because he won't suffer, what I suffered. (Participant #15, PwD)

While this was the only example of advice against a particular course of action, it demonstrates the importance of drawing on the experience and knowledge of asylum seekers and refugees with disabilities. While the journey by boat might have been tolerable for someone without a disability, according to this participant it was extremely uncomfortable, painful and perhaps even dangerous for someone with a disability such as himself. It is this kind of first-hand information that might be valuable to someone who was considering leaving their community in Colombia to seek asylum in Ecuador, that is, information that could be shared through a network of people and families with experience of the intersectionality of disability, conflict and displacement.

Decision making recommendations

The next type of recommendations related to attitude and the impact that attitude has on decision making and the way you live your life. As someone with a disability, the wisdom that was shared by the participants was both moving and profound. It is the kind of wisdom

that can only be offered by someone who has lived through extreme challenges and trauma, yet is the kind of wisdom that can impact anyone who wants to listen.

Have faith

Many of the participants expressed a deep commitment to a higher being. Given that Venezuela, Colombia and Ecuador are countries whose populations predominantly identify as Catholics or Christians, it is unsurprising that the participants recommended other families affected by conflict, displacement and disability, put their trust in God:

> Be patient and ask the Lord to touch the hearts of people who support you. (Participant #12, PwD)

> I would tell them, find refuge in God. That God has a path of hope for them. And the people hosting them are very important. I tell them [local people] to put themselves in their shoes. Host them in the best possible way, make them feel like they have a family. A family sent by God. Because for us, as displaced people, that is our greatest challenge. That when we arrive to a country we feel rejected. As for us, we thank God for being here in Ecuador. But there is a misconception within Ecuadorians, they think that migrants or foreigners are here to take away [from them]. But no, we come to share. We come here to grow with them. To have a new brotherhood. To learn about their culture, to get to know them, and also to teach them about us. It's an encounter. That those misconceptions have to be removed. (Participant #3, Family)

> And don't lose faith, because without that, you can't move. (Participant #18, Family)

> Confront the situation with high morale and pray to God. (Participant #6, PwD)

> Well, the advice that I would give to another person who is the same situation as me, like I said, the hope is first to trust the Lord and carry on, keep fighting because we know that if we make an effort, we can carry on, we can do any kind of job, anything we can do for our own benefit. […] Therefore, with my disability, I can give as an advice to move if they can move, to walk, to talk to people, to look out for things, because to tell you the truth, we feel cheered up when we do things, and that power is very helpful […] (Participant #7, PwD)

Withhold your anger and frustration

One of the most heartfelt recommendations was offered by a nine year old boy from Venezuela, who lives with autism. Having fled with his family from Venezuela, through Colombia and into Ecuador, his advice to other refugee children with disabilities was to try to not get angry or frustrated, especially if you have left something behind; a simple yet important reminder for all people regardless of age, ability or status:

> Son: One of my favourite books is 'The Cow's Fault'. It's a book with different stories and each story has a message. There was one about the cycle of anger. The book said there was a man who was very famous, and this man got angry and he came to the office and got mad at another man. So, then the second man also got angry and told a

woman that she couldn't do anything right. So, the woman got angry and she hit a dog. So, then the dog got angry and bit another guy. This man was angry because the dog had bitten him, and he went to his mother's house. And because he was angry he said, 'I don't like your food,' to the Mum. But the Mum responded, 'I understand, I may not have your favourite food right now. But one day I will be able to buy your favourite food." So, the message of the story is that negativity is passed on to people.

Interviewer: Yes, it's true, so be positive right?

Mother: But also, what he wants to tell you with that story, it's a book about self-growth. So, the story says that my anger is reflected on to you. But if you cut it off you will not reflect that anger to another person. It's the chain. The man got angry, told the lady, the lady hit the dog, the dog bit the man but then the mother cut off the chain.

Interviewer: […] So, we want you to give us advice for another kid your age who also has to do a long trip like you guys did – what advice would you give that kid?

Son: Umm, don't get too angry. He should think about the good things that you can find in your country and the new opportunities you can have. You shouldn't get frustrated if you should leave some things behind. I think that's all. (Participant #3, Family)

Patience was also the advice given by parents of children with disabilities for other parents:

Father: The advice I would give him is that you have to try move forward with your child. That is, give good affection to the child and... because the children are not to blame, and they were born, it was, in that matter, and it's time to move forward, right? (Participant #16, Family)

Mother: Well, first of all be patient, because children like that are very restless […]. (Participant #18, Family)

Mother: First of all, to have patience. Because one can get stressed out and thus have everyone experience stress. To be tolerant, to calm down, and know how to react with those with a disability. That is, how to interact with them. (Participant #4, Family)

Accept your situation

The next piece of advice came from Family #3 and was for asylum seekers with disabilities and their families: accept your situation as it is, try to consider what it is like for host populations (such as Ecuadorians), and do your best with whatever you have:

Father: I think the best option in these types of situations, first of all you need to accept your situation. The father of the house, which in theory should be the guide and the strength, something that most men have, so the Dad really has to talk to the rest of the family and consult with them so especially in a situation that I know will affect them. I really need to consult them [my family] and support each other. I try to involve the kids as much as I can, even though they're very young. Now we're having some problems with our rent, the Visa, problems with jobs, basically we have problems in every area, but I try to involve them to a certain extent of course. First of all, so they have an idea of what's going on, if the problem actually comes to a head it won't take them by surprise. That will prevent them from reacting violently or aggressively. And the other one is accept the choice you have to make. It's not so easy to change your country, your people, your beliefs, the things you're used to. I think that's the hardest, the things you're used to. Changing the things you're used to for someone else's customs. The other thing is you need to know you're leaving your country for another place because you can no longer be in your own country. You need to accept that. You just need to

know you can't go back, you can't live there anymore. So, you accept that and then you focus on what is coming. The things I'm looking forward to. I can't come to Ecuador thinking I will get my same house, my same car, my same truck or anything I had in Venezuela. I came to make something new here. That's what you need to focus on. And you need to transmit that same feeling to your family. […] One more thing you need to accept, is that when you arrive to a foreign country, a country that is not yours you are entering someone else's home. And you wouldn't want a stranger to come into your home acting in ways you're not used to. So, for example, we come from a warm country and we love to walk around without our shirts on. But if another person comes into my home without his shirt on, I'd feel disrespected. That's just an example. Those are things you need to learn. Maybe you come to a new place and you won't be treated the way you're used to. But you need to try to understand why they're treating you that way and rather than criticising this person or getting angry at this person and falling into the cycle of anger like the boy said, you need to cut that anger and just move on.

Mother: So, all I say, and I tell the other Venezuelans, is we're here and we need to respect them. You can't start criticising this country because you are a stranger in this country. So, if they think about you that way. You need to try and find a way, so they can see that you're not, that you're a friend. And try to say the things you like about Ecuador. And if there are things you don't like, don't say it.

Father: Yes, if you leave your country then you need to focus on the new place. You can't keep thinking about your past. It's no good to keep reminding yourself of what you left. And it's not helpful to tell other people about how good you had it in the past.

Mother: My advice is to focus on the good things they can find in the future. Because God always has good things waiting for us. Everything that happens in life is to make us stronger and to learn. We should focus on the good things we're learning. There are times where the learning comes from negative things, and you think it is negative, but in reality, it's making you stronger so it's positive. So, for example, in my life, I once saw [my son] as a very negative thing, the diagnosis, but now I see it as a blessing. He teaches me new things every day. He's teaching me to become a better person, a better human being. (Participant #3, Family)

Focus on what you have

The next piece of advice was again provided by Participant Family #3, whose wisdom and experiences have featured throughout these findings chapters. To give some context to their story, the father of this family had worked as a policeman in Venezuela and had established a stable and successful life for himself and his family. However, after refusing to carry out tasks that he inherently disagreed with, the family was forced to flee for their lives. As previously discussed, the second eldest son lives with autism and a variety of other health conditions. Having left everything behind, they spoke of the courage and determination it took to move to Ecuador, and what it means to focus on what you have rather than what you do not. Listed below are a collection of excerpts from their interview. I have decided not to interpret or analyse their words, so as not to lose the depth of wisdom they shared – wisdom that left both

the translator and I speechless and feeling quite emotional, as we reflected on what it truly means to appreciate the best of what is:

Mother: I want to tell you something that is very important for your study. For your study and for other people to know about our experience having a child with Asperger's, that they can't focus on what you don't have, but what you already have. Take advantage of all the positive things that you have and the positive traits of these human beings. They have different qualities to the ones was call 'normal'. But if you think about it, there are many things we 'normal' people have similar to them.

Mother: I want to clarify something. Our experience was not positive, we made it positive. Because sometimes the bus stopped, and we didn't have money to buy the food everyone else was buying. So, we focused on looking at the cars. We made the situation be positive. Because I don't know if you know people who even in positive times they still focus on the negative. So even when we didn't have anything to eat we'd just be like, 'Look at the car, how pretty! Look at this…'. So, we wouldn't go there [where everyone was eating], we'd come here. Because we were trying to save everything we had for when we arrived in Ecuador. We didn't know what we were coming to. And the kids they were happy, they were thinking about the cars and playing.

Father: I don't know if you've ever watched that movie A Beautiful Life. That movie for us, changed our lives. Remember how the Dad in that movie changed such a negative situation to a positive thing for his son? He even gave his life for his son in the movie. And so are we. We're painting them a beautiful story. [Through tears] Our heart is up here [points to throat], we're worried…
Mother: But we don't show that to them. For example, we can only eat rice and lentils, so we start talking about how the lentils are and they have onion and carrot, how nice, how good right? We have to be grateful to God for what we have. We always focus on the good things we have. And that's why I think life feels somewhat easier for us. There had been times where we say wow, what are we going to do? But they don't see that. We don't want them to feel that frustration. Sometimes we overhear them talking about the good food they had that day, and we say, 'Remember we didn't eat for two days that time?'. We want them to learn to see the good things, the positive things in life. And if there are no positive things, you create a positive thing. You have to create it, you have to find it.

Get involved

For Participant #17, one of the key challenges he faced within the disability community was the sense of victimhood, self-pity and a lack of participation. His advice was twofold. First, asylum seekers and refugees with disabilities should reflect on their own attitudes and work through any trauma that is affecting their day to day existence and wellbeing. Second, get involved. Society should provide opportunities for asylum seekers and refugees with disabilities to get involved in all aspects of public life, and asylum seekers and refugees with disabilities should take those opportunities by becoming involved:

Participant: First, to improve wellbeing and good living, first the person would have to […] get rid of, let's say, of a life that… of a situation that happened and that does not have to keep tormenting him. That is first. We can have all the possibilities of the

world, but if the past life traumatises, and the difficulties that we are going through are still tormenting us, that is not going to allow our situation, our life, to improve or change, yes? So, that is one of the first steps. […] But, you have to continue continuing. You have to continue working on that issue so that the person does not live with that resentment. Because sometimes that resentment remains, and when that resentment is left, that is what occupies us, our heart and our whole being and does not allow us to advance.

Participant: See, there are those who participate, the fronts of citizen participation. The problems are there, the problems are always going to be there, right? The reluctance or impediments, or the lack of interest of the agents or the authorities, will always exist, only that we have to actively participate, we have to recognize ourselves, we have to stop being those victims.

Interviewer: In your opinion, how do we… how do people with disabilities believe in their strengths? What are some practical ways we can help people with disabilities believe in themselves?
Participant: Well, two things mainly. One, as I said earlier, to be full of consciousness and training. Another, after they become aware… to be trained is to be an active part, to participate actively in organizations of management, of political management, of the organizations, of management of resources, of all types of resources
Interviewer: So, become politically active?
Participant: If we [people with disabilities] participate, everything will be different. Because here, in our midst, in the sector where we live, the authorities, those who are elected by popular vote, everyone goes there and fights for ideals, but ideals are ideals of convenience. Then, if that is so, if we live it, so we know it already, and if people we train each day, each one of us, not just me, but each one of us is aware of that reality, what will happen? So, we can, among ourselves, also send people from us to do part of this and also go to fight for that equality. That's it, I think that's a challenge, I think that's one, I think that's an ideal too. […] And, it seems to me, I think we can't rest.

Destiny: Actioning Change

The final D of the 4D line of questioning is destiny, referring to the invitation to construct the future through innovation and action (Ludema et al., 2001). When reflecting on participant responses, the question at the forefront of my thinking was: "Yes. But, how?" How do you share information during dangerous and harrowing situations? How does an NGO reach out to those affected by disability, conflict and displacement, given the need to leave quickly, quietly, while trusting no one? How do you avoid the scrutiny and termination of support mechanisms? How do you logistically and financially enact the suggestions provided by those with lived experience? These are all very important questions that problematize, and in some ways negate, the recommendations presented in this chapter.

As highlighted by Bushe (2011), the destiny stage of appreciative inquiry is the one that provokes the most confusion and least consensus amongst appreciative inquiry advocates:

"[…] one of the most common complaints about appreciative inquiry from users is that while energy for change is high after the Design phase, implementation can be very spotty" (Bushe, 2011, p. 2). Advocates of appreciative inquiry have suggested solutions to the challenges of the destiny stage, including encouraging participants to personally commit to take action consistent with the design element, whereby the leadership role is to track and fan innovation (Bushe, 2011). However, when working with marginalised communities, such as people with disabilities who may have experienced significant impairment effects, as well as the imposition of restrictions by people in positions of power to exclude (Thomas, 2004a), then placing the onus on the disability community is unlikely to advance positive peace. Even so, appreciative inquiry practitioners have noted that when all of the 4Ds were practiced over an extended period of time (such as three years), and when the restrictive grip of deficit vocabularies had been loosened and vocabularies of possibility were unleashed, then:

> …energy for action was immediately boosted within the system. People began to feel a sense of hope, excitement, cooperation and ownership about the future, and they began to unleash a veritable revolution of positive change and innovation. (Ludema et al., 2001, p. 10)

Admittedly, due to limitations in time, access and resources, the destiny stage of the 4D cycle received the least attention during the interviews. However, upon reflection I believe the dilemma of "how" reinforces the necessity of inclusion and access within PACS research and practice. While this research cannot present a comprehensive answer, what it can do is lean on the social-relational and rights-based models of disability to gain a broader perspective on how to implement the suggestions provided by participants. From this perspective, constructing the future through innovation and action must therefore be informed by rights-based approaches, driven by the disability community ("nothing about us, without us") in partnership with those who are in positions of power to exclude, and in a way that acknowledges, respects and addresses impairment effects.

As will be discussed in the following chapters, simply by partaking in the interviews, participants demonstrated the unique ability to navigate barriers, limitations and restrictions, and a spirit of resilience and entrepreneurship. They are survivors. When these characteristics are represented by people with lived experience amongst leadership, management, advisory groups, steering groups, and so on, together with people in positions of power to exclude (for example, academics, researchers, leaders, philanthropists, investors, employers, politicians, and other stakeholders), then the design and implementation of conflict and displacement policy, research, response, and interventions, are more likely to reflect the needs of those

affected by conflict and displacement. Again, this is a concept that is strongly reflected in peacebuilding theories such as Lederach's (1995, 1997) elicitive approach to conflict resolution and peacebuilding. As highlighted by António Guterres (former United Nations High Commissioner for Refugees and current Secretary General of the United Nations):

> Too often invisible, too often forgotten and too often overlooked, refugees with disabilities are among the most isolated, socially excluded and marginalized of all displaced populations. As this pioneering research by the Women's Refugee Commission reveals, those with disabilities are more limited by our actions than by their own physical and mental abilities. The way we design and construct camps can impede their access to vital services; the way we distribute food without taking their specific needs into account impacts their health and safety; the way we exclude them from vocational training and income generation programs promotes the view that they are helpless and dependent; and when we don't actively encourage their participation in refugee leadership structures, we give the impression that they are less able. (as cited in Reilly, 2008, p. 1)

I would suggest the first step might be to draw on the few existing examples of positive field practice that demonstrate the benefits of ensuring people with disabilities have equitable opportunity to contribute to the design and implementation of mainstream and targeted services during conflict and displacement.[11]

In summary, I have no doubt that when the 4Ds of appreciative inquiry are paired with Disability Studies research and evidence that demonstrates the benefits of lived experience (Powers et al., 2002) and self-advocacy (Goodley, 1997), then solutions to the question of "how" will begin to materialise. Change is possible. Although this, my own, research did not have the capacity to investigate "how" participant recommendations could be enacted, I am instead presenting a bricolage-type (Kincheloe, 2005) discussion inspired by a range of factors, models and theories that have potential to construct a future of positive peace through inclusive and accessible innovation and action. This is indeed a very exciting area for future research.

Research Question #2: Learning from Lived Experience

These last two chapters have detailed participant narratives and responses to appreciative inquiry's 4D line of questioning. The second key research question of this thesis is: What can we learn from people with disabilities about protecting and promoting the freedoms, rights and dignity of people with disabilities affected by conflict and displacement (as outlined in Article 11 of the CRPD)? In a broad sense, Chapters Eight and Nine have demonstrated the

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[11] For example, the Women's Refugee Commission report: *Disabilities Among Refugees and Conflict-Affected Populations* (Reilly, 2008).

depth of insight and knowledge that can be developed from the absence of freedoms, rights and dignity, and the presence of direct, structural and cultural violence. These chapters have also shown the importance of collaborating with the disability community as equal partners in change. More specifically, the appreciative inquiry line of questioning challenged participants to think of their own experiences of intersectionality as important to ensuring such experiences are discontinued in the future. Responses included:

- Feedback on what had already been useful and helpful for the participants;
- Feedback on what participants want and need more of;
- Suggestions for improved future supports;
- Suggestions for other people affected by disability, conflict and displacement.

Summary

The pearls of wisdom that have been presented in this chapter are treasure-like; rare and hidden diamonds that have been forged from within the most unimaginable and traumatic circumstances. This chapter has only begun to touch on the knowledge and expertise of people with disabilities affected by conflict and displacement, and what they bring to discussions on positive peace, human rights, freedom and dignity. In many circumstances the dreams and advice presented in this chapter would have been subjugated and excluded by researchers, academia, peacebuilders and society in general; a sobering thought. Although one of my greatest regrets is not being able to spend more time learning from those with lived experience, these conversations have given PACS a taste of the wisdom that people with disabilities bring to the table.

This chapter began with a glimpse into the life the participants dreamed of for themselves in five years' time. That is, a life where their rights are being upheld. Responses revealed that almost all of the participants envisaged a life where their basic needs are being met. I then reflected on these dreams and discussed the meeting of basic needs in relation to positive peacebuilding. My analysis concluded that for peace to be truly positive and inclusive of marginalised populations, then basic needs must simply be the starting point and not the end goal. Although this is not a new concept, interview findings suggest that the disability community is yet to be included in this way of thinking. The chapter then presented participant responses to questions about human rights and the dreams they envisaged. Recommendations were targeted at future asylum seekers with disabilities as well as NGOs and governments, and included recommendations for particular courses of action, recommendations against particular courses of action, and recommendations for making

decisions. Finally, the challenges of the destiny stage of the appreciative inquiry line of questioning were addressed. While questions about "how" participant suggestions might be logistically and financially implemented remain unanswered, the case for inclusion, leadership, lived experience and self-advocacy, together with equitable partnerships with those in positions of power, provide a framework for future attempts to progress inclusive and accessible innovation and action.

The next chapter of this thesis moves towards the third research question by reflecting on discourse and the process of appreciative inquiry. Chapter Ten draws together the ideas, themes, experiences and narratives collated during this research, into a compelling argument about the importance of inclusion and diversity within PACS and positive peacebuilding.

Chapter 10 – Reflection: Discourse and Process

"There is a quote that says, 'To be called a Refugee is the opposite of an insult; it is a badge of strength, courage and victory.' I would argue that so too is this label of 'disability'. […] Indeed, it is only when we start to see people for their strengths, rather than their weaknesses or deficits, that we can truly start talking about peace."

- Robbie Francis (PACS researcher, 2017b).

Introduction

The previous three chapters of this thesis, for the most part, have documented the unfiltered responses of participants in guided conversations. This chapter, however, takes a step back in order to gain a wider perspective by beginning to address research question number three, which moves from the knowledge of participants (pure research) to a discussion on inclusion and access within PACS (applied research). While a key contribution of this thesis has been acknowledging and valuing the unique perspectives of people with disabilities within PACS research, it is also crucial to ensure that the underlying roots of ableism within our field are challenged, removed, and then replaced with effective tools for ensuring future pursuits of positive peace are inclusive and accessible.

Chapter Ten begins with a summary of participant responses, followed by a reflection on the impact that academic and popular discourse can have on marginalised populations. Following this, I discuss my own experiences with the methodologies of this thesis. As outlined in Chapter Four, appreciative inquiry and narrative inquiry were employed to explore the expertise of people with disabilities affected by conflict and displacement. This chapter presents my own analysis of these processes, including a discussion on the shadow of human experience, the importance of flexibility within language and the expression of emotion; and whether appreciative inquiry fulfilled its potential as an inclusive and rights-based methodology that is transformational and generative of change.

Participant Responses: A summary

The first aim of this thesis was to use pure research to de-subjugate the knowledge of people with disabilities affected by conflict and displacement. Subjugated knowledge refers to knowledge that has been disqualified as non-conceptual, hierarchically inferior, beneath the required level of erudition, and knowledge that has been rejected by the mainstream (Foucault, 1980). Earlier in this thesis, the exclusion of people with disabilities from academia, humanitarian responses during conflict and displacement, as well as peacebuilding activities, was demonstrated. This led to the formation of the first two research questions, which asked what we can learn from people with lived experience about intersectionality and rights. In short, the answer to these questions is: a great deal. Through the process of narrative inquiry and appreciative inquiry, participants shared their trauma, peak experiences (standout or high points), recommendations and ideas. From their narratives, I was able to begin to document the intersectional experience of disability, conflict and displacement, as well as identify commonalities across the narratives. Listed below is a summary of the main findings of the field research, derived from both the participant interviews, and my own observations and analysis:

- Participants reported experiencing high instances of direct, structural and cultural violence. They also reported additional layers of intersectionality, including homelessness, poverty, and racism.

- According to participants, the unique and specific needs of refugees and asylum seekers with disabilities remained, for the most part, unmet within mainstream interventions. It was unclear whether this was a result of limited funding, resources, ableist ideologies, and/or for other reasons. However, when the unique and specific needs of participants with disabilities *were* considered, it had significant impact on their well-being.

- Participants reported that the attitudes of local populations and their sensitivity towards the intersectionality of disability and displacement were important to their wellbeing and survival.

- Participants valued interventions that met their basic physiological and safety needs. However, there was less focus on fulfilling the more abstract levels of needs, such as identity and freedom needs (Galtung, 2012).

- Many of the participants believed that people with disabilities should be prioritised within mainstream governmental, NGO and civil society interventions during conflict and displacement.

- I observed the importance and effectiveness of lived experience at grassroots, mid-levels and high-levels of leadership, especially when coupled with rights-based approaches to disability.

- Participants provided unique insights into what they imagined life could be like when their human rights, freedoms and dignity were being promoted, protected and respected (as outlined in the CRPD).

The next section is a reflection on my own discoveries that developed in response to the insights disclosed by participants.

Changing the Discourse

My first reflection relates to the shared rhetoric and discourse between refugees and people with disabilities, the impact that language and discourse can have on marginalised populations, and how PACS research and practice can help to develop and change discourse in a way that is conducive to positive peace. According to the interviewed service providers, public and political discourse surrounding asylum seekers and refugees was one of the most difficult challenges to overcome when working with host communities. Listed below are excerpts from an interview with a staff member from Asylum Access, who articulated the importance of language and discourse when referring to the experiences and journeys of people affected by conflict and displacement:

> For nearly a century we have thought about refugees as people who need humanitarian aid. That's not 100% inaccurate, but it's not empowering. So, we're changing this paradigm. We know that these people are not people with needs, these are people with rights that are being violated. And we're seeking justice for them, and we're seeking together with refugees, justice for refugee communities. And that's very revolutionary in refugee response. The majority of money for refugees goes to temporary housing and food and medical aid, which are not unnecessary, but they're also not long-term solutions (Service Provider #21, Asylum Access).

This same rhetoric that has been used to describe people affected by conflict and displacement has also been used to describe people with disabilities (Davis, 2013). If I was to take the interview with the Asylum Access staff member and replace references to refugees and asylum seekers with references to disability, the discussion would very much remain the same. Take for example, the quote below, where I have added references to disability in square brackets:

> The dichotomy of discourse that we hear about refugees [people with disabilities] is really interesting, […] refugees [people with disabilities] are these poor people that need our help. Both are violent. Both of these discourses generate violence. And the

only discourse that does not generate violence is understanding that refugees [people with disabilities] are human beings like you and me that have rights. And it's not a charity, it's an obligation to accept these people as human beings with human rights. (Service Provider #21, Asylum Access)

These sentiments, when reframed to include disability, reflect the shift that has taken place between the charitable and rights-based models of disability. The rights-based model of disability holds that society must ensure all people, including people with disabilities, have access to equal possibilities of participation (Degener, 2016). As highlighted by the Asylum Access staff member, popular rhetoric and discourses around refugees, and (I would add) people with disabilities, are generative of violence. Or to use the terminology of this thesis, popular rhetoric and discourses can cause and perpetuate direct, structural and cultural violence. This also reflects PACS research and literature that analyses conflict as a social construct (for example, see Jackson & Dexter, 2014). Furthermore, as the Asylum Access staff member went on to state, such rhetoric and discourses not only cause violence against the concerned individual or group but are also in fact detrimental to the wider community; are detrimental to positive peace:

> And so, we had, I think, 8,800 that came to apply for asylum in Mexico, of a country of 100, 000, 000. That's not crisis. It's only a crisis if those people cannot integrate into the new country. Accepting those people and integrating them into the economy only grows the economy and grows the diversity of work environments and you only have more people that can buy goods and services, buy houses and live lives in that country. It's when we don't allow them to do these things, when we deny people their rights, then that they become marginalised groups, without hope or a future and that causes poverty. (Service Provider #21, Asylum Access).

> I like this vision of people with rights and not needs. Because we often think of the stories that we hear of refugees are of these really tragic stories whose message is, 'this person needs your help so donate money'. Instead, we're showing people what is possible when they invest their donations in services that allow people to access their human rights – the incredible potential refugees have to contribute to society, the economy, and the culture of a community when given the chance. (Service Provider #21, Asylum Access).

So how can PACS help change the discourse around people with disabilities affected by conflict and displacement? Earlier in this thesis, I argued against the use of the word "vulnerable" in academic and grey literature as a blanket descriptor for groups, minorities and entire sectors of society, due to the exclusion it can lead to. I remain adamant that this argument holds, even more so now that I have witnessed the negative impact such a discourse can have on marginalised populations. As highlighted by the Asylum Access staff member, there needs to not only be a change in terminology – specifically, how we refer to marginalised populations – but also a paradigmatic shift in how we think about and respond to

them. Again, this is a sentiment that is at the heart of the disability rights movement, the rights-based model of disability, as well as the CRPD:

> And part of my job is, as sort of the communications focal point for the region, is to innovate the way that we talk about refugees and change the language of how we talk about their situations. So, one of the biggest ways that we do that is that we don't talk about the refugee 'crisis' because the refugee crisis isn't a crisis. The refugee is not the crisis. The refugee not the problem. What creates crisis is how we react to it. So, if we allow people to come in and access a process that allows them to exercise their rights, you no longer have a crisis because you're allowing people to contribute to the economy, to society, to the culture and you only grow your population and your economy and a new understanding of society. But if you close borders, detain people, and marginalise them, you create more poverty, more violence and, with that, these violent structures that cause crisis. There's no crisis of refugees in Europe. There's a crisis of how people and institutions in Europe are responding to new people coming across their border. (Service Provider #21, Asylum Access).

My interviews with the participants demonstrated that even though they had faced moments of compounded intersectionality, discrimination, marginalisation, ableism, disablism and all types of violence, these were experiences that did not necessarily define who they were as human beings, and most certainly did not alter their status as equal rights bearers. As highlighted by a 2017 report by the Women's Refugee Commission on vulnerability- and resilience-based responses to the Syrian crisis, people with disabilities are often considered to be a homogenous at-risk group, and as a result, protection assessments automatically assume negative capacity. Very rarely do responses and interventions analyse capacity, or use a strength-based approach, which can identify resources, skills and assets and how to protect them (Lee & Pearce, 2017). If I was to describe the kinds of traits held by the participants who contributed to this research, words that come to mind include survivors, resilience, hopeful and entrepreneurial. Outlined below is an excerpt taken from a blog I wrote while in Ecuador, detailing my own personal response to the experiences of interviewing asylum seekers and refugees with disabilities; that is, people who have traditionally been perceived as the "poor people that need our help" (Service Provider #21, Asylum Access), yet, for the most part, have missed out on help altogether:

> […] it's June 2017 and I'm writing this blog from the Ecuadorian Amazon. Donna-Rose's words continue to ring in my ears. What happens to people like us during war? I'm here to ask this same question of those who know the answer. The experts. To those with experience. Over the past month, I have been interviewing people with disabilities and their families, all affected by the horrors of conflict and violence in Colombia and Venezuela. Their stories are beyond anything you could imagine. Violence. Rape. Murder. Poverty. And then there's the experience of disability on top of that. Unlike myself, who have chosen to pursue PhD research in this area, their expertise has been forced upon them because of circumstances beyond their control. Every day they live with the compounding effects of disability, displacement and poverty. But I don't want to simply recount the horrors of what it's like to live with a disability during war. I want

to tell you about courage and resilience. The people I've met are fighters. They are survivors. So often we read about the 'global refugee crisis'. But I can't help thinking we've got it wrong. They are not a 'crisis'. Not the people I've met. I've met human beings, who against all odds – disability, conflict and poverty – are still here. And it is these experiences that have given them real and raw insights into life and humanity – the good and the bad. There is a quote that says, 'To be called a Refugee is the opposite of an insult; it is a badge of strength, courage and victory.' I would argue that so too is this label of 'disability'. My time here in Ecuador has taught me that it is those wearing badges of strength, courage and victory, who are the ones we should be welcoming into our countries and communities as heroes. With offers of jobs, homes, safety and security. I am absolutely certain the knowledge and expertise that refugees with disabilities bring to the table should be considered invaluable assets within any community, business or school. Indeed, it is only when we start to see people for their strengths, rather than their weaknesses or deficits, that we can truly start talking about peace. (Francis, 2017b)

With these discussions in mind, PACS researchers and practitioners are now faced with a unique opportunity to contribute to meaningful and transformative impact on the lives of people affected by disability, conflict and displacement, other marginalised communities, as well as wider human networks. In order to change the discourse around "vulnerable" populations, we must first acknowledge that many people with disabilities (including Disability Studies scholars) have rejected the charity model of disability and embraced the preferred social, social relational and/or rights-based models of disability (Shakespeare, 2013; Thomas, 2004a). As outlined within equal opportunity theory, some people experience advantages in life beyond their control (Mithaug, 1996). Similarly, within the social relational model of disability, Thomas (2004a) refers to people who are in positions of power to exclude. Such people (including PACS scholars and practitioners) have an obligation to improve the prospects of self-determination for individuals and groups who do not experience said advantages or power (Mithaug, 1996; Thomas, 2004a). This includes recognising and responding to the direct, structural (disablism) and cultural violence (ableism) experienced by people with disabilities, acknowledging the collective strength of the disability community, supporting people with disabilities to determine their own identity and agenda, and increasing the visibility of the rights of people with disabilities (Johnstone, 2001). Within PACS research and practice, this means that we too must embrace the social relational and rights-based perspectives of disability by ensuring people with disabilities have equitable opportunity for participation, leadership, and to determine their own agenda within research and practice – not as a question of humanity or charity, but as a right. In doing so, not only can PACS have an impact on disability discourse within academia, but also within conflict resolution activities, peacebuilding endeavours and within the pursuit of positive peace.

Appreciative Inquiry

My next reflection is on the methodologies and processes used within this research. The decision to take an appreciative inquiry narrative approach entailed a certain amount of risk. To my knowledge, appreciative inquiry has not been used with people affected by disability, conflict and displacement, and seems to go against the problem-centred research approaches that are commonly utilised within academia. Outlined below are four key points that emerged from my own experience of using an appreciative inquiry narrative approach, as well as a discussion on the potential of transformative and appreciative rights-based approaches within PACS.

Reflection: The shadow of human experience

As outlined in Chapter Four, one of the key criticisms of appreciative inquiry is the tendency to focus exclusively on the positive (Bushe, 2007). When embarking on this research journey I was aware of the dangers of ignoring the shadow of human experience (Reason, 2000). I also knew that people who experience systems deeply embedded with resentment and repression, such as the intersectionality of disablism, ableism and racism, may be less likely to tolerate appreciative inquiry as a methodology (Bushe, 2005). With this in mind, my approach was simply to use appreciative inquiry as a starting point (Michael, 2005). It soon became clear that creating a safe space for trauma and the shadow of human experience to be explored and documented would be vital to the development of the interviews, as well as my obligations under the Belmont Report, which relate to respect, beneficence and justice for participants (National Commission for the Protection of Human Subjects of Biomedical Behavioral Research, 1978). Any previously held concerns of not knowing how to respond appropriately to narratives of trauma quickly disappeared. I believe this was the result of the shared experience of disability, a rapport that seemed to break down any barriers and power imbalances that might have been experienced between myself and the participants. We were simply human beings with a shared experience of difference, meeting up for a cup of coffee to discuss how to create a better future based on life experience.

When conversations turned towards the negative aspects of disability, conflict and displacement, I responded by asking clarification questions. I then attempted to reframe participant responses to instigate generative conversations of change. For example, in the excerpt below, the participants had just finished describing a traumatic experience where their daughter had been traumatised by a police officer in Venezuela. Instead of focusing on the

traumatic experience, I redirected the conversation towards the potential of the disability ID card as a means of developing generative dialogue:

> Mother: So that day I went and spoke to the military guard and I kept the ID in my hand. I didn't notice that while I was waiting a lot of people came around us and were trying to skip the line. So, they called the police (the riot police) to stop these people. So, they arrived, and they got their baton thing out and they started waving it up. He came towards us and towards the girl. And she started to scream. So, I screamed at him quickly, 'Sir please, she has a disability, please!' And I put the ID card on his face. He immediately put the baton down and said to my girl, 'No love, it's not with you.' But it was too late, she was petrified. Since then I cannot take [my daughter] to the shop with me. Every time she saw a police officer she would start crying.
> Father: And if you receive money there is no guarantee you will receive food….
> Interviewer: So, in some ways it [the disability ID] helps? Because in New Zealand we don't have this card. It's a different situation, but we don't have the card.
> Mother: What country is that?
> Interviewer: New Zealand. So, the card, if it worked well it can be life-saving?
> Mother: Yes, yes, it works. Actually, here [Ecuador] and in Venezuela they work very well. (Participant #1, Family)

While my attempts were at times hindered by language barriers, this process was crucial for not only ensuring participant experiences could inspire solutions and ideas, but it was also a necessary aspect of respecting the journeys that had brought us together to meet in that particular time and space. It was also important to acknowledge these narratives in written form. Chapter Seven is just that, a tribute to the extraordinary journeys of the participants who generously shared their narratives with me.

My experience with appreciative inquiry methodology confirmed my hope that, as a process, it affords the freedom and opportunity to be heard. By "setting the stage for the freedom to be heard, it opens the doors for people who felt ignored, without a voice to offer information, ideas and innovations" (Whitney & Trosten-Bloom, 2010, p. 274). Indeed, as was revealed in Chapter Nine, important and innovative solutions to direct, structural and cultural violence can be found amongst marginalised fringe voices (Bushe, 2011). It is important that disability is *not* considered a liability. As highlighted by Garland-Thomson (2012), instead, disability might be considered a valuable asset in the navigation of barriers and exclusion. My research has shown how important it is for PACS researchers and practitioners to acknowledge the experiences of marginalised communities such as people with disabilities. This can first be achieved by ensuring people with disabilities are supported to determine their own research agenda and lead PACS research and practice themselves, as well as by providing time, space and resources for the experiences of participants with disabilities to be expressed within research design, analysis, presentation of research findings and future applications of the

research (Nind & Vinha, 2014). Second, is to go beyond simply documenting traumatic experiences, by helping participants to reframe those experiences to create a foundation from which generative and transformational dialogue can flow.

<p align="center">Reflection: Basic and complex emotions in appreciative inquiry</p>

My next reflection relates specifically to the use of language. In earlier writings, "positive" is an adjective used by appreciative inquiry's creators to describe the types of narratives stimulated by 4D interview questions as well as the underlying ethos of appreciative inquiry (Cooperrider & Whitney, 2001). However, in later writings the adjective "generative" is used more widely, specifically in reference to types of conversations that have the potential to help transform social realities:

> For me, the important issue is the call to create a generative human science and theory that opens the world to new possibilities. While deconstructing the dominant language of deficits and problems, the conclusion I came to was that *the field's deficit-based assumptions were holding back its generative capacity*. And what we were finding at the Cleveland Clinic was the more we study what gives life, the more we surface moments of courage and inspiration and hope. Instead of a search for positivity, I would call it, "What is it that gives life when human systems are most alive and we are at our best?" That *search itself* feeds the imagination in the mind that opens the conceptual floodgates. (Cooperrider, as interviewed in Grieten et al., 2018, p. 107)

This shift in language and thinking is something I experienced within my own journey with appreciative inquiry. Looking back at the direct translations of the interviews, I can now see that there were moments when language barriers between myself, the translator and the participant meant that impromptu interview questions were unintentionally translated into Spanish using words that very much focused on positivity and happiness. This led to participants attempting to recall positive and happy moments amongst extreme trauma without going through the reframing process, which was an incredibly difficult task. The use of the adjective "positive" was challenged by the mother of Participant Family #3, who reiterated, "I want to clarify something. Our experience was not positive, we made it positive."

On the other hand, there were times when the questions appeared to be too abstract or complex for participants to fully comprehend. This seemed to be the case when speaking to asylum seekers and refugees who originated from rural communities and who had low levels of literacy. For example, generative questions that had been formulated and used successfully during interviews in Quito were found to be confusing for some participants in the provincial regions. Outlined below is an excerpt from one of the first interviews in Lago Agrio, which

includes the direct Spanish to English translation of a question that had been adapted and interpreted by the translator:

> Translator: How do you think conditions can be enhanced? How do you think we can promote security, dignity and respect for people with disabilities?
> Participant: I don't understand, I don't understand the question. I don't have the answer. (Participant PwD #6)

In response to the participant's confusion, the translator resorted to asking closed questions about a specific subject (such as healthcare, employment, travel, and so on). The translator also switched to using basic positive language rather than generative language:

> Translator: Is there any positive moment that you remember from your travel from Colombia?
> Participant: No. (Participant PwD #6)

Following this, the participant became increasingly short in his responses, repeating that there was nothing positive about his experience of disability and displacement. After this interview was complete and following further consultation with my supervisors, I opted to simplify the interview questions even further, and encouraged the translators to avoid translated terms such as "positive" and "happiness". This example highlights the necessity of flexibility when considering the different access needs of research participants, particularly when utilising appreciative inquiry in research that is inclusive of marginalised communities.

Of course, the most obvious limitation was my inability to speak fluent Spanish, which meant that some of these issues and discrepancies went unnoticed until after the interview was completed, transcribed and translated. This will be discussed further in the limitations section of the next chapter. More importantly, these experiences reveal that a standard approach to appreciative inquiry (or any qualitative research) might not always be the most accessible or empowering. It is possible for lines of questioning (such as generative questioning) to become inaccessible for people who are unfamiliar with, or uncomfortable with, expressing their emotions and ideas. When considering appreciative inquiry alongside psychology literature and research, it is important to acknowledge the difference between basic and complex emotions. Basic or simple emotions such as anger, surprise, happiness or fear, tend to happen automatically without much cognitive processing. Complex emotions such as shame and pride require self-reflection and self-evaluation (Weir, 2012). Generative dialogue within appreciative inquiry can, at times, require participants to engage in complex emotions as well as self-reflection and self-evaluation, which are processes that do not necessarily come naturally or easily to everyone. As the excerpt above highlights, the natural response of the translator was to resort to simplifying the language used and asking questions relating to basic

emotions, such as happiness. However, as has also been established, asking participants who are from marginalised communities and who are experiencing repressive systems to recall moments when they felt "happy" can be distracting and insensitive.

Similar challenges were also experienced by Booth and Booth (1997) during their comparative narrative study on adult children of parents with learning difficulties. Given the inherent link between memory and narrative, the success of narrative inquiry often depends on the responsiveness of participants. For example, inarticulateness, which originates with restricted language skills, can be compounded by other factors such as a lack of self-esteem, learned compliance, loneliness and social exclusion. A second challenge for was temporality, which refers to the relationship between the self and time:

> Language is necessary in order to abstract the self into the past (or an anticipated future). It is only through language that the self has a sense of itself in the past. For people with restricted language skills, like those with learning difficulties in our study, the inability to objectify the self found its expression in a strong present orientation and a concrete frame of reference that countermanded the tick-tock essentials of good storytelling. (p. 137)

Further challenges included the reticence of participants (being unsure they had anything to say), poor recall, and "interview cuckoos", such as family members and friends who tended to speak on behalf of the participant (Booth & Booth, 1997, p. 137).

While I have only briefly touched on these ideas, my experiences lead me to reflect on the importance of flexibility within appreciative inquiry and in qualitative research in general, especially in relation to the tone of language used and how different people express themselves. Influencing factors such as the expression of simple or complex emotions, verbal inarticulateness, temporality, reticence, and recall within research are areas that need further attention. This is especially important when ensuring PACS research is accessible to all people, and that practitioners have an understanding of alternative means of communication

Reflection: Appreciative inquiry – When it works, it works

At the outset of this research journey, prioritising the "best of what is" over documenting the challenges faced by marginalised communities and the shortcomings of flawed and repressive systems, felt awkward, unnatural and somehow backwards. However, with time and practice it also began to make sense. Utilising peak experiences as a means of inspiring change is not a new concept, but it seems to be an underutilised and underestimated approach within academic inquiry. I certainly found it to be an effective tool for challenging repressive

ideologies such as the charitable and medical models of disability. Appreciative inquiry in this context serves to redistribute power and expertise, which has traditionally been held by medical experts, researchers, politicians and people without disabilities (Brown & Leigh, 2018; Kitchin, 2000; Oliver, 1992), back into the hands of people with disabilities themselves. Drawing on my own experiences and observations throughout the appreciative inquiry research journey, it is clear that as a methodology, appreciative inquiry can help participants re-focus their thoughts on peak experiences. In response, the role of the appreciative inquiry researcher is to help reframe lived experience, facilitate dialogue about what can be learnt from peak experiences, and then work with the participant on imagining how those learnings can inspire future change (Cooperrider, 2012). It is my belief that an effective appreciative inquiry researcher is able to do this in an inclusive and accessible way.

At the outset of my field research, I did not know how the participants would respond to the appreciative inquiry line of questioning. Initially, the appreciative inquiry approach felt slightly unnatural as the participants struggled to recall peak or life-giving moments. For many of the participants, they seemed to enter the conversation as victims. Having faced unimaginable direct, structural and cultural violence, they, of all people, undoubtedly had a right to self-identify as victims. Indeed, I cannot imagine a more trying situation than living with disability during conflict and displacement. Other participants entered the conversation asking what I could offer them. This stance is not unique to the disability community, but it is reminiscent of deeply embedded ideologies of the charitable model of disability and the consequential dependency it imposes onto marginalised populations. Other participants immediately launched into rehearsed narratives of trauma, narratives that I imagine have been shared with countless unsympathetic or perhaps under-resourced authorities, to no avail.

As highlighted by Michael (2005), one of the benefits of appreciative inquiry is when participants reconsider experiences in a new light and begin to share narratives in a candid and unrehearsed way. In my experience, as the interviews progressed, so too did the tone of the conversation. Questions that felt like unnatural interruptions soon inspired fresh perspectives, including the recollection of peak experiences of life, courage, inspiration and hope. It was not long before the sense of victimhood appeared to transform into a sense of valued expertise and knowledge. My personal observation would be that most of the participants entered into the interview dialogue as victims but appeared to depart feeling like they had contributed expertise. While I cannot independently verify this statement without consulting with the participants themselves about the appreciative inquiry process, many of

them started with tearful recollections of trauma, but departed with blessings and well wishes for the future of this research:

> Participant: Anyway this, at least this conversation for me has also been important. Yes, for me it has been very important. It makes me feel more confident that we are not alone. There are more people elsewhere.
> Interviewer: That's so true. I think we need to stick together as disability rights advocates. It is important.
> Participant: Yes, we have to stick together. I agree. (Participant PwD #17)

> Daughter: Well I, because we could possibly spend the entire day talking, but the subject itself would be to thank her for coming from such a far-away country, to worry about people that really need it here […] there are few people working on the subject and there are many departments here, many people in charge of the work on disabilities. But they do the minimum necessary, there is no profoundness in the subject. The problem that we live in society, then I'd like to thank her. A person that worries about this type of problem that we have here in Ecuador. (Participant Family #10)

> Mother: I also want to say thank you, for choosing me, to come to my humble house, and to wish the best success and to keep fighting for that dream you have established, and that wherever you go, that God blesses you for that dream, and that you can fulfil it and fight for it, because it's a battle that has to be fought more day by day. And you have to stand tall to say, 'I want this, and don't want this', and I congratulate you for that strength. (Participant Family #10)
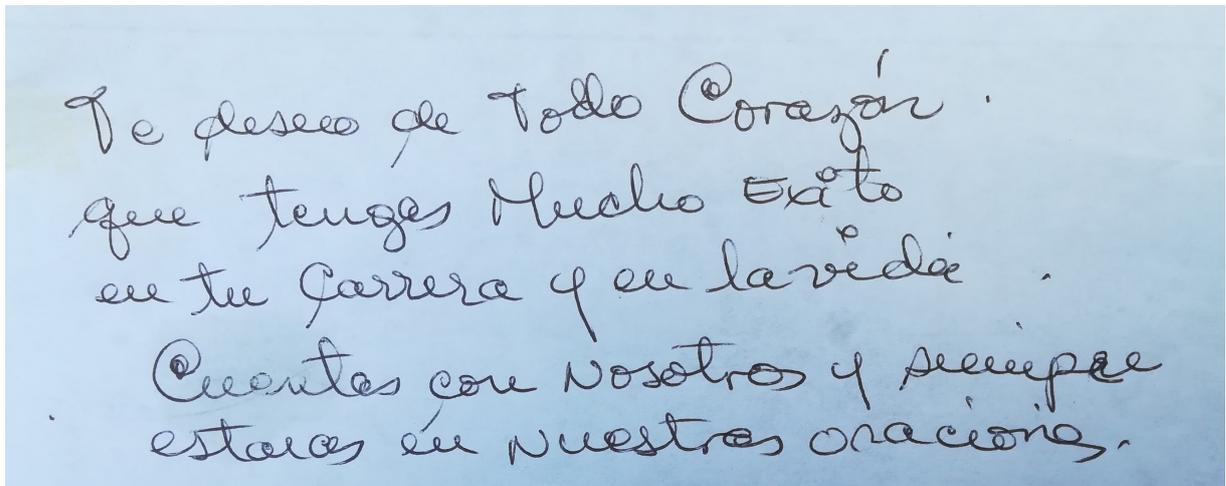
Figure 6. Photo of a handwritten note by a participant (translation below).

> Mother: I wish you, from the bottom of my heart, that you are successful in your career and your life. You can count on us and we will forever keep you in our hearts (Figure 6, written by the mother of Participant Family #1).

Reflection: Is appreciative inquiry really generative of change?

This brings me to my final reflection on appreciative inquiry; as a research methodology and method, can it really be generative of change? Within its original context of organisational development, appreciative inquiry has been hailed as a useful tool for generating positive

change within organisations (Cooperrider & Whitney, 2001; Cooperrider et al., 2008; Whitney & Trosten-Bloom, 2010). However, as highlighted by Stace (2011), research involving the disability community cannot be judged transformative until it translates into ongoing and reviewable improvements to practices that benefit people with disabilities. Considering the limitations of this research, only time will tell whether the use of appreciative inquiry contributed to generative dialogue and transformational change. Given the circumstances under which these conversations took place, it is likely that I will never know whether the interviews themselves led to the participants' personal transformation, as was one of the intentions. While I believe I observed many of the participants transition from victim to expert within the duration of the interview, I cannot say this conclusively. My greatest regret has been the inability to pursue further dialogue with the majority of the participants, which I will discuss in the limitations section of the next chapter. However, I do believe appreciative inquiry can be used as an effective tool for de-subjugating the voice of marginalised communities, respecting the shadow of human experience, reframing negative experiences and drawing on peak experiences to co-create a better future. For me, these are sure signs of appreciative inquiry being a useful PACS tool in the scholarly pursuit of inclusive and accessible positive peace.

From a personal perspective, the process of appreciative inquiry as a PACS researcher with a disability has been profoundly transformative. The knowledge disclosed by the participants was shared under the understanding that this research will be used to inform practices that impact and benefit the disability community (as suggested by Stace, 2011). Although my relationship with most of the participants concluded following the initial interviews due to reasons beyond my control, my commitment to protecting and upholding the rights, freedoms and dignity of people with disabilities affected by conflict and displacement is even stronger than when I started on this research journey. In order to honour my commitment to transformation, it is my responsibility to ensure that this research provides a foundation from which further generative dialogue, practice, research and action can grow in the future.

Summary

This chapter has largely focused on my own reflections and the third key question of this research. The chapter began with a summary of participant responses, before my own analysis and observations were presented. This began with a focused discussion on the discourse around marginalised populations in both academia and places of conflict. I concluded that as PACS researchers and practitioners, it is our responsibility to promote inclusion and access

within peacebuilding activities by promoting discourses that empower those who are affected by the subjects we study.

I also reflected on the methodological approach of appreciative inquiry, through an in depth discussion on the shadow of human experience, language within appreciative inquiry, and the need to remain flexible within our expectations on how individuals express themselves. I also discussed whether appreciative inquiry can really be generative of change. Based on my own experiences I concluded that appreciative inquiry can be used as an effective tool for promoting inclusion and access within PACS and positive peacebuilding activities.

The next chapter asks the important question: "where to now"? Knowing what we now know, how can PACS contribute to inclusive and accessible positive peacebuilding endeavours?

Chapter 11 – Discussion: Where to Now?

> "I think that the project of reaching out to people that really live and know what it's like to live with someone with a disability, is really good. Because a professional knows to a medical extent, what a disability is, how it's lived and what medication to use. But from there, to live with someone with a disability, only the family knows, and they, who live with him."
>
> - Participant #10 (sister and mother to brother and son with intellectual/learning disabilities, 2017)

Introduction

As this thesis comes to an end, the final question is: where to now? While this doctoral journey may be complete, transformative dialogue must not end here. Given the unprecedented nature of this research, it is important to identify practical tools for ensuring the work can continue. Throughout this thesis, it has been argued that inclusive, accessible and transformative methodologies must be employed within PACS to ensure its processes reflect the ultimate goal and outcome of positive peace. However, if this movement is not driven and guided by people with disabilities themselves, the challenge of inclusion and access will remain just that, a challenge and nothing more. As the reviewed literature revealed, there is a small number of scholars and practitioners who, like me, have identified the gaping hole in academic literature and who have questioned where the voice of the world's largest minority within peace and conflict research and practice is (for examples, see Aaron et al., 2014; Crock et al., 2012; Crock et al., 2017; Gottschalk, 2007; Grove et al., 2010; Reilly, 2010; Shivji, 2010; Simmons, 2010). Yet very few within academia have ventured further than this, to challenge and critique our own contribution to their exclusion and to ask people affected by disability, conflict and displacement about what they have experienced, what they think, feel, want or need.

This chapter might be considered as the early stages of a PACS inclusion and access toolkit. Based on my own experiences as a PACS researcher with a disability, together with the responses of the participants and their families, this chapter aims to inspire other researchers and practitioners to take steps towards ensuring their own endeavours are inclusive of, and accessible to, marginalised communities. The chapter begins by outlining the limitations and

strengths of this research and presents an honest reflection on the challenges and benefits of my own research journey. Following this, the chapter continues to address the third key research question by outlining practical steps that might be taken towards practising inclusive and accessible positive peacebuilding. The twin-track approach is suggested as a useful framework before, finally, the implications of this research for PACS, people with disabilities, and the wider community are examined.

Limitations and Strengths

As with any academic project, there were aspects of this research that worked well, and other aspects that did not. Listed below are the challenges I faced, as well as the strengths of this thesis, which can provide insightful contributions to the development of inclusive and accessible PACS research and practice in the future.

Limitations

The first and most pressing limitation of this research was funding, and the significant impact that the lack thereof could have had on its execution and delivery. I was fortunate enough to secure funding through the University of Otago, the University of Otago National Centre for Peace and Conflict Studies and a June Opie Fellowship, which enabled me to carry out this research with the basic access needs of the participants in mind, as well as my own. However, had I been faced with a situation where I was required to cover the cost of more significant disability specific access needs, for example, a sign language interpreter to ensure a D/deaf or hard of hearing (HoH) participant could participate fully and equally, it is likely that I would have had to inform that person that they could not participate. When addressing the very real challenge of ableism within academia the funding pinch can mean the difference between the inclusion and exclusion of marginalised voices. The lack of funding for inclusion and access within academic research is a major factor in the disability community's absence, and a significant barrier to realising the rights of people with disabilities.

The second and third limitations were time and access. Had funding not been a limitation, this research would have benefited from a longer period of field research, a greater number of interviews, and repeated engagement with the participants. While the intention had been to spend longer periods of time with the participants, on multiple occasions, and for them to review the findings (a key principle of PAR and reflexive research), limited time and funding made this difficult. Given the circumstances that many of the participants lived in, it was

often unfeasible for them to meet with me on more than one occasion, due to challenges associated with poverty, a lack of accessible transport, and a lack of access to technology. Some participants did not know where their next meal would come from, or whether they had somewhere to stay that night, let alone being able to commit to meeting with me more than once and spending valuable "peddling" time answering research questions. While paying participants for their time might have been a solution to this limitation, this was not a viable option due to the ethical considerations of the organisations responsible for setting up the interviews, who could not be associated with recruiting their clients for paid activities. For those participants who did have access to technology, more specifically the Internet, I sent each of them a Spanish transcript of their interview for review, as well as draft findings chapters, and invited them to provide feedback to ensure I had represented their views accurately. Of the six I made contact with, three agreed to review their interview transcripts and the research findings, but only one asked to make minor amendments. Due to the nature of this research, the limitations of time and access, together with funding, were my biggest challenges. Throughout this journey, I have discovered that inclusive and accessible research takes more time, resources, creativity, flexibility and funding, than research that is not inclusive or accessible. Until greater resources for inclusive and accessible research can be found, these limitations will continue to be barriers to doing, barriers to being, and as a result, barriers to positive peace.

The next major limitation I experienced was the language barrier between myself and the participants. As a native English speaker with limited Spanish, I was at a disadvantage during the interviews, and on occasions missed out on key points and responses that should have been pursued and elaborated. While I was fortunate to have the assistance of bi-lingual translators, there was a noticeable difference between the translators who had previously engaged in PACS and disability rights work and those who had not. Going forward, I would insist that all translators and assistants have a basic awareness of PACS, disability rights and appreciative inquiry, as this research would have benefitted significantly from having a single translator with experience in these areas. Again, this would require further funding, but would ensure a much more ethical and inclusive experience for all involved. It would be even more beneficial if I, as the PACS researcher, had been able to speak fluent Spanish myself.

The final major limitation relates directly to the other four, in that funding, time, access and language barriers meant I was unable to practise truly authentic inclusive research. As highlighted by scholars, key principles of Disability Studies include promoting and practising

research that is driven, directed and led by people with disabilities themselves (Nind, 2017; Nind & Vinha, 2014; Oliver, 1992). Even though I am a researcher with a disability, a more genuine approach would have ensured the involvement of refugees and asylum seekers with disabilities in the planning of the research, formation of research questions and methodologies, data collection, reviewing and analysing data and, finally, co-authoring this thesis. So again, until institutions and funding bodies acknowledge and embrace the social relational and rights-based models of disability, then time, funding and access will continue to limit the authenticity of inclusive research, and hence, positive peace. While this is not impossible, much would have to change for this to be realised.

Strengths

Given that one of the aims of this thesis has been to promote and demonstrate the benefits of inclusive and accessible research, most strengths have already been discussed in great depth throughout the preceding chapters. However, there are three strengths that are worth reiterating, the first being the application of a rights-based research methodology that enabled people with disabilities to participate in PACS research on a full and equitable basis. While service providers contributed supporting evidence and context, the voices of people with disabilities and their families took centre stage in a way that, to my knowledge, has not been seen in PACS before. Through their responses, valuable insights and recommendations were discovered, which have potential to significantly impact PACS and positive peacebuilding in the future.

While keeping in mind the final limitation that was discussed in the last section, the second key strength was my role as a partial-insider researcher. Insider research is commonplace within the Humanities, and for me the benefits included a deeper level of understanding afforded by prior knowledge, the ability to consider social actors at the centre of the experience of disability, and most importantly, a quicker establishment of rapport and trust due to the shared experience of disability (Taylor, 2011). Given that disability discourse has traditionally been dominated by people without disabilities (Brown & Leigh, 2018; Kitchin, 2000), it is all the more important to recognise and celebrate the benefits and insights that scholars with disabilities bring to academia. My experiences researching disability related subjects, as a researcher with a disability, are reflected in the quote below:

> A disabled identity can help bridge the gulf between the worlds of the researcher and participant, offering a point of connection. Thus, while being attributed a disabled identity can sometimes be experienced as invalidating, during interviews it can unify,

facilitate rapport and challenge traditional barriers of power and status. (Brown & Boardman, 2011, p. 25)

The third strength of this research was that it went beyond simply adding pure research to the PACS knowledge base, by also contributing applied research. This meant going further than simply affirming the absence of the disability narrative, which, as previously discussed, has already been highlighted by scholars and practitioners alike. It also meant going beyond superficially injecting the disability perspective into PACS theories and concepts. Instead, one of the main strengths of this research is the practical knowledge gained from my own research journey, and lessons on how inclusion and access can be applied within future PACS research and practice. This will be discussed in greater depth in the next section of this chapter.

Research Question #3: Inclusion, Access and Positive Peace

The third and final research question of this thesis investigated the role that PACS can play in promoting inclusive and accessible positive peace. Throughout this thesis I have argued in favour of PACS methodologies that are inclusive of people with diverse life experiences. The term "inclusive research" is reasonably new, and characterises the move away from research *on* people, to research *with* them (Nind, 2017). But what does inclusion and access even look like? I have found it helpful to begin by looking at what inclusion and access *does not* look like.

Figure 7. All welcome #1 (Francis, 2016a).

Figure Seven (Francis, 2016a) is a cartoon that shows peace talks taking place in a room located at the top of a flight of stairs. Although the sign pointing to the room reads, "Peace talks all welcome", this scenario could also be applied to PACS processes of data collection, such as interviews or focus groups. At the bottom of the stairs is a person with a vision impairment who is unable to read the sign, together with a wheelchair user and parent with a pram who cannot get up the stairs to attend the meeting. For many, this picture is more than comical irony; it represents the lived experience of structural violence (disablism) and cultural violence (ableism) within peacebuilding. This figure is a visual representation of the exclusion that some sectors of society have traditionally faced within research and peacebuilding activities; a depiction of deeply rooted ableist ideologies. Take, for example, literature presented in Chapter Three detailing the exclusion of people with disabilities from peacebuilding activities in Sierra Leone (Gottschalk, 2007), Northern Uganda (Barriga & Kwon, 2010) and Northern Ireland (Irvine, 2015).

Having established the importance of rights-based approaches to PACS research and practice in Chapters Nine and Ten, it is now important to start developing a strategy for implementing change within PACS by providing practical and useful contributions to the field. Inspired by guidelines presented by Williams and Moore (2011), the following points outline steps that

PACS researchers and practitioners can take towards ensuring that the development and execution of their research ideas, interventions and initiatives are inclusive, accessible, transformative, and are in line with the ethos of positive peace.

<center>Understanding who is in, who is out and how come (Slee, 2011)</center>

Before embarking on the PACS research or practice journey, one of the first tasks, I believe, is to analyse one's own understanding of the experiences of marginalised communities in the context at hand. This can be particularly difficult when you do not know what you do not know, so to speak. However, as PACS researchers and practitioners, we should already be sensitive to the fact that in every society there are people who are systemically marginalised as a result of culturally and structurally violent systems and direct violence. Given that people with disabilities are the largest minority in the world (United Nations, n.d.; World Health Organization, 2018), an experience that crosses all other identities (including gender, sexuality, ethnicity, class, amongst others), and something that most of us will experience either personally or indirectly at some point in our lives even if only as senior citizens, the disability rights movement and guiding models can be useful tools within PACS. As was highlighted earlier, the models of disability demonstrate a wider shift in the way we think about people with diverse life experiences and marginalised communities. That is, a shift that has started to take place from thinking about people who are "different" as objects of charity or who need fixing, to thinking about all human beings as equal rights bearers, regardless of identity. It is also a shift that has been acknowledged within PACS (Galtung, 2012), but as this research has revealed, one that has so far left people with disabilities behind; hence, a valuable contribution of this research.

Changing deeply-rooted culturally and structurally violent ideologies, attitudes, mind-sets and mentalities can take a long time (Symonides & Singh, 1996). But we must begin somewhere. As such, there are some simple steps that PACS scholars and practitioners can take to familiarise themselves with the models of disability, as well as the epistemological underpinnings of ableism as it applies to not only disability, but also gender identity, age, ethnicity, sexual orientation, and so on. This might begin with a reflection on one's own perceptions of what is "normal" and what is "different", discovering how people with diverse life experiences are represented within relevant literature, as well as actively seeking out social and cultural perceptions that may impact research participants or the target audience of the peacebuilding activity at hand. If people with disabilities, for example, are absent from the literature, relevant documents or discourse, their absence needs to first be noticed, and then

the question becomes, why are they absent? What systems have led to their absence, and how does this impact the wider pursuit of positive peace?

Employing transformative methodologies

The next step towards inclusive and accessible PACS research and practice is developing effective strategies for ensuring that the process, design and execution of research or an activity is just as transformative as the outcomes of the research or activity itself. This includes ensuring a resilience- and asset-based approach (such as appreciative inquiry) that acknowledges and analyses resilience factors among marginalised groups as a gateway to inclusion and access (Lee & Pearce, 2017). This point has already been well covered in previous chapters: inclusive research must aim to transform the social situations of people with disabilities both through its methods and its outcomes (Mertens et al., 2011; Oliver, 1992; Stace, 2011). There is a large body of literature within PACS, development studies, feminist studies, and so on, that examines and suggests ethical research methods including PAR, emancipatory and transformative research, which aim to de-subjugate subjugated knowledge and establish or restore power balance between the researcher and participant (Dahler-Larsen, 2018; Olesen, 2018). Within Disability Studies, there is also a body of literature outlining ethical standards when conducting disability related research (for example, see Barnes & Mercer, 1997).

Practical tools and strategies for inclusive and accessible PACS: A twin-track approach

The twin-track approach outlines two equally important strategies for ensuring people with disabilities have equitable access and opportunity in any given circumstance. When applied within PACS, the twin-track approach recognises that positive peacebuilding research and activities need to be accessible to all people. It also recognises that for some people there are also disability specific needs that must be met in order to enable their inclusion (CBM, 2012). The first-track, Universal Design – that is, design that is usable by all people, to the greatest extent possible (United Nations, 2006a) – outlines the responsibility of the wider PACS and peacebuilding community to ensure mainstream services and supports are inclusive of, and accessible to, all people (Office for Disability Issues, 2016). The second-track relates to disability specific needs and outlines how PACS researchers and practitioners can support and empower specific individuals with disabilities to participate on an equitable level as their peers.

For example, my prosthetic leg helps me with mobility and independence. Not everyone needs a prosthetic leg, but everyone, including myself, benefits from an elevator in a building. Both devices (prosthetic leg and elevator) enable access and inclusion, but one is specific to my needs, while the other is beneficial to all people. The twin-track approach lends itself to the social relational model of disability, which recognises the distinction between impairment effects (restriction of activity that arise directly from impairment) and "disability" which is imposed by ideological, social and environmental circumstances (Reindal, 2010; Thomas, 1999, 2004b). Although I propose the twin-track approach with the disability community in mind, as a framework it can be used to ensure inclusion and access for all different sectors of society (for example, the refugee community). Figure Eight below shows a relationship graphic used by CBM (2012, p. 23) to illustrate the twin track approach:
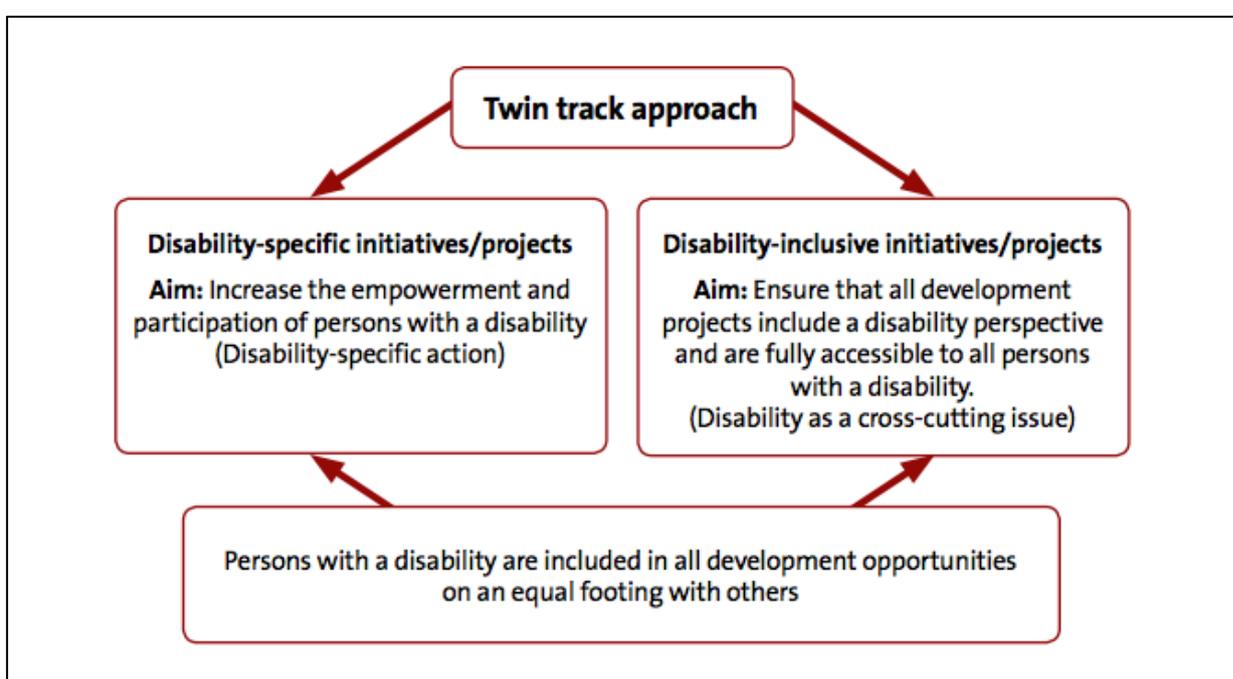
Figure 8. Twin-track approach (CBM, 2012, p. 23)[12]

[Image Description: A single box at the top of the image reads "Twin track approach". This points to two boxes below it. The box on the left reads, "Disability-specific initiatives/projects Aim: Increase the empowerment and participation of persons with a disability (Disability-specific action)." The box on the right reads, "Disability-inclusive initiatives/projects Aim: Ensure that all development projects include a disability perspective and are fully accessible to all persons with a disability. (Disability as a cross-cutting issue)". Below these two boxes is

---

[12] CBM adapted from Make Development Inclusive: How to include the perspectives of persons with a disability in the project cycle management guidelines of the EC.

one box that reads, "Persons with a disability are included in all development opportunities on an equal footing with others". Both the top and bottom single boxes have arrows pointing to the middle two boxes.]

Track-one: Universal Design

Originally coined by architect Ronald Mace to describe the designing of all products and the built environment to be usable to the greatest extent possible by everyone, regardless of their age, ability, or status in life (Story, Mueller, & Mace, 1998), Universal Design has become a foundational concept for the disability rights movement and Disability Studies (for example, see Albrecht et al., 2001; Davis, 2013). Article 2 of the CRPD refers to Universal Design as "[…] the design of products, environments, programs and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design" (United Nations, 2006a). Universal Design is good design that works for everyone from the outset, rather than retrofitting for accessibility. It is about making sure everything is accessible to, understood by, and used to the greatest extent possible by everyone, without adaptation or requiring little adaptation. Not only does Universal Design apply to built environments, but also to services, supports, curricula and technologies (Office for Disability Issues, 2016). In this way, Universal Design can also be applied to PACS research and practice in the following ways.

Access to information, content and environments

There are many strategies and tools PACS researchers and practitioners can use to ensure information, content and environments are accessible and inclusive. From calls to participate, advertisements, information sheets and consent forms, to interview and event locations, meetings and peacebuilding activities, Universal Design is a framework that can help ensure inclusion and access for as many people as possible. Listed below are some of the ways this might be achieved:

- Plain language: plain language is a style of writing in which the wording, structure, and design of verbal or written information all works together to help the participant. A document written in plain language is easy to read, understand, and act on after just one reading (Plain Language Association International, 2018). Plain language allows people who are illiterate, do not speak the presented language fluently, who are senior citizens, or people who live with intellectual, neuro or sensory disabilities, to participate more easily because the presented information is easier to understand. All of the documents used in this research were provided in plain Spanish.

- Accessible text: For users who are blind or have low vision, all digital information, communication and content should be easily accessed by a screen reader. Screen readers are software programs that allow blind or visually impaired users to read the text that is displayed on the electronic device with a speech synthesizer or Braille display. Website images should always use the alt attribute to describe the function of each visual, which helps the screen reader describe what is in the image. With regards to written communication, all extra digital content (such as email attachments) should be provided in a ".doc format", as graphs, images and Portable Document Formats (PDFs) cannot be recognised by a screen reader. For example, within this thesis all figures have image descriptions, that is, written text describing what is in the picture. For people with low vision, the contrast, font, spacing and size of digital and print text is important; the larger, more spaced out and contrasting the text is, the easier it is for all people to see (Blind Foundation, 2018).

- Captions: For participants who are D/deaf or HoH, it is important that all video and audio content is captioned. This is also helpful for people who are not fluent in the spoken language, as well as others whose comprehension is enhanced by print, audio and visual media.

- Accessible venues: Interviews, events, activities and meetings should be held in accessible locations. This includes ensuring there is easy and dignified access in and out of the venue, at least one accessible bathroom, mobility parking is available or alternatively, that the provision of reasonable and accessible accommodations for participants who do not have their own transport is provided, if needed.

- Data collection: According to Article 31 of the CRPD, data collection is an important aspect of understanding the diverse needs of a population (United Nations, 2006a). All PACS research and data should not only be disaggregated by traditional demographic details such as age and gender identity, but also be desegregated by disability and diverse life experiences (with the participants' permission) (Lee & Pearce, 2017). This will help PACS researchers and practitioners understand the unique needs, perspectives and rights of the disability community and will help to inform inclusion strategies and action plans that are generative of change.

To illustrate the concept of Universal Design, Figure Nine (Valbrun, 2017) is an adaptation of a widely cited image that depicts the difference between equality, equity and Universal Design. The image shows three different scenarios of three people trying to watch a sports game from behind a fence at a sports stadium. The image to the left represents the egalitarian

school of thought, which shows all three people being provided with equal resources (a wooden box to stand on) in order to watch the game. However, this only serves to perpetuate the privilege divide between the person to the left who is very tall, the medium-sized person in the middle and the smaller person to the right (who in other versions is depicted as a wheelchair user). Alternatively, the picture in the centre depicts a non-egalitarian scenario, but one that is based on the theory of equity. Equity refers to systems of justice and fairness whereby individual needs and requirements are taken into account and responded to accordingly (Surbhi, 2016). In the centre picture, the tallest person to the left, who can already see over the fence, has no wooden box. The medium-sized person in the middle has one wooden box so they can see over the fence as well. The smallest person on the right has two wooden boxes so they too can easily watch the game. While the systemic challenges facing the people in the scenario are not solved by equality, equity has meant that the medium-sized person and the smaller person have equitable opportunity to watch the game as the tallest person. In other contexts, the debate between equality and equity has also been related to affirmative action and positive discrimination; that is, laws, policies, guidelines, and administrative practices that are "[…] intended to end and correct the effects of a specific form of discrimination" (Feinberg, 2005, p. 272). The third picture, on the right, shows all three characters watching the game without adaptation because the fence is made from a transparent material. This is a prime example of Universal Design, whereby the design of the fence suits the needs of all people, to the greatest extent possible, without need for adaptation (United Nations, 2006a). Both the barriers to doing and barriers to being have been removed by someone in a position of power to exclude (Thomas, 1999, 2004a), which, in this case, is likely to be the owner or manager of the stadium.
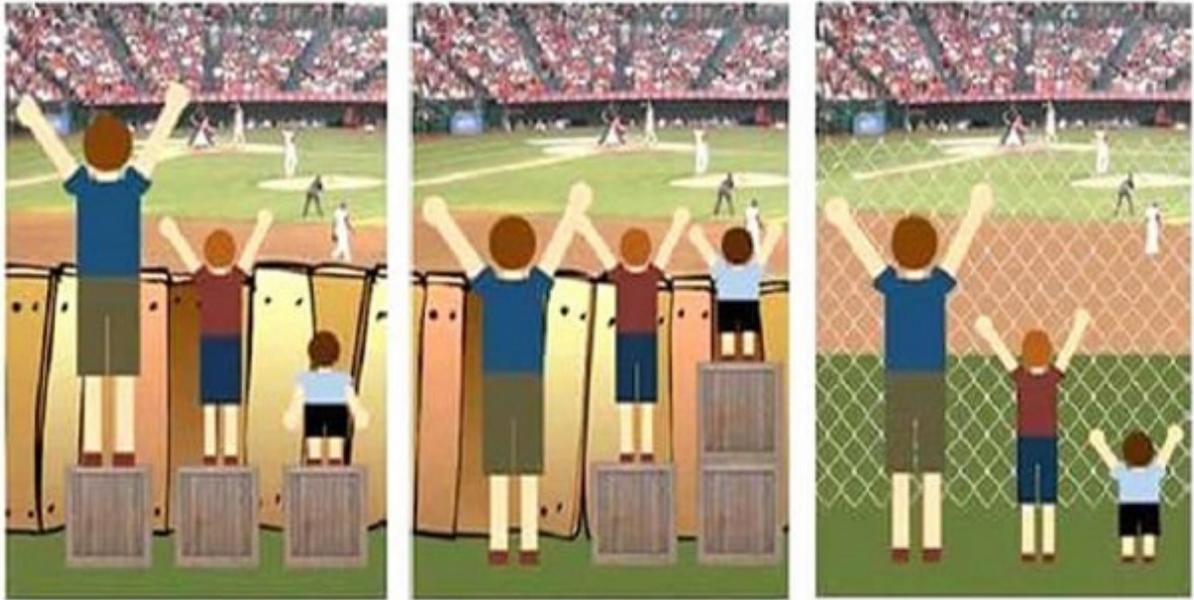
Figure 9. Equity vs. equality: Eliminating opportunity gaps in education (Valbrun, 2017).

As Figure Nine reveals, Universal Design is not just for the benefit of the disability community, but for everyone. This includes older people, people who are injured, caterers with food trolleys, musicians with sound equipment, parents with young children; the list goes on. The suggestions presented above represent only a small selection of Universal Design standards, more of which can be found online (for example, see National Disability Authority, 2014).

Track-two: Disability specific design

The second track of the twin-track approach recognises that some people will need unique or specific supports to be able to participate in PACS research and practice. When coupled with Universal Design, disability specific supports can ensure a more equitable, inclusive and accessible experience for everyone. Listed below are a selection of disability specific supports that mean people with unique disability needs can be included in, and contribute to, PACS and positive peacebuilding:

- Easy Read: Easy Read is a form of communication designed to support people with intellectual and learning disabilities so that they can better understand written information. While it uses the same principles as plain language, it builds on them by utilising pictures instead of words, clear spaces, fewer words and no jargon or acronyms. Easy Read benefits people who have difficulty reading and understanding written information and can also be useful for some people who have low literacy levels, are not fluent in the spoken language, senior citizens, use Sign Language or

who have sensory conditions (People First New Zealand, n.d.). An example of an Easy Read translation of the plain English executive summary (Appendix B) of this thesis can be found in Appendix C.

- Comforting experience: Some people with neuro disabilities, such as autism, may not feel comfortable in certain environments due to lighting, noises, crowded spaces, long queues, and so on. Careful planning around environments and sensory elements can help reduce triggers or stress and can ensure that the individual and their family can participate fully.

- Accessible information: If necessary, it is important to invest in multisensory and flexible options for participant recruitment, data collection, reflexivity processes and final outputs (Williams & Moore, 2011). This includes Braille, augmented communication devices, sign language interpreters and video and audio media.

By ensuring people with disabilities are provided with opportunities to lead and determine research agendas themselves, the path to inclusion and access will be driven by lived experience, the most informed type of expertise. When a researcher or practitioner does not know how to include someone with a disability, the first point of action is to consult with someone who does, such as the potential research participant themselves. However, if this is not possible, the next option for ensuring access and inclusion is to ask another person with that disability and/or their family, friends and allies. People with disabilities are not a homogenous group and have different capacities and needs. The best way to find out what supports any individual might need to fully participate, regardless of ability, is to ask (Williams & Moore, 2011).

For example, during one of the interviews that took place in a café, it was necessary for the participants and I to move from sitting outside near the road to further inside the café. We did this because the son, who lives with autism, found it over-stimulating and too loud outside. Another example is the interview with Participant #2. It took several attempts to make contact with this participant due to the uncertainty of his situation. It was also difficult to arrange a meeting place and time that was both wheelchair accessible and convenient, given his socio-economic situation. As was discussed in the limitations section of this chapter, inclusive and accessible research typically requires more time, resources, funding, and consideration than standard research. It also requires creativity, flexibility, patience and the ability to think outside the box. This research has shown, however, that there is great value in applying the twin-track approach to PACS research and practice. By ensuring the knowledge, advice and

recommendations of people with disabilities affected by conflict and displacement and other marginalised populations are at the forefront of PACS research and practice, both as leaders and as participants, we are actively progressing positive peace.
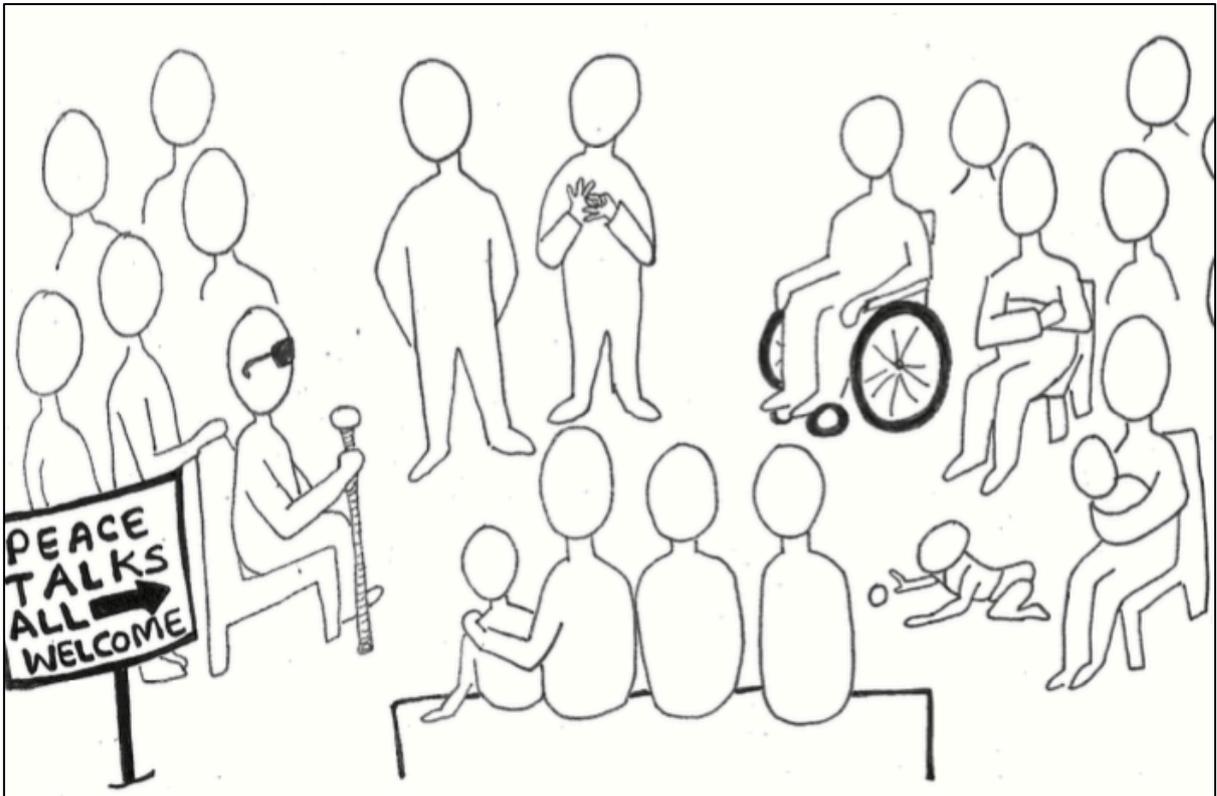
Figure 10. All welcome #2 (Francis, 2016b).[13]

[Image description: Figure Ten (Francis, 2016b) depicts an alternative scene to the one shown in Figure Seven. Figure Ten is the author's illustration of inclusive and accessible peace talks, which are being attended by all kinds of people. To the left of the picture is the same sign shown in Figure Seven, which reads, "Peace talks all welcome". However, this time the twin-track approach has been applied, with both Universal Design (accessible environment and seating) and disability specific supports (sign language interpreter) for a wide variety of people attending the talks (including people who are standing, a person with a vision impairment, people who are sitting, a family, a parent with a baby and a sign language interpreter)].

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[13] This illustration was inspired by the 'Building Capacity for Disability Inclusion in Gender-Based Violence Programming in Humanitarian Settings' toolkit developed by The International Rescue Committee (IRC) and the Women's Refugee Commission (WRC) (Women's Refugee Commission, 2015).

Inclusive and accessible PACS research and practice outcomes

Finally, we come to the outcomes and outputs of inclusive and accessible PACS research and practice. Earlier in this thesis, the strained relationship between researchers and the disability community was explored, with some people with disabilities even going so far as to referring to academic researchers as "parasites" (Hunt, 1981, as cited in Barnes & Mercer, 1997, p. 2). I again refer to the powerful quote by Michael Oliver (1992), who claimed that research conducted by researchers without disabilities often serves the agenda of the researcher, but does not represent the knowledge and experiences of people with disabilities and ultimately fails to implement change:

> … such research does not fundamentally alter the social relations of research production and not for nothing has this kind of research been called in another context "the rape model of research" (Reinharz, 1985) in that researchers have benefited by taking the experience of disability, rendering a faithful account of it and then moving on to better things while disabled subjects remain in exactly the same social situation they did before research began. (p. 109)

Throughout this thesis it has been argued that positive peacebuilding is inclusive, and it is accessible. If positive peace is the purpose of PACS, then PACS must also aim to be inclusive and transformative. As PACS researchers, we must avoid at all costs research that elicits information from people with disabilities (and other marginalised communities) without working towards changing their social situation according to an individual's wishes (Oliver, 1992). I have suggested that this begins by understanding who is in, who is out, and why (Slee, 2011); ensuring people with disabilities are supported to lead their own research agendas (Nind & Vinha, 2014); carefully selecting research methodologies and processes that are transformative in themselves (Mertens et al., 2011); and by employing a twin track to research design (Office for Disability Issues, 2016). Finally, PACS research and practice should not only actively support people with disabilities to be present and participating in all matters that affect them (Articles 4 and 7 of the CRPD), but also ensure that research findings and outcomes contribute to change (Oliver, 1992; Stace, 2011).

Going forward, my commitment as a PACS researcher is to not only present the findings of this thesis publicly, but to also ensure that the findings are presented in an accessible way for the disability community, prioritising the access needs of the participants. This includes making available a plain language executive summary in English and Spanish, as well as an English and Spanish Easy Read version. This research will also be used to influence academic discussion around research ethics, as well as for developing resources for PACS educators on inclusion, access and the experiences of people with disabilities affected by conflict and

displacement. Finally, these findings will be presented to key stakeholders engaging in humanitarian response to conflict and displacement.

The Value of Diversity and Inclusion: Implications for the Field

This research has drawn attention to a large and concerning gap within PACS research and practice. It is a gap that may leave readers feeling defensive or even regretful for not having noticed it sooner. For others, it may be a great source of inspiration, motivation and excitement, as they search for ways in which their research and practice can be more inclusive and accessible to people with diverse life experiences. Regardless of the emotional response, in the words of New Zealand singer Brooke Fraser, "Now that I have seen, I am responsible" (Fraser, 2007).

Outlined in Figure Eleven is a Venn diagram of what I believe to be the heart of this thesis, and the simplest visual representation of the path towards inclusive and accessible positive peace. This research has drawn together the strings of various theories, models and concepts from a range of fields and disciplines, to argue in support of universally designed positive peace that is underpinned by a rights-based discourse. The voices of participants contributed lived experience, expertise and meaning to the call for: "nothing about us, without us". The use of appreciative inquiry methodology then helped make sense of the stories, experiences and recommendations, that were so generously shared.

Figure 11. Bringing it all together.

[Image description: A Venn diagram shows two overlapping circles. The left circle is entitled "Disability Studies", and the right circle is entitled "Peace and Conflict Studies". Within the left circle is the core message of Disability Studies: "Nothing about us, without us." In the right circle, is the core message of Peace and Conflict Studies: "Positive peace". Where the circles overlap in the middle, is the word: "RIGHTS". At the bottom of the Venn diagram is an arrow pointing downwards to a box that reads: "INCLUSIVE AND ACCESSIBLE POSITIVE PEACE."]

It is commonplace at this point in the thesis journey to make suggestions for future areas of research. However, if I was to start documenting suggestions I would need to list every topic and sub-topic within PACS that has not already included the voices and perspectives of people with disabilities. Instead, my suggestion for future research is this: regardless of the subject, ensure the research or activity is inclusive and accessible to diverse and marginalised populations, both in its process and in its outcomes. In the case of this thesis, the solutions that have been presented have arisen from the experiences of extreme hardship and trauma. In all aspects of our work as PACS researchers and practitioners, the mantra "nothing about us, without us" should be at the forefront of our thinking. As stated in the opening quote of Chapter Two, disability rights are human rights, which in turn, impact all of society:

> By investing in recognizing the rights of persons with disabilities, we're in fact investing in the full recognition of the concept of universality of Human Rights. When we advance the rights of persons with disabilities, we are advancing the rights of every single group in society. (Devandas, 2017)

Indeed, now that the gap has been noticed and acknowledged, exploratory research conducted, and tools, strategies and frameworks are starting to fall into place, the prospects of actively reducing direct, structural and cultural violence, while pursuing inclusive and accessible positive peace for all people, is an exciting one.

When considering the experiences of people with disabilities during conflict and displacement amongst the wider context of #blacklivesmatter campaigns, #TimesUp, the #MeToo movement (Nicholas, 2018), and other current global human rights trends, PACS is now being presented with a unique opportunity to develop our own version of an "inclusion rider". Within the global film industry, an inclusion or equity rider is a contract provision that ensures casting and production staff meet certain levels of diversity regarding the inclusion of women, people of colour, queer and gender diverse people and people with disabilities (Smith, 2016). Contextualised within PACS, this might look like a collective commitment to conducting PACS research and practice that is inclusive and accessible, not only because it is good practice, but also because as this research has revealed, all humans are rights-bearers, because marginalised and subjugated voices contribute value to PACS, and because positive peace leaves no one behind. As summarised by Webel and Galtung (2007, p. 24), peace favours diversity:

> *Diversity as a source of mutual enrichment*, presupposing curiosity, respect, dialogue, for mutual exploration and learning. Reciprocity and symmetry have to be extended to any other party with legitimate goals as defined by legality, human rights and basic human needs. Diversity with inequality is mutual impoverishment, and so is equality with uniformity. Diversity with equality spells peace.

The challenge has been set; if PACS scholars and practitioners choose to respond to this challenge favourably, there is no telling how significant and widespread the potential implications for the field and the pursuit of positive peace might be.

Summary

This chapter is the final of five findings chapters. Its focus has been the future of PACS and how, as an academic field, it is our responsibility to apply what we now know to our shared pursuit of positive peace. The chapter began with a presentation of the limitations and strengths of this research, which included funding, time, access, language barriers, and

shortcomings in my attempts at inclusion, as well as the strengths of the methodology (the inclusion of people with disabilities and their families as expert contributors), insider research, and the applied aspects of this research. Next, the chapter responded to the third key research question by exploring practical steps that can be taken towards inclusive and accessible PACS research and practice, with the twin-track approach being presented as a guiding framework. Using my own PACS research experiences as a guide, suggestions for track-one Universal Design and track-two disability specific supports were presented. Finally, this research was contextualised within a wider global movement towards equitable outcomes for marginalised populations, and the implications this research might have within PACS and on the wider pursuit of positive peace.

The next chapter concludes this thesis by summarising the research journey, findings, and implications.

Chapter 12 – Conclusion: Now That I Have Seen, I Am Responsible

> "We live by each other and for each other. Alone we can do so little. Together, we can do so much."
>
> - Helen Keller (American author, political activist, and lecturer, n.d.)

I have heard it said that the most dangerous phrase in the English language is, "It has always been done that way". The introduction to this thesis began with a poignant image of a blue wheelchair amongst Gazan rubble. The story that followed suggested that in all wars, conflicts and disasters, it is those who are already living in vulnerable circumstances that are impacted the most. In reading about the destruction of the home for people with disabilities, I felt a deep sense of devastation. I also felt a hint of fear. What if it were me? No human is immune to disability or disaster. As I started to think about the research journey I was about to embark on, I also began to worry that my own research would do little more than affirm what was already widely assumed: "It is tragic, but this is how it always has been, and how it always will be."

This research has taken us all – the participants, myself, and readers – on an emotional journey of discovery. At times, it has felt uncomfortable, heart-wrenching and devastating. At other times, the hope and resilience shared throughout the narratives has been life-affirming, uplifting and inspiring. Most importantly, this research has demonstrated how it is possible for knowledge that was once subjugated and unheard, to be exposed, de-subjugated and to re-emerge; having transformed into expertise.

The first two literature review chapters addressed research from within the fields of Disability Studies and PACS. The purpose of these chapters was to demonstrate both the similarities and disconnect between the fields, as well as the impact that the disconnect has had on people affected by disability, conflict and displacement. Chapter Two began by outlining six key models of disability, including the moral, charitable, medical, social, rights-based and social relational models of disability. Throughout these explanations, the shift in the way society has perceived and responded to disability started to become clear. Largely driven by the disability

rights movement of the late twentieth century, this shift in thinking saw people with disabilities collectively demand the right to determine their own identity and futures, and to be afforded the same rights as people without disabilities.

The marginalisation and discrimination of the disability community was examined, and then discussed as harmful manifestations of deeply-rooted disablist and ableist ideologies. The absence of the disability narrative from PACS was then demonstrated, and evidence from various sources outside of PACS revealed the devastating circumstances experienced by people with disabilities during conflict and displacement. Drawing on Galtung's violence triangle and his theory of negative and positive peace, these experiences were then used to reiterate the foundational concept of this thesis: for peace to be positive, it must be inclusive and accessible. Until all people (including people with disabilities) are liberated from direct, structural and cultural violence, there will be no positive peace. From this foundational concept, the research questions of this thesis were formed:

1) What can we learn from people with disabilities about the intersectionality of disability, conflict and displacement?

2) What can we learn from people with disabilities about protecting and promoting the freedoms, rights and dignity of people with disabilities affected by conflict and displacement (as outlined in Article 11 of the CRPD)?

3) How can PACS research contribute to inclusive and accessible positive peace?

Over the course of Chapter Four, the seemingly broad, ambiguous and daunting challenge of somehow progressing inclusive and positive peace was gradually whittled down, to the specific role that PACS research and practice can play. Critical theories, the transformative paradigm, appreciative inquiry and narrative inquiry were all presented as methodologies that have influenced this research, before Chapter Five detailed ethical considerations and the design of data collection methods. The context of the Venezuelan crisis, Colombian armed conflict and Ecuador as a country of asylum were then discussed, setting the scene for the twenty-five participant narratives that were collected over the course of five weeks.

The first key finding of this research confirmed what reviewed literature had suggested, with participants reporting that the intersectionality of disability, conflict and displacement is unique and often resulted in harrowing experiences of direct, structural and cultural violence. My own observation is that this experience of intersectionality has largely been excluded from academia and, according to participants, excluded from practice and humanitarian

interventions. I would also conclude that it is an intersectional experience that should only be articulated by those who have lived it.

The next two findings chapters addressed the second key research question which investigated what can be learnt from people with disabilities about protecting and promoting the rights of people affected by disability, conflict and displacement. This began with an appreciative inquiry line of questioning that sought out the "best of what is" and the "best of what has been". Common aspects that participants appreciated about life in Ecuador included the tranquillity and security, support from charities and humanitarian organisations, as well as support from local populations. I also observed the effectiveness and importance of leaders with lived experience of disability.

The next chapter then discussed what an ideal future looked like where the rights of people with disabilities affected by conflict and displacement were being upheld, as well as participant recommendations for realising such a future. A key finding derived from participant responses confirmed that people with disabilities offer valuable and unique insights into what is working, what is not working, as well as suggestions on how to improve the circumstances of others who, like them, are affected by disability, conflict and displacement. Although this finding may seem simple and obvious, when considered alongside the concerning lack of disability perspectives within PACS literature and practice, it is a finding that I believe needs to be simply and clearly stated. Suggestions for realising Article 11 of the CRPD, which directly relates to people with disabilities affected by conflict and disaster, included participant advice for people with disabilities, advice for service providers, and areas for investment and improvement. For example, participants offered recommendations on modes of transport and travel routes, how service providers can improve their responses to the unique needs of people with disabilities, what supports best promote independence and wellbeing, new ways to support families, as well as advice for asylum seekers and refugees with disabilities themselves regarding attitudes and faith.

The final two chapters detailed my own reflections on the third key research question, which inquired how PACS research can contribute to inclusive and accessible positive peace. Throughout my analysis I noted that participant dreams for the future were hopeful, yet limited in scope. In some ways, their dreams were reminiscent of rejected models of disabilities, which the disability rights movement has fought long and hard to overturn. This included moving beyond just the satisfaction of basic needs, and towards a more holistic

approach to wellbeing and freedom. I wondered how PACS research and practice could contribute to ensuring this shift in thinking also occurs amongst populations affected by conflict and displacement. Further reflection led me to the next key finding, which is that for inclusive and accessible positive peace to be realised, PACS research and practice must be rooted in rights-based epistemology and ontology. This reflects the work of Kerr (2013) in Northern Ireland, which highlighted that the needs of people with disabilities in a post-conflict setting has traditionally been characterized by the medical model of disability. As a result, this has led to the neglect of structural and cultural violence experienced by disability populations. Approaches must therefore be informed by the social model of disability, which I have also extended to include the social-relational and rights-based models of disability. It might be noted that this is not limited to the disability community. However, as a model, the rights-based approach to disability sets a high standard that is relevant to, and inclusive of, all people, regardless of identity, ability or disability. A further finding was elicited by the appreciative inquiry methodology, which pointed to the urgent need to challenge discourses around "vulnerable" participants in research and practice. If academia continues to classify people with disabilities affected by conflict and displacement only as victims or only as vulnerable, we risk missing out on crucial experience, knowledge, expertise and wisdom that is directly relevant to PACS and positive peace. In saying that, there is no doubt that participants experienced vulnerable circumstances and periods of vulnerability and victimization. However, they also exhibited traits of resilience, hope, knowledge, strength and an entrepreneurial spirit, which are invaluable in the pursuit of inclusive and accessible positive peace. I concluded that as an academic discipline, PACS is in a unique position to collaborate with the disability community on reversing harmful and disempowering discourses.

The next, and final findings chapter, provided practical suggestions on how PACS researchers and practitioners can take steps towards challenging structurally and culturally violent discourses regarding people affected by disability, conflict and displacement. This includes employing a twin-track approach to peace research and peacebuilding activities, which ensures maximum inclusion for all people, while providing specific assistance to those who need extra support to participate.

Finally, the implications for the field were discussed. The key findings of this thesis are simple. What can we learn from people with disabilities about the intersectionality of disability, conflict and displacement? Participants confirmed that from their own experiences,

the intersectionality of disability, conflict and displacement was often dangerous and harrowing. What can we learn from people with disabilities about protecting and promoting the freedoms, rights and dignity of people with disabilities affected by conflict and displacement? A great deal. Research participants shared valuable insights and knowledge on how to navigate the intersectionality of disability, conflict and displacement. How can PACS research contribute to inclusive and accessible positive peace? My own research journey has shown that when PACS research endeavours and activities are rooted in rights-based approaches, and that those who are affected are leading and determining the research agenda, while being present and participating, then inclusive and accessible positive peace has already begun to advance.

In conclusion, with these findings at the forefront of our thinking, it is possible for PACS to start to deconstruct and disempower the most dangerous phrase in the English language, which has justified and promoted ableist ideologies for far too long, simple because "it has always been done this way". This thesis is one of the first steps in the journey towards inclusive and positive peace. What began as a whisper in Chapter One, I now state with confidence: "It may have always been like this, but it doesn't have to be". When PACS researchers, activists and practitioners take up the challenge of ensuring their research and practice is inclusive and accessible, there is no telling how far the impact might be felt.

This is just the beginning. The challenge is thus set and the way forward is clear. Now the hard work must begin.

Appendix A – Interview Questions

1) What do you like about your life here in Ecuador?

2) What was life like back in Colombia/Venezuela for you/your family member with a disability?

3) Tell us a little bit about your journey from Colombia/Venezuela to Ecuador.
PROMPTS:
- What helped you get from there to here?
- How was this journey for you/your family member with a disability?
- How did other people respond to you/your family member with a disability along the way?
- What was helpful in keeping you/them safe?
- Can you give me an example of an experience during your journey from Colombia/Venezuela to Ecuador, when you/your family member with a disability felt safe, respected and included?

4) Can you think of someone – perhaps a family member, friend, teacher, service provider – who has had a positive impact on you/your family member with a disability?
PROMPTS:
- Who, what, where, why, when, how?

5) Around the world people with disabilities face barriers, exclusion and danger during conflict and displacement. Often more so than people without disabilities. How do you think the safety, respect and dignity of people with disabilities during conflict and displacement can be upheld?

6) If you were to give advice or encouragement to a person with a disability and their family affected by a conflict in another country, for example in Syria, what would it be?

7) Thinking ahead to five years' time. Imagine you/your family member with a disability is leading a full and meaningful life where they feel safe, equal, included and respected within your/their community. What would life look like for you/your family member?
PROMPTS:

- What will have changed between now and then?
- What is needed for this to happen?

8) What human rights are most important to you?
PROMPTS:

- What is most important to your/your family member's survival?
- What are the most important things for you/your family member with a disability to lead a dignified life?

9) Have you heard of the Convention on the Rights of Persons with Disabilities? If yes: what does it mean to you?

Appendix B – Executive Summary (Plain English)

This research was part of my Doctorate degree at the University of Otago National Centre for Peace of Conflict Studies in Dunedin, New Zealand.

I am a twenty-nine year old student with a physical disability. The bones in my legs did not grow properly before I was born, so I walk with a prosthetic left leg. My right leg is also affected.

When I studied and worked overseas I became interested in the experiences of disability, conflict and displacement. Conflict is when different people or groups are fighting each other. Displacement is when a person or group of people must leave their home because of fighting, or because they are in danger and are afraid. In my academic field (Peace and Conflict Studies) there is not much information or research that tells the stories of people with disabilities living in these situations. This is a problem.

This document is a summary of my research. My research is about intersectionality, that is, all the different experiences a person with a disability might have during times of conflict and displacement. For example, a person might live with a disability and be a refugee, while also living in poverty. It is also about how these experiences impact each other. When displaced people go to another country they are called asylum seekers. They might talk to an organisation such as the United Nations about becoming a refugee. Being a refugee enables access to services that can help. This research is about why some people experience discrimination (unfair treatment) or are left out of research and peacebuilding activities. It is also about how we can use peace research and activities to create better and safer situations for refugees and asylum seekers with disabilities.

Background

My thesis begins by talking about other research that has been done on disability, conflict and displacement. Some of this research comes from universities, reports from organisations, or from the media. This is called a literature review. I discuss the history of the disability rights movement and six key models of disability. Models help us to understand how society has viewed disability throughout history. The models I discuss include:

- The moral model of disability: This model is where society sees disability as a punishment from God.

- The charity model of disability: The charity model is when society treats people with disabilities as helpless, and in need of charity.

- The medical model of disability: The medical model is where disability is seen as a problem that needs to be fixed with medicine, science and rehabilitation.

- The social model of disability: The social model is the idea that people are not disabled by their impairments but by the barriers they face in society. It is society's responsibility to remove these barriers.

- The rights-based model of disability: Like the social model, the rights-based model sees people with disabilities as individuals with their own unique political voice. People with disabilities have the right to equal opportunities and the right to participate in society.

- The social relational model: The social relational model recognises both the effects of impairment, as well as the barriers created by society (especially people in power). An individual's experience is both of these things together.

These models also help us see how our views of disability have changed over time. Since the 1980s people with disabilities started to fight for their rights and determine their own identity and status within society. This is what is known as the disability rights movement. Following this, my thesis talks about the historical roots of discrimination and different human rights tools for protecting the rights of people with disabilities during conflict and displacement.

The literature review then focuses on Peace and Conflict Studies literature and practice. Academic literature refers to texts written by people from academic institutions, such as universities. Practice refers to how the literature, research and findings are applied in real life. A brief history of Peace and Conflict Studies is given, and I discuss how people with disabilities are represented in Peace and Conflict Studies literature and research. I find that there is not a lot of reference to disability. I then look at other sources for relevant information. Through this process, I discover that people with disabilities experience:

- Discrimination (unfair treatment) during conflict and displacement;

- Abandonment (being left behind when everyone else runs away);

- Punishment (for example, when a blind person cannot tell violent people where to find someone);

- Recruitment (for example, undertaking suicide missions during conflict);

- Unequal treatment (the different ways people with different disabilities are treated);

- Being excluded from peacebuilding activities.

I also discuss resources and toolkits that have been created to help humanitarian organisations working with refugees and asylum seekers consider the rights of people with disabilities (such as the United Nations and the Women's Refugee Commission).

I think about these experiences from the perspective of Peace and Conflict Studies theories. A key Peace and Conflict Studies scholar, Johan Galtung, says that there are different types of violence:

- Direct violence is when one person or group hurts another.
- Structural violence is harder to see but includes discrimination and racism.
- Cultural violence is found in religion, law, language, art, science, and is made possible by institutions such as schools, universities and the media.

Galtung says that we often think about peace as being when there is no direct violence, but he calls this negative peace. The alternative – positive peace – is when there is no direct, structural or cultural violence. This is what we should be working towards. Having reached the end of the literature review, I present three questions my own research seeks to answer:

1) What can we learn from people with disabilities about the intersectionality (overlapping experiences) of disability, conflict and displacement?

2) What can we learn from people with disabilities about protecting and promoting the freedoms, rights and dignity of people with disabilities affected by conflict and displacement?

3) How can Peace and Conflict Studies research contribute to inclusive and accessible positive peace?

Process

The next part of the thesis talks about my own research: what I was looking for and how I was going to find it. It was important for me to understand my own motivations and how these fit with other ideas about how we know things. For many people with disabilities, the experience of participating in research has been a bad one. Researchers have used the stories of people with disabilities for their own purpose but have done nothing to change their situations. I needed to think carefully about how to conduct ethical, sensitive and respectful research.

First, I decided my research needed to be critical. This meant it needed to examine how disability is thought about in research, even if it meant challenging my own academic

discipline (Peace and Conflict Studies). Second, it needed to create change. Transformative research is an approach that considers people with disabilities as experts (people who know the most). The researcher is there to serve the research needs of the disability community and that the researcher will use the findings to improve life for people with disabilities. I discuss appreciative inquiry as being an important part of my research. Appreciative inquiry focuses on what is working in any situation and tries to build on that to help make good changes. I also talk about the importance of telling personal stories, my role as a researcher, and my own experience of disability.

After this, I talk about how I collected the information that was needed to answer the research questions. With the help of organisations working with refugees and asylum seekers, I interviewed twenty people with disabilities and family members of people with disabilities. All of these people had been affected by the Colombian armed conflict or the Venezuelan crisis and are now living in Ecuador as asylum seekers or refugees. I also interviewed five service providers to help give context.

All of the participants were asked to meet me for a face-to-face interview in a location of their choice (such as their home or in a cafe). In this part of the thesis I also discuss the steps I took to make sure that the research was ethical and respectful. The greatest strength of this research, was that it drew on the knowledge of people with disabilities, adding a new and unique perspective to Peace and Conflict Studies.

Findings

I begin the findings chapters by providing a short history of the Colombian Armed Conflict, Venezuelan crisis and the experience of disability and displacement in Colombia, Venezuela and Ecuador. I discuss what the participants told me during the interviews. This began by sharing their stories about what it is like to live with a disability in a place of conflict and violence. Participants shared what it was like to leave their homes, the journey to a new life in a new country (Ecuador) and their experiences of different types of violence (direct, structural and cultural). The findings then focus on stories of survival, resilience and hope. Participants shared what they enjoyed about living in Ecuador. This included the tranquillity (calm) and the security, help from charities, and support from local Ecuadorian people. I also noticed how important it was that people with disabilities are represented in leadership roles.

Next, I provide a summary of participant responses about their hopes and dreams for the future. I asked them what a future looked like where they have rights, freedom and dignity. I also asked for their suggestions and advice on how to make that future real. Many participants told me they dreamed of a future where they had food, housing and security. They also gave advice for other refugees and asylum seekers with disabilities. For example, participants recommended different ways of travelling to another country, how service providers can give better support for people with disabilities, new ways to support families, as well as advice for asylum seekers and refugees with disabilities themselves (including attitudes and faith). I then reflected on the research process, the interviews and the research questions.

In summary, my research findings are as follows:

- People with disabilities who experience conflict and displacement know a lot about survival and resilience. They also know what works for them and what does not. Although this finding may seem simple and obvious, it is a finding that needs to be simply and clearly stated. By saying it out loud, we can start to be more inclusive of people with disabilities in research and in practice.

- Positive peace is inclusive and accessible to all people, even if someone lives with a disability or another diverse identity. If people with disabilities are excluded, there can be no positive peace.

- Peace and Conflict Studies researchers and practitioners must promote positive peace that is inclusive and accessible. This can be achieved by treating people with disabilities as people who have the same rights as everyone else; supporting people with disabilities to lead research and peacebuilding activities themselves; making sure all research and peacebuilding activities are inclusive of, and accessible to, people with disabilities; choosing research methods that support human rights; and by treating people with disabilities as experts, rather than as vulnerable or as victims.

The final part of my thesis suggests how Peace and Conflict Studies researchers and practitioners can also make sure their research is inclusive and accessible. This includes the twin-track approach. The twin-track approach has two parts, the first being Universal Design. Universal Design refers to design that is good for everyone. The second track is disability specific design, which recognises that some people need extra support to participate. For example, my prosthetic leg helps me with mobility and independence. Not everyone needs a prosthetic leg, but everyone, including myself, benefits from an elevator in a building. Both

devices (prosthetic leg and elevator) support access and inclusion. However, one is specific to my needs, while the other is beneficial to all people. I argue that Peace and Conflict Studies research and practice can learn a lot from the twin-track approach.

Implications

In conclusion, the implications of this research are limitless. If Peace and Conflict Studies researchers and practitioners work towards positive peace by being inclusive and accessible, there is no telling how big the impact of this research might be. It has potential to impact both people with disabilities as well as others who experience discrimination during conflict and displacement. It is my hope that the disability rights mantra, "nothing about us, without us" becomes a guiding principle for Peace and Conflict Studies and peacebuilding activities.

Easy Read Version

Peace is for everyone

A short version of Robbie's research on:

Disability

Conflict

Displacement

Peace

What is in this easy read document?

- Who am I?

- What is research?

- Why am I doing this research?

- What is this research about?

- Background

- Research questions

- Method

- What I found out

- Things I found out

- What does my research mean?

- Why?

- Glossary

Who am I?

My name is Robbie Francis.

I am 29-years old.

I am amputee.

This means I only have one leg.

I use a fake leg to help me walk.

I am a student.

What is research?

This Easy Read document is a short version of research I did at **university.**

> **University is a large school where adults learn and do research.**

Research is when you ask questions about something to find out more information.

I have been doing this research for 3 years.

Why am I doing this research?

I have lived in places of **war**.

War is where people fight and hurt each other.

5

This made me wonder:

What happens to disabled people during war?

6

To find out what happens to

disabled people during war I looked in:

7

- Books

- Articles

I also asked other people this question.

8

I found there is not much information about

disabled people living in places of war.

This is a problem.

What is this research about?

This research is about:

- **Disability**

- **Conflict**

- **Displacement**

- **Peace**

9

> **Disability is something a person lives with that might make it hard to do everyday things.**

Very often, it is made hard by other people, not just the disability.

Conflict is when different people or groups are fighting each other.

Displacement is when a person or family has to leave their home because of fighting or violence.

10

Violence is when someone hurts another person with their:

- **Words**

- **Actions**

- **Ideas.**

11

Peace is when there is no violence.

Peace is when all people are free to be who they want to be.

12

13

People who experience war and violence often feel afraid or are in danger.

This research is also about:

14

- Why some people experience unfair treatment called **discrimination**.

Discrimination means being treated unfairly or not getting the changes you need because you are disabled.
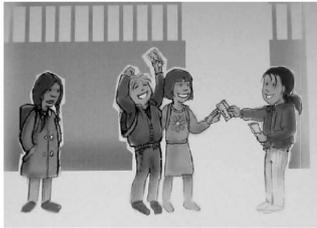
15

- Why some people are left out of research and peacebuilding activities.

16

- How to create better and safer situations for disabled people.

Especially those who experience conflict and displacement.

Background

My research starts by looking at what other people have written about similar topics.

- This is called a **literature review**.

17

The topics of my literature review included:

18

- How people who do not have disabilities think about disability.

- How disabled people think of them selves.

19

- How this has changed over time.

- Why some disabled people experience discrimination (unfair treatment).

20

- Different laws and rights that protect disabled people.

I then look at Peace and Conflict Studies research.

21

Peace and Conflict Studies is the name of the subject I study at university.

22

I look at articles and books written by other researchers and ask:

Where is the voice of disabled people?

23

We have not been included.

I also look at:

- Newspaper articles

24

- Other research

- Reports.

I learned that during conflict and displacement,

disabled people often have very bad experiences.

25

Sometimes during conflict and displacement disabled people are:
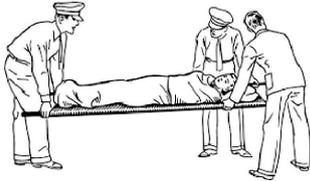
26

- Hurt

- Forced to do things they do not want to do

27

- Left behind when everyone else runs away from the violence.

Sometimes they do not have:

28

- Money

- Food

- Shelter.

29

I think about these experiences and what this means for **peace**.

Peace is when there is no:

30

- Violent actions

- Violent words

- Violent ideas

- Discrimination **unfair treatment**.

Peace is when:

31

32 & 33

- Everyone feels safe.

- Everyone has food and a house to live in.

- Everyone can be who they want to be.

- Everyone has equal opportunities.

Peace is for everyone, including disabled people.

34

Research Questions

After looking at all of these topics, I make up my own research questions.

These are called key research questions.

Research questions help me focus on what I am trying to find out.

35

242

Question 1:

What can we learn from disabled people about the **intersectionality** of disability, conflict and displacement?
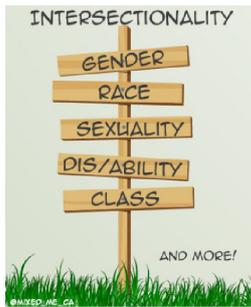
Intersectionality means all the different parts of who a person is, and all the experiences they might have.

Question 2:

What can we learn from people with disabilities about protecting and promoting the freedoms, rights and dignity of people with disabilities affected by conflict and displacement?

This question relates to Article 11 of the **Convention on the Rights of Persons with Disabilities.**

This is an international agreement.

It sets out what countries have to do to make sure that disabled people have the same rights as everybody else.

Article 11 is about making sure disabled

people are ok during dangerous or violent

situations.

This includes during war.

41

Question 3:

How can Peace and Conflict Studies research help to make sure that peace is inclusive and accessible?
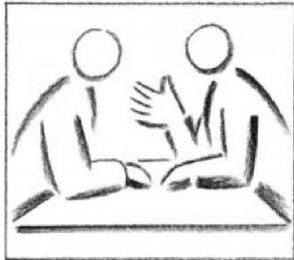
42

Inclusion is about making sure disabled people are asked what they think.

It is also about disabled people helping to plan and organise research and activities.

43

Access is about making sure disabled people can easily take part in research and activities.

Method

Method means how I answered the key research questions.

I decided to use methods that focus on lived experience.

Lived experience is what disabled people know about things because they have lived it.

44

People are experts of their own lives.

I chose to focus on ideas that makes things better.

45

I talked to organisations working with

asylum seekers.

46

An asylum seeker is someone who has left their home because they were in danger.

An asylum seeker is someone who tries to find peace and safety in a new place.

47

The organisations helped me to find and interview asylum seekers who are also disabled.

48

An interview is a face-to-face meeting to talk about the research questions.

In my research I called the people that I interviewed participants.

This means they took part in the interviews.

I interviewed 20 participants

and family members of disabled people.

49

50

All of the participants had left their countries because of violence.

They were afraid and in danger.

They had left behind their:

51

52

- Homes

- Families

- Friends

- Jobs

- Lives
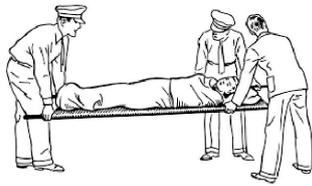
Some had been hurt very badly.

53

All of them had experienced

psychological trauma.

Psychological trauma is the way our brain responds to experiencing and seeing bad things.

54

55

They now live in Ecuador as asylum seekers.

Living as an asylum seeker with a disability can be very hard.

Sometimes other people treat them badly because they are both disabled and from another country.

Many of them:

56

- Had nowhere to sleep at night

- Had no food to eat

- Had no money.

I also interviewed 5 service providers.

57

Service providers are people who work

with asylum seekers as a job.

They help asylum seekers get the help

they need.

What I Found Out

Participants shared what it was like to
leave their homes.

They also talked about life in their new
country (Ecuador).

58

The good parts and the bad parts.

They told stories of:

- **Survival**

- **Resilience**

- **Hope**.

59

60

Survival is what a person does to stay alive.

Resilience means how a person keeps living their life after bad things happen to them.

Hope is believing that something good will happen in the future.

Participants shared what they liked about living in Ecuador.

This included:

- The safety

61

- Help from charities (organisations that help people)

- Support from local Ecuadorian people.

62

I also noticed how important it was that disabled people were in leadership roles.

63

Next, the participants told me about their hopes and dreams for the future.

I asked them what a future life might look like where they felt equal and included.

Many participants told me they dreamed of a future where:
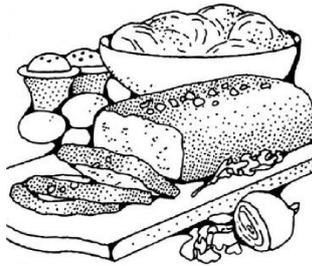
64

- They had food

65

- They had a house to live in

- They felt safe.

They also shared their ideas about how to make this happen.

Participants told me about:

66

- Good ways to travel to a new country

- How service providers can support disabled asylum seekers better

- How to support families

67

- Ideas on how disabled asylum seekers can make better decisions.

Other things I found out

Disabled people who experience conflict and displacement know a lot about:

68

- Survival

- Resilience

- Hope

69

70

- What is working for them

- What is not working for them.

I also found out that:
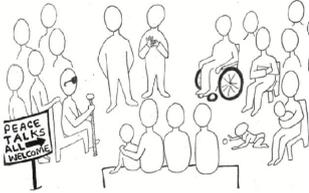
71

- Peace is inclusive and accessible to all people.

72 & 73

- If disabled people are left out, there can be no peace.

Also, it is important for Peace and Conflict Studies researchers and peace builders to make sure:

74

- Disabled people can make their own decisions about what is important to them

- Their research and activities are inclusive and accessible to disabled people

75

- They treat disabled people as experts.

What does my research mean?

This research is important because it:

76

- Tells everyone who reads it about the experiences of disabled people during conflict and displacement

77

- Shows Peace and Conflict Studies researchers and peace builders how to make their work more inclusive and accessible.

Why?

78

Because:

- Disabled people have lots of ideas about how to remove barriers

79

- Disabled people have lots of ideas about how to stop discrimination.

This is very important for peacebuilding.

As the disability rights slogan says,

nothing about us, without us.

80

If it affects disabled people, we must be included.

Inclusive and accessible peace is very important

81

because it helps all people to lead better and safer lives.

List of hard words

Asylum Seeker:

Someone who has left their home because they were in danger.

Conflict:

When different people or groups are fighting each other.

Convention on the Rights of Persons with Disabilities:

The Convention is an international agreement that sets out what

countries have to do to make sure that disabled people have the same

rights as everybody else.

Disability:

Something a person lives with that might make it hard to do everyday

things. Very often, it is made hard by other people, not just the disability.

Discrimination:

Being treated unfairly or not getting the changes you need because you are disabled.

Displacement:

When a person or family has to leave their home because of fighting or violence.

Hope:

Believing that something good will happen in the future.

Intersectionality:

The different parts of who a person is and all the experiences they might have.

Literature Review:

When we think about what other people have written about a topic that we are interested in.

Method:

How I answered the key research questions.

Psychological trauma:

The way our brain responds to experiencing and seeing bad things.

Research:

When you ask questions about something to find out more information.

Resilience:

How a person recovers after bad things happen to them.

Service providers:

People who work with asylum seekers as a job.

Survival:

What a person does to stay alive.

University:

A large school where adults learn and do research.

Violence:

When someone hurts another person with their words, actions, or ideas.

War:

When people fight and hurt each other.

This Easy Read document was produced with help from Stace and Ash.

Picture	Description	Where the Easy Read picture came from:
1	Robbie Francis	Drawing by Stace Robertson, 2018
2	Legs	Personal photo collection, Robbie Francis, 2014
3	University of Otago National Centre for Peace and Conflict Studies	https://www.critic.co.nz/news/article/3479/masters-by-coursework-on-the-rise
4	Thinking person with question mark	Drawing by Stace Robertson, 2018
5	Soldier	https://openclipart.org/detail/189079/italian-soldier-of-ww2
6	Thinking person with question mark	Drawing by Stace Robertson, 2018
7	Robbie reading book	Personal photo collection, Robbie Francis, 2018
8	Newspapers	http://weclipart.com/newspaper+stack+clipart
9	Wheelchair stairs	https://www.uaa.alaska.edu/about/accessibility/_images/WheelchairStairs_1.JPG
10	Family holding hands	https://pixabay.com/en/war-torn-refugees-poor-destitute-2069727/
11	Bullying	Drawing by Ash Spittal, 2018
12	Dove	Drawing by Ash Spittal, 2018
13	Scared to death	https://cdn.tutsplus.com/vector/uploads/2013/09/cartoonemotions-15.jpg
14	Exclusion	https://img.lelivrescolaire.fr/upload/celine.gomes/800.max.p17n82jnqgh33g8fr9o165b1kj94.jpg
15	Exclusion	https://www.researchgate.net/profile/Christine_ROLAND-Levy/publication/280253799/figure/fig1/AS:441754487922689@1482333885809/Social-exclusion-drawing-presented-to-girls-An-

		identical-drawing-depicting-boys-was.png
16	People holding hands around the world	http://www.clker.com/cliparts/t/a/C/n/w/j/people-holding-hands-around-the-world.svg
17	Books	Canva.com illustrations, 2018
18	Person thinking about disability	Canva.com illustrations, 2018
19	Clock	http://etc.usf.edu/clipart/34000/34054/nclock-07-40_34054.htm
20	Wooden court gavel	http://sweetclipart.com/wooden-court-gavel-1073
21	University of Otago National Centre for Peace and Conflict Studies	https://www.critic.co.nz/news/article/3479/masters-by-coursework-on-the-rise
22	Pile of paper	http://crafts.es.ht/paper-clip-clipart-black-and-white.html
23	All welcome #1	Drawing by Robbie Francis, 2016
24	Newspapers	http://weclipart.com/newspaper+stack+clipart
25	Family holding hands	https://pixabay.com/en/war-torn-refugees-poor-destitute-2069727/
26	Injured person on a stretcher	https://encrypted-tbn0.gstatic.com/images?q=tbn:ANd9GcT2o4pl8iteZ9VtmJP7uxFFDpWayHA6furbGgg2QTY6GnYY5NoK
27	Boy with guards	http://en.prothomalo.com/contents/cache/images/800x500x1/uploads/media/2016/05/25/eb2cbfc024cb6c62a144d79f40d8d4c9-9.jpg
28	Money	http://www.clipartpanda.com/clipart_images/money-clip-art-6967637
29	Dove	Drawing by Ash Spittal, 2018
30	Bulling with red cross	Drawing by Ash Spittal, 2018
31	Family, house,	Canva.com illustrations, 2018

	safety	
32	Smiley face	https://www.pinterest.nz/pin/340162578088102741
33	Blind man	http://mzayat.com/singlec/3079084.html
34	Building peace	https://pixabay.com/en/peace-peacebuild-peacebuilding-2288954/
35	Magnifying glass	Drawing by Ash Spittal, 2018
36	Magnifying glass	Drawing by Ash Spittal, 2018
37	Intersectionality	https://mixedincanada.com/intersectionality/
38	Magnifying glass	Drawing by Ash Spittal, 2018
39	UN logo disability	http://www.easpd.eu/sites/default/files/sites/default/files/un_log_disa.jpg
40	Disability rights	http://progressive.org/op-eds/scalia-s-damage-disability-rights/
41	Magnifying glass	Drawing by Ash Spittal, 2018
42	Interview	http://www.open.ac.uk/ccig/events/research-methods-and-analysis-interview-techniques-for-postgraduate-researchers-workshop-3
43	Woman at desk	https://www.istockphoto.com/nz/vector/young-african-business-woman-signing-documents-gm878046030-244917585
44	Idea	Canva.com illustrations, 2018
45	Humanity Inclusion photo	https://hi-canada.org/en/news/bangladesh-crisis-handicap-international-hi-beefs-up-its-emergency-assistance
46	Running boy	http://www.clker.com/cliparts/F/l/I/J/P/m/run-lil-boy-md.png
47	Participant photo	Personal photo collection, Robbie Francis, 2017
48	Study together	https://clipartxtras.com/download/fac280437f442332738863999663300ed15fc9b7.html
49	Study together	https://clipartxtras.com/download/fac280437f442332738863999663300ed15fc9b7.html
50	Refugees	Canva.com illustrations, 2018
51	House	http://www.clker.com/clipart-house-39.html
52	Family	http://letterforfriend.site/admin/clipart/lds-family-

		clipart-black-and-white/
53	Injured person on a stretcher	https://encrypted-tbn0.gstatic.com/images?q= tbn:ANd9GcT2o4pl8iteZ9VtmJP7uxFFDp WayHA6furbGgg2QTY6GnYY5NoK
54	Amputee thinking about bombs	Drawing by Ash Spittal, 2018
55	Map of Ecuador	Designed by Robbie Francis, 2018
56	The homeless, Paris	https://commons.wikimedia.org/wiki/File: The_Homeless,_Paris.jpg
57	Jesuit refugee service	https://ignatiansolidarity.net/blog/2018/02/21/jesuit-refugee-service-trump-budget/
58	Person telling story	Drawing by Ash Spittal, 2018
59	Friends helping each other	https://clipartxtras.com/download/ 937a5eb98fc94f1dc874e0a3d408cef782ecfcf3.html
60	Imagining with smiling face icon	Drawing by Ash Spittal, 2018
61	Locals helping refugees	http://www.dailymail.co.uk/news/article-3346135/Syrian-refugee-families-receive-warm-welcome-locals-not-weather-arrive-new-homes-Scottish-Isle-Bute.html
62	President Lenin Moreno	http://www.internationaldisabilityalliance.org/lenin-moreno
63	Imagining with smiling face icon	Drawing by Ash Spittal, 2018
64	Food	https://www.pinterest.nz/andi540724/food-clip-art/
65	House	http://www.clker.com/clipart-house-39.html
66	Airplane	http://lemonize.me/clipart-for-airplane.html/clipart-for-airplane-planes-many-interesting-cliparts
67	Thinking of ideas	Drawing by Ash Spittal, 2018
68	Survival	http://www.clipartpanda.com/categories/survival-clip-art-free
69	Check mark	https://openclipart.org/detail/258557/
70	Cross	Drawing by Ash Spittal, 2018
71	All welcome #2	Drawing by Robbie Francis, 2016

72	Dove	Drawing by Ash Spittal, 2018
73	Cross	Drawing by Ash Spittal, 2018
74	Expert	https://www.punchydigitalmedia.com.au/videos-and-events/
75	Easy read	https://equalityhub.org/easy-read/
76	Disability focus group	http://www.essexice.co.uk/picture-resources/graphics-with-agreed-meanings/
77	Disability inclusion	http://blogs.rj.org/rac/2015/04/20/at-consultation-spotlight-on-disability-inclusion-and-advocacy/
78	Barriers	Drawing by Stace Robertson, 2018
79	No bullying	Drawing by Ash Spittal, 2018
80	Nothing about us, without us	http://www.dinf.ne.jp/doc/english/global/david/dwe001/dwe00103.html
81	Disability inclusion	http://thecsrjournal.in/wp-content/uploads/2018/03/Disability-Inclusion.png

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