The Open Borders of Latin America:
A Descolonial Hope of Being

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Resumen

Esta tesis es una investigación auto-etnográfica enraizada en las teorías feministas descoloniales que explora 'metodologías otras' en las interseccionalidades imbricadas de (dis)capacidad, migración forzada y maternidad. Esta es una narrativa de aprendizaje de una madre-activista sobre cómo poner en práctica una investigación activista feminista decolonial en Colombia con madres refugiadas Venezolanas, cuyos hijos pueden o no tener un diagnostico de (dis)capacidad, y con profesionales que trabajan en el sector de las ONG para y por refugiados en Bogotá.

El punto de partida es mi posicionalidad como psicóloga Venezolana y madre de una hija con un diagnóstico de autismo, trabajando dentro del aparato moderno de la Psique, así como en alianza decolonial con familias en el habitar de la (dis)capacidad y la migración forzada. Soy una madre en busca de espacios alternos de producción de conocimiento con ojos fronterizos 'mestizos' norteados. Varias pausas en la investigación, una pandemia global y la mayor migración en mi continente me llevaron a una ruta activista co-fundando una Organización Liderada por Refugiados (OLR) en alianza con mujeres refugiadas venezolanas. Estas pausas y experiencias cambiaron las preguntas de la investigación hacia una reflexividad ética sobre cómo llevar a cabo una investigación descolonial, cómo ser una investigadora reflexiva, no pretender representar las voces de otros y cómo descolonizar mi yo mestiza norteada.

Esta tesis se fundamenta en críticas a la interseccionalidad desde el feminismo descolonial y en las genealogías de la "otredad" para imaginar más allá de los discursos dominantes universalizadores que se sitúan firmemente en raíces étnicas geohistóricas europeas. El giro genealógico de las feministas descoloniales abre un cuestionamiento fundamental de las nociones mismas que me había propuesto explorar: (dis)capacidad y migración. Las exploraciones de esta tesis no pretenden ser explicaciones genealógicas concisas sino más bien un cuestionamiento de la lógica categorial que produce "otredades" y que, por tanto, hizo necesaria la reformulación de las preguntas de investigación que incluían nociones de otredad. En este sentido, esta tesis describe una exploración metodológica de 'metodologías otras' con amor y una esperanza descolonial del ser desde los espacios de activismo, maternidad y comunidades de refugiados.

Palabras Claves: Feminismo Descolonial, Discapacidad, Otredad, Metodologías Descoloniales, Forced Migration, Venezuelan Children

Abstract

This thesis is an autoethnographic research rooted in descolonial feminist theories exploring 'methodologías otras' (altern methodologies) in the imbricated intersectionalities of (dis)ability, forced migration and motherhood. This is a mother-activist's learning research story about how to enact descolonial feminist activist research in Colombia with Venezuelan refugee mothers, whose children may or may not have a labelled (dis)ability, and with professionals working in the NGO refugee sector in Bogota.

The starting point is my positionality as a Venezuelan psychologist and mother of a child with an autistic label, working within the modern Psyche apparatus as well as descolonial allyship with families inhabiting (dis)ability and forced migration. I am a mother looking for altern spaces of knowledge production with borderland 'mestiza' northerned eyes. Various research pauses, a global pandemic and the largest migration on my continent led me to an activist route to co-found a Refugee Led Organisation (RLO) in allyship with Venezuelan refugee women. These pauses and experiences changed the research questions towards ethical reflexivity on how to enact decolonial research, not purport to represent others' voices and how to descolonise my northerned 'mestiza' self.

This thesis draws on some critiques on intersectionality from descolonial feminism and on the genealogies of 'Otherings' to imagine beyond the universalising dominant psyche discourses of the Global North. The genealogical turn of decolonial feminists opens up fundamental questioning of the very notions I set out to explore: disability and migration. The explorations in this thesis are not intended to be complete genealogical explanations but rather a questioning of the categorical logic that produces 'othering' and hence necessitated the reformulation of the research questions that included 'othering' notions. In this sense this thesis describes a methodological exploration of 'metodologias otras' with love and a descolonial hope of being in the spaces of activism, motherhood and refugee communities.

Key Words: Decolonial Feminism, (Dis)ability, Othering, Decolonial Methodologies, Forced Migration, Venezuelan Children

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Margot me recuerda siempre que en las historias de nuestro árbol de vida son muchas las mujeres constructoras de vida sin nombre. Esta tesis se la dedicó a mis mujeres: Patricia, Margot, Lucia, Nilda, Anna, Cristina, Heidi, Julieta y a Margaret Elizabeth la abuela que no conocí y por la cual podemos decir gracias a la vida.

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Glossary of terms

Abya Yala - Is a term used to signify the land most commonly known as Latin America. In the Kuna language in it means 'land in its full maturity' The relevance of the use of the term is where it places the writer (and the reader) geo-socio-politically in terms of the relationship between the global modern/colonial paradigm and Global South cosmologies and knowledges from Latin America (Oberlin Molina and Chiaradía, 2019). The term was taken up by indigenous rights movements as a unifying name and is widely used in research, literature, regional and international legal documents, conventions and protocols. The Aymara leader Takir Mamani proposed that all Indigenous peoples in the Americas utilise it in their documents and oral declarations. "Placing foreign names on our cities, towns and continents, is equal to subjecting our identity to the will of our invaders and to that of their heirs." (Native Web, n.d)

Descolonial or Decolonial - In Spanish descolonial is the correct grammatical word representing the idea of undoing coloniality, but in English the translation has always been decolonial. There is a contested difference between descolonial and decolonial that responds to politics within decolonial movements, tension between academic and praxis movements. I prefer the term descolonial but I do use the term decolonial when that is the term used by an author.

(Dis)ability - I use the brackets, as do many other authors (Goodley, 2013; Schalk, 2017) to highlight that throughout the thesis I am calling the conceptualisation of disability into question and putting tension on the different meanings with which it is used. It is also a reminder to myself and the reader that we all have different multiple understandings of what is (dis)ability that require troubling and dialogue.

Global North and Global South - I use this terminology to refer to the global capitalist system in modernity where the Global North refers to those countries who are culturally and economically dominant on a global stage particularly in regards to knowledge production. Global South countries include formerly colonised countries, are economically dependent and indebted, they are categorised as underdeveloped and peripheral countries. This is an over simplistic binary that doesn't address the layers of differences globally between and within countries but is a commonly used signifier of hegemonic global hierarchies.

Refugee- I use the terms refugee, migrant, forced migrant and displaced people interchangeably in this dissertation. By not using the legal definition of refugee I am also questioning the narrowness of the definition, and a reminder that this definition has contested colonial roots questioned in critical migration studies.

Abbreviations

CDS - Critical Disability Studies

DF- Descolonial feminism

GIFMM- Grupo Interagencial de Flujos Migratorios Mixtos

LatAm - Abbreviation for Latin America
It refers to all countries in the American continent that speak Spanish or Portuguese.

MC- Migracion Colombia is the department of the Colombian Ministry of Foreign Affairs in charge of migration

RLO - Refugee Led Organisation.
In this thesis the term is used specifically to refer to the RLO I collaboratively founded in Bogota, Colombia in Jan 2021. When using the term to refer to the movement and/or other organisations the acronym is used in the plural form RLOs

R4V-Interagency Coordination Platform for Refugees and Migrants from Venezuela
The platform is made up by over 200 organisations (including UN Agencies, civil society, faith-based organisations and NGOs, among others) that coordinate their efforts under Venezuela's Refugee and Migrant Response Plan (RMRP) in 17 countries in Latin America and the Caribbean.

UNHCR (In English) - ACNUR(in Spanish)
United Nations High Commissioner for Refugees is the original name of this agency of the United Nations, it maintains this acronym but is now called The UN Refugee Agency.
ACNUR is the spanish acronym for the agency: Alto comisionado de las Naciones Unidas para los Refugiados, also now known as La Agencia de la ONU para los Refugiados

Declaration

I, Elizabeth Arenas Thomas, confirm that this Thesis is my own work. I am aware of the University's Guidance on the Use of Unfair Means (www.sheffield.ac.uk/ssid/unfair-means). This work has not previously been presented for an award at this, or any other, university.

First Words

Dear Reader, before I tell you what this research is about and describe the structure of the thesis in the preface I would like to explain some choices I have made regarding language, the writing style and translations. I hope this helps the reader feel comfortable with some of the bilingual dancing between Spanish and English.

Writing Style

The writing of the thesis has become the research process in itself as I hope will become apparent as you read through. I have used a style of writing inspired by two Latin American ideas: 'escrevivencia' and 'sentipensar'. Brazilian Conceiçao Evaristo penned a form of writing called 'escrevivencia' which can be loosely translated as 'writingliving' (Marugán Ricart, 2022). Evaristo's writings, as a black woman, are grounded on the precarious living realities of black women in Brazilian Favelas. 'Escrevivencia' is a political form of writing that takes on the intimate relationship of travelling between writing about lived experiences, identity and society and proposes a feminist descolonial ethical position in the production of knowledge. The second influence on how I have chosen to write is 'sentipensar' (feelthinking) from Colombian sociologist Fals Borda who is best known globally for developing Participatory Action Research. Fals Borda (2009) initiated a 'sentipensar' sociology for Latin America which comes from ancestral practices that mean 'thinking with the heart and feeling with the head". 'Escrevivencia' and 'Sentipensar' are the academic methodological writing attitudes I use in my descolonial writing in this research. I will be using some terms in Spanish to remind the reader of the context of this research on my continent Abya Yala (Latin America). The Glossary is at the start of this thesis for easy reference.

Translations

This research has been carried out in Colombia and online in Spanish, the 'vivencias' are the stories I have written based on conversations and interviews are in Spanish and the bulk of the

theoretical literature review and references I have read are from Latin America mostly written in Spanish. I have made the choice of keeping both the original Spanish version and my translation into English, side by side, when quoting relevant literature and for the 'vivencias'. I hope keeping both languages on the page allows bilingual readers to see the full range of meanings, and by endeavouring to keep to non-literal translations I hope non Spanish readers can perceive a sense of the discourse of the specific cultural and political context of Venezuelans and Colombians talking from within the Venezuelan diaspora.

Regarding non-literal translations I look to Venuti's (2021) review of theories of translation where he distinguishes between the instrumental model that defines translation as reproduction beyond time and place; and the hermeneutic model where translation is defined as contingent on localised historical moment and cultural space. The choice of non-literal, culturally relevant hermeneutic translation localised in Colombia with Venezuelan refugees is consistent with the descolonial localised praxis of this research. Here the translations offer a possibility of dialogue across linguistic, historical, cultural and geographical boundaries to build coalition bridges across critical theories in the Global South and the Global North.

Venuti (1986, 2001, 2021) is consistently critical of the instrumental model, for him translation is never linguistic sameness. The acts of interpretation needed to translate from one language to another constitutes additive explanations and transformations which reconstitute new meanings. Venuti (1986) assumes a theory where language is slippery because it is contextually determined. Translations with their added transformations are fluidly ever more slippery. He says 'translation is imitative yet transformative' (2021, pg. 166).

Visually I want to leave my bilingual understandings on the page, side by side, and even though both languages are the languages of colony, using both offers a sense of immersing into different worlds and perspectives. It is a visual metaphor for plurality and irrationally I feel it is a homage to the lost pluralities and languages of Abya Yala. I also offer my subdued apologies to mono-lingual English readers about the lengths and structures of some of my sentences, they have been edited by bilingual critical friends to make sure they are comprehensible in English, however I have not polished my writings to be as those of a monolingual English academic

writer. I am bilingual, my understandings are bilingual and mestizas. Staying close to the Spanish even when it threatens to twist English into strange new forms is a way of making visible the translation tensions to the English reader as well as my mestiza bilingual cultural identity within the writing. Maybe the English words on these pages can also withstand some descolonising. Throughout the thesis all translations unless otherwise cited are my own.

One Last Word in Spanish

One last word I wish to explain that threads through every page of this dissertation is 'descolonial'. The word used in Spanish from the beginnings of the descolonial turn in Latin America with Quijano's (2000) Essay 'Coloniality of Power, Eurocentrism and Latin America' has been 'descolonial'. It has been translated to English as 'decolonial'. It has been argued (Pratt, 2019; Mendoza-Alvarez, 2020) that this translation is not accurate as in Spanish descolonial and decolonial (without the S) would imply different words as in Spanish both are grammatically possible whereas in English 'descolonial' has no linguistic representation. There has been in these arguments a distinction between contexts and the users of the two words in Spanish. The original term 'descolonial' has been in use in social movements in Abya Yala associated with emancipatory praxis and remains connected to historical indigenous, campesino and black movements. Whereas the use of 'decolonial' in Spanish has been associated with Latin American male authors writing academically mostly in the Global North but also in the Global South. Pratt says: 'It is not possible to overlook the gendered and racial dimensions of this confrontation, nor the potentially colonising relation of English to Spanish.' (2019, pg 124). The argument is that the term 'decolonial' in Spanish is an anglicism of the translation of 'descolonial' and by using it in Spanish we revert to the hierarchy of knowledge produced from the North. I do not resolve this argument but I have chosen to use the word descolonial throughout (except when quoting an author who uses decolonial) as a sentipensar writing device. Dear Reader, I hope by using the Spanish 'descolonial' in an English written text sets the scene for this naive, yet unapologetic thesis on the epistemological learning tensions explored in the under researched gaps of (dis)ability and forced migration using the theoretical lens of Descolonial Feminism and Critical Disability Studies in Abya Yala.

Preface

The words of this preface are the last I have written and the first words you will read and I am cognisant of opening this space in a welcoming and loving way for what has for me been a painful writing process but hopefully not a painful reading one for you. I do hope it is an unconventional read. I have left the writing process with more questions, future community research proposals, fewer worries about my research naivety at the start of this research and more worries about how one epistemology grounded in colony continues to dehumanise peoples from all walks of life, in all regions of the planet in the Global North as much as Global South.

This thesis is the story of my research in Colombia with Venezuelan refugees whose children may or not have a diagnosed (dis)ability, as well as with Colombian and Venezuelan refugees volunteers and professionals who work within the non-profit humanitarian roots based organisations in Colombia. The theoretical and positional stances in this research are Descolonial Feminism and Critical Disability Studies. In all truthfulness this is a very personal self-descolonising learning story about Latin American resistance to hegemonic knowledge production and methodologies. My intentions changed during the research process from writing an academic thesis with the traditional sequencing towards writing an academic story attempting rupture with dominant academic forms of writing, of researching and of producing knowledge. This is an autoethnographic research on researcher positionality and activism.

There have been many pauses in this research due to the COVID pandemic, personal and family circumstances and the awakening to the need to descolonise myself as well as descolonising the research itself. The research pauses have been filled with self doubt and self-shame as I have had to jump, leap and scramble through leaves of absence, being unenrolled by the university, and having to reveal personal circumstances to unknown people on the other side of the university online administration. I have missed deadlines, have had two tutors, had to resubmit my ethics twice and request amendments a further two times and definitely not met the expectations of my university's timelines of completing the EdD in 4 years. I am grateful to my tutor Katherine Runswick Cole who helped me navigate the pause spaces with empathy as well as with intellectual solidarity. I am grateful for the research pauses as they gave me time for the flow of

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listening, learning, living, connecting, reading, thinking, and the opportunity to learn from writers, refugees, mothers, activists, professionals and to take group action with fellow aid volunteers and workers.

In essence the main research question became how to descolonise myself. Looking through autoethnography I have grappled with the irony of attempting social justice research by navel gazing. I recognise the privilege of being able to navel gaze, to have the time to view the twists and turns of my personal/family life and global events. I had nihilistic feelings of pointlessness, for what is the point of research if I cannot engage in action that is meaningful to the very community I want to work with and serve? The many pauses in the research and writing led me into unexpected life experiences and wonderful coalitions.

In this preface I set the scene for the reading of this thesis by clarifying the structure, I outline the chapters, I explain the use of Spanish and translations, and I describe the writing style I have engaged in.

Structure of this Thesis

My invitation is to read this doctoral thesis primarily as a methodological and epistemological exploration. A key idea I invite you to keep in mind as you read is that I started with the intentionality of exploring descolonial research questions about (dis)ability through the traditional layout of theoretical literature reviews, ethical approval for interviews, followed by analysis and conclusions. But at every turn of the process there were lived experiences where I felt it unethical to proceed as planned, and which flipped my intentions over and over. These turns led me to delve deeper into understanding descoloniality, and to shift my solidarity stance from raising the voices of those who are 'othered' to the unpeeling my own privilege and complicity in coloniality. This change of stance took place at many identity levels internally, personally, emotionally, professionally and in relationality with the people I talked with and with the university, the protocols, the deadlines and research expectations.

Hence the structure of the thesis does not follow the traditional structure, I have still included all the elements required for a doctoral dissertation such as a literature review, research questions, a

methodology, ethical considerations and analysis but these are not separated into sections or chapters but are interspersed in every chapter. This thesis writing moves from experiences to theoretical readings and critical weavings, from praxis to reflection and action and back again. The writing of this research story is a procedural attempt, intrinsic to the descoloniality learning I have gone through during this research, and is itself part of the descolonising of the methodology.

So having forewarned you why the structure of this thesis departs from traditional academic thesis structure, I would like to frame your reading by outlining the structure I have experimented with. In writing from a descolonial feminist lens about descoloniality and disability, I have written not only about descolonial epistemologies but also in an experimental descolonial method. I would like to say that although it has been a painful slow process for me in the writing because I was experimenting with an unknown form (for me at least) I hope that by laying out this structure here in the preface it helps you, the reader, to follow as I thread my research and activist experiences for you in a storytelling thesis. This is the structure I have experimented with and I hope this outline assists your reading. Each chapter will follow this structure that I describe briefly:

- A prelude
- A *vivencia*
- Chapter overview
- Theoretical threads woven with critical reflections
- Methodological implications
- Research question review

A prelude

Each chapter will be prefaced with a quote, poem or song to frame the 'sentipensar' of the chapter. The prelude will offer a brief naming of the themes of the chapter. I wish to allow the grounding of the themes to arise from each chapter's autoethnographic stories, 'vivencias', that lead to the theoretical review and the relevant critical reflections.

'Vivencias'

Each chapter has at its heart a vivencia, an autoethnographic recount of my experiences, whether autobiographical or from conversations with participants or a fictionalised fusion of these. 'Vivencias' in Spanish can be (mis)translated into 'lived experiences', however that translation doesn't fully capture the meaning. I use the word 'vivencia' for the autoethnographic stories in this thesis as it better encapsulates the feeling of how lived experiences stay within your heart, mind and soul, how they mould your character and your history. Vivencias are memorable, they are vital moments in life, they change you and when retelling vivencias you relive them.

I have created the vivencia in each chapter based on the conversations with the women I interviewed and/or on my own autoethnographic stories. In a (non)-traditional academic sense these vivencias can be read as my data and data analysis, they are my enactment of a descolonial methodology, as such I do not use references in these vivencias, they are stories and reflections from my experiences that set the ground for the theoretical lines of research in the literature. The justification for the use of vivencia writing and fictionalisation will be laid out in chapter three on the methodology of autoethnographic research.

The vivencias often feature some encounter or memory of Esperanzita, a fictionalised Venezuelan mother who walked thousands of kilometres to Bogota looking for a better life for her daughters. She embodies many of the women that I interviewed and the stories I was told by refugee aid workers in local refugee-led organisations in Bogota. Esperanzita is not one woman but many women, she is not representative of all Venezuelan refugee mothers but of my connections with the women I have spoken with. The vivencias are based on interview transcriptions, my thoughts and feelings. I have tried to remain faithful in Spanish to the ways of speaking that were at the heart of the dialogue rapport between me as a Venezuelan and the Venezuelan or Colombian interviewees. The first two vivencias are written in English, the remaining three were originally written in Spanish and translated into English. When they wished and could, the interviewees reviewed the vivencias, made comments and amendments.

Chapter Overview

In the overview for each chapter I set out the structure and an introduction to the themes addressed in the chapter and its sections.

Theoretical review and Critical Reflections

This section is the literature review on the theoretical threads and themes arising from the vivencias. I weave the theoretical literature with my critical reflections focusing on how to disentangle from western hegemonic understandings and reweaving descolonial imaginary perspectives.

There is an emphasis throughout the thesis on epistemology, and how to do the research. Weaving from descolonial feminist thought and the praxis of activism I move between theoretical concepts on (dis)ability and the descolonial turn and the epistemological doubts that arise.

Methodological Implications

Each chapter weaves towards epistemological reflections and methodological implications. I describe the essential outcomes of the epistemological turns I am learning and are important to take forward to the next chapter. Each experience I have had in the research and each vivencia has led me to activism and action, and to break away from hegemonic ways of doing research. My intention is that the methodological reflection of each chapter should come together as a summary focused on research methodologies principles to take back, for further consultation and development, to the Refugee-led organisation I work with and where I have done most of the interviews.

Research Question Review

I conclude each chapter, following from the methodological reflections, with a reformulation of the research questions that leads on to the next chapter. In the research process I have critically reviewed my initial research questions and in one sense put them to one side as I needed to relearn a whole new epistemology that forced me to trouble the original research questions and their epistemological grounding.

Something about writing this dissertation and the whole research experience has bridged the gaps between the different places I have called home, has healed my nostalgia for dancing with family and friends, for the Caribbean coast of Venezuela where I grew up and has helped me find a purpose in coalition with people from my culture. I hope your patience with me as a reader will persist and grow through the chapters as the threads of this thesis unravel the descolonial learning in this longing for home. Here is the outline of the chapters:

Chapter One Coming Home

The first chapter tells the story of the first research twist after a planning trip that led me to question my role as an insider/outsider researcher and my mestiza identity. The geography of the research plan moved from Chile to Colombia with the objective of researching the conceptualisations of (dis)ability in the lived experiences of forced migrants and refugees from my home country. Here is where I first see Esperanzita. The theoretical focus is an introduction to descoloniality and outlines conceptualisations that lay the ground to explore the synergies between descoloniality and critical disability studies later in the thesis.

Chapter Two Tent Research

The second chapter starts with the impact of the COVID pandemic on the research. This was a further pause in how to enact descolonial methodology in the research in the light of the repercussions of the pandemic for those who are marginalised, discriminated against, and that inhabit the peripheries of humanity, and the borderlines of 'otherhood'. The catastrophic effects on the most unprotected due to social inequality, discrimination and the systemic indolence of modernity obliged me to stop reflecting on my positionality and moved me towards concrete action. Together with a coalition of Venezuelan women refugees we set up a Refugee-led organisation. The theoretical focus of this chapter became researcher activism and the critical reflections shifted to descolonialising methodologies and to a search for altern methodologies.

Chapter Three Vulnerability

The third chapter starts with an RLO worker giving a lift to Esperanzita on the route of the caminantes (as Venezuelan walkers crossing borders are known). This chapter describes the methodology of the research: autoethnography and vivencia writing. I argue the epistemological justification for the unconventionality of fictionalising the narratives from the research interviews. The research design and implementation are described, as well as, the ethical conundrum of interviewing and conversing online with people for my research during some of the hardest moments of their lives. How the research could be formulated and enacted to focus on community-initiated research rather than researcher- initiated became a central intention. It is a chapter exploring epistemic plurality and methodological disobedience.

Chapter Four: We are Warrior Mothers

The fourth chapter narrates a conversation between three Venezuelan mothers Esperanzita, Xiomara and myself on school placements and navigating (or not) the process of their child's diagnosis within the educational and medical systems. In this chapter I turn to the main theoretical conceptualisations of this research: (dis)ability, mothering and 'othering'. I explore the Descolonial Feminist (DF) methodology of genealogy to find nodes of dialogue between Critical Disabilities Studies (CDS) and Descolonial thinking.

This chapter is the theoretical focus of my initial research questions where I explore what does descolonising (Dis)ability mean. I set out as a mother to seek knowledge production about (dis)ability that is not regulatory knowledge but emancipatory knowledge. I look to localised critiques of imported pathologizing systems that can offer 'other' methodologies to produce knowledge and practises.

Reading the decolonial turn is not a quest to find pre-colombian epistemologies but it is a quest to create multiple threads, stances, and vocabulary that defy the single story of the west, the common sense rationality of western scientific inquiry that I was trained within as a psychologist in Venezuela.

Chapter Five: Intersectional Vivencias

The vivencia in this final chapter is a conversation with fellow colleagues at the RLO that highlights the complex intersectionalities we see in the work we do everyday. I review the notion of intersectionality which I argue can explain the gaps in policies and the resulting invisibility of Venezuelan forced migrant children with a (dis)ability. I highlight the vacuum in research, governmental policies and internal agencies planning in the intersectionality of (dis)ability and forced migration on the continent. A final review of the research questions and methodology takes up Lugones' call for questioning the categorial logic of identity. I dare to frame the epistemological wondering of the abandonment of categories.

I have spent most of this research pondering how to ethically enter into this intersectional research of (dis)ability and forced migration in the Colombian context of the massive Venezuelan diaspora. As an activist researcher I am committed to continue decolonising myself in the work that I do. At the end of this research I hope that sharing issues that have arisen in this descolonial feminist methodological exploration with my colleagues at the RLO can strengthen situating the research we may produce from within our community.

Chapter One Coming Home: Positionality

Chía mi señora   Chia my mistress

dame la chicha de tu valor inmenso   give me the taste of your immense courage

dame a comer en carne   give me to feed in flesh

el odio al invasor.   the hatred towards the invader.

Canto Guerrero De Los Cuicas (López, 2012)   Warrior Song Of The Cuicas (López, 2012

Prelude

This research was initially planned to be carried out in Chile in two schools exploring conceptualisations of (dis)ability from a feminist descolonial perspective. This first chapter is concerned with ethical critical self-reflection arising from the experiences and conversations during a planning research trip to Chile and Colombia that shifted the methodology and context of this research. There are many lines of thought amongst academic descolonial thinkers that focus on fragmentalising and problematising the certainties of the naturalised Eurocentric world premises. In this first vivencia I problematise my own certainties. This vivencia is called Coming Home and it is an autoethnographic story about my research proposal and the start of my research based on journal entries, photos and memories of my trip to Abya Yala (Latin America) in 2019, it sets the scene for the first descolonial turn on the research process and on myself.

Vivencia Coming Home

We started the descent, we could see the contours of the Brazilian coast and the border of the continent. I focused on the practicalities of landing and filling in the form we had been handed for customs. The plane was buzzing with many languages at the end of the long transatlantic crossing. The pilot's landing comments: Welcome to South America choked me up, surprised tears of homecoming. I wasn't landing in my homeland Venezuela but the welcome words unexpectedly assaulted my sense of being home. Excited giggling daughters next to me, happy to be arriving, we had been looking forward to this trip to see family and friends in Chile, Brazil

and Colombia whom we hadn't seen in years. For me this was also a planning trip for my research.

The initial proposal for my doctoral dissertation was focused on using decolonising lenses to conceptualise (dis)ability in alternative understandings from the Western canon. The EdD research planning focused on the question of understanding the conceptualisations of (dis)ability in various communities of Chilean society, and how these understandings are enacted in schools. I was particularly interested in researching the descolonial perspective on understandings of (dis)ability in the Mapuche cultures that are resistant to Western colonial influences and how these differed from mainstream Chilean understandings and the policy guidelines of the Chilean government.

I embarked on the EdD programme motivated by my personal and professional experiences grappling with the processes families go through when their child receives a diagnosis classifying them as different and the impacts for their lives and education. I trained as a psychologist in Venezuela, I was trained in the classic Western canon of knowledge of the psyche sciences but throughout my professional life and master's studies in Early Childhood I had become suspicious of the knowledge I had been trained within. This knowledge was particularly put to the test when two children in my family went through the process of being diagnosed as autistic, one of them being my youngest daughter. As a mum I was motivated to understand how this diagnosis could help (or hinder) my daughter in her school life, and look at the notions of diagnostic labels from alternative critical views.

This planning trip included informal conversations with descolonial Chilean academics in the fields of education, meeting families and hopefully visiting a particular Mapuche community in the south of Chile that actively resists interactions and influences from mainstream Chilean government and society and who works with local academics in directing their own research. This exploratory trip and the meetings I had were prior to a final research proposal and to a submission of ethics so I cannot under university rulings report specific conversations. However their anonymous influence on my changing understandings and research intentionalities was pivotal. In particular, the Mapuche communities I have read about and was interested in are

extremely wary of people outside of the community whether from government orgs, ngos or academics. One academic told me about years of efforts to gain their trust.

My stay in Santiago in the summer of 2019 was coupled with the growing realisation of the extent of the exodus of Venezuelans, at this time the estimated exodus was around the 3 million mark but the magnitude was still not clear in mainstream media now in 2024 it is over 8 million, the largest forced migration of the 21st century (together with the Syrian) and the one that is least reported about. What first struck me in Chile was that I encountered Venezuelans everywhere along its long territory that is 7500 km away from Venezuela. For UK based readers that is equivalent to the distance from the UK to Tanzania. I saw Venezuelans working in all areas of social life in the markets, restaurants, hospitals, petrol stations, shops and offices. In a university canteen of Talca, a city three hours south of Santiago, all the servers were young Venezuelan women who smiled at me with curiosity as a fellow Venezuelan who was on the other side of the client-server diad. My car was filled with petrol by a Venezuelan engineer who told me how he missed his family but was content to know they were able to eat with his monthly remits.

The second striking experience for me was how most Chileans I met reported that Venezuelans were amazingly hard workers and that they contributed so warmly with high energy and enthusiasm to all the endeavours they engaged in. I confess to feeling dissonance. I grew up in a country with a self perception and self-stereotyping of being exceptionally warm, hospitable, happy people and where we celebrated la 'viveza criolla'. This could be translated as 'native wittiness and craftiness' and denotes the idea that work is a survival necessity coupled with an attitude to do the minimum possible using our wit. 'La viveza criolla' is an identity that for many Venezuelans carries a happy go lucky attitude as well as a narrative of shamelessness and mediocrity that corrodes us, many of us work to question and defy it and at the same time have internalised it as well as a normalised attitude. This tattered self esteem of 'la viveza criolla' underlied our national identity as a survival resistance strength in the Venezuela I grew up in. Venezuelans carry with us an inheritance of complacent vileness. I found it so refreshing and energising to hear about the new generation of Venezuelan forced migrants in Chile who were forging a new identity far away from 'la viveza criolla'**.**

The next experience that struck me and has stayed with me happened during the same summer but further north in Colombia. Thanks to the privileges that multiple passports have afforded my family, we are not part of the forced migration exodus of Venezuelans, however due to the situation in Venezuela we have had to spread around the world in the forced exile of not being able to return to our home country not have access to retirement pensions family members were entitled to. Our family encounters are rare treasured events where we make memories, build ties for our children and tell them the history of their roots in Venezuela and Colombia, in the territories where they have never lived.

I travelled with my brother and daughters from Chile to Colombia to see our paternal family whom we had not seen for around a decade, and our second mother, our nana, my mother's best friend. I was also going to meet colleagues of a Venezuelan NGO I had been working with remotely online. This visit was an experience filled with love and the feeling of having never been away from family, and it was also charged with xenophobic attitudes, sometimes surprisingly from the same loving people.

In Colombia the situation was very different from that I had seen and experienced in Chile and it was hard to witness. Most Venezuelans migrating to Colombia were arriving with no money, many of them arrived walking. The borders were still open for those with documentation but those without papers were (and continue) crossing the border illegally with people smuggler gangs committing exploitation and unimaginable abuse. In Abya Yala Venezuelans are not placed in refugee camps as for example Syrians, Iranians, Congolese and Afghans are in other parts of the world. Venezuelans arrive to work and rent or live on the streets, some manage to integrate whilst many live on the margins of society with none of the protections afforded to 'legitimised citizens'. The suffering of the Venezuelans I witnessed was a small window into hard indescribable experiences of social abandonment and survival desperation.

We visited family in Cucuta, one of the most important border towns of the Venezuelan migration to Colombia. Close by is the Simon Bolivar bridge which we had travelled a zillion times in the many summers and Decembers of my childhood. We would cross from San Antonio leaving my native Venezuela for family holidays in my father's homeland of Colombia.

Venezuelans for decades were welcome over the border, Venezuela was bountiful and rich and Colombians opened their arms to welcome Venezuelans. Colombians crossed the border in their millions to find work and make lives in Venezuela, just like my father and my nana. Now Colombia was opening her arms, with much hardship and many complexities, to Venezuelan forced migrants.   It felt like everywhere I went there were Venezuelan families living on the streets, children huddled in precarious places, teenagers asking for work, and people carrying heavy bags or old suitcases - the Venezuelan walkers known in Latin America as 'Los Caminantes' who traverse countries to reach imagined destinations of hope.

There are many images that have stayed with me, not all the images are miserable because I met activists and people finding a multitude of ways to remake their lives and making the active choice to support others. Some images are difficult to remember and impossible to forget. There is one image that keeps coming back to me and was the final push for me to change the direction of my research and stung my awareness of the privilege of my life and research positionality. The scene was while visiting my family in Cucuta. The numbers of people living on the streets in the most precarious circumstances was overwhelming. My family were driving us to dinner at a restaurant, in a dark car with smoked windows. I saw a mother standing at a busy traffic light on a large avenue in a well-to-do area of Cucuta. At the red light, she approached waiting cars with requests for help. Her young child, maybe three years old, sat still in the centre traffic aisle as she moved around the cars. The child didn't look up, didn't move. Our car was next and the light changed, someone in our car said, "this is everywhere now, all the time, you have to be careful, don't get close to them." A few hours later when we drove back to the family home we passed by the same traffic lights, the scene had not changed, the child was sitting in the same place as if frozen in time. The mother's determination to find a way to survive and the child's static body have stayed with me. I am a mother of two. I work with children of this age group everyday, the child's vacant look seemed frozen, in my perception the child had not moved. I saw many families on the streets during my days in Colombia travelling with my Colombian family, the family at the traffic lights in my mind represents the desperation and strength of a mother and of thousands upon thousands of displaced Venezuelans, in actual fact eight million and counting. There have been many others but this scene flipped something for me. An

imperative and an obligation. To do research in a place where I have feelings of belonging and could perhaps have some impact. To use my privilege.

Already having done voluntary work from abroad for a Venezuelan-led NGO in Colombia I felt that the ethical justification of research to mobilise knowledge to help address very real issues became an obligation. It doesn't escape me that my original research project in Chile and this shift now to do the research with Venezuelans in Colombia comes from the privilege of having the financial means and citizenships to travel without worrying about borders. My privilege as a researcher, privilege as a knowledge user, generator or extractor is an ethical responsibility meant I could not now contemplate staying in an exclusive academic stance. A radical change of research proposal and of ethics was required.

In Chile my belonging was tenuous, my connection was that I was Latin American, that I had close family living there, that there was a child in my family attending school there as a person with a diagnostic label. The reality was that I was not rooted in Chilean culture, I didn't belong there and hence the research I realised would be a pompous externalising observation, the total opposite of what I set out to do when I was looking to question conceptualisation of (dis)ability from a descolonial perspective in Chile.

My internalised white-washed, European-labelled-Latina, mestiza-naivety slapped me in the face. The Latina motherly rebellion that was in the pit of my stomach that drove me to question Western conceptualisations of (dis)ability was deeply embedded in the snake pit of the colonialism I grew up in. I felt self-disgust and growing anger at the coloniality my education was rooted in and my first research pause began.

Chapter overview

This first chapter responds to the change of direction of the research arising from a homecoming planning trip that uncovered the imbricated coloniality in the research proposal and questions, descolonial intentions notwithstanding. Responding to this Home Coming autoethnographic vivencia I lay out in this chapter the research methodological implications of realising the inadequacy of the questions planned for in the original research proposal. This chapter lays out the literature review and critical reflections that laid the ground for a change in the research questions. Simultaneously I hope to make explicit how this first change of the research process represents the shift of this thesis moving towards a methodological exploration alongside exploring the conceptualisation of (dis)ability from descolonial lenses. My intention had not been to write about this first research proposal and its failure, but I have come to realise that this first change has been pivotal to the descolonial attitude learning I have undergone as a researcher and as a mestiza mother. I hope that by laying out this thesis as I have, as a narrative weaving the personal, the theoretical, the praxis and the methodology, I can describe my unlearning. I hope to engage you the reader in the route I have experimented rather than laying out a final destination piece of writing. My tutor has very gently and thoughtfully kept reminding me of signposting and clearly telling the reader where I am going. I confess to having felt resistance to this at times, feeling that signposting the terms of reference did not reflect my painful unlearning process central to this research. Actually her reminders have kept you, the reader, in my mind as a dialogue and this has greatly enriched the process of writing for me. I hope I have laid out signposting that helps keep the reader engaged and perhaps follow your own internal dialogue with my process.

In this chapter I start by laying out the research questions from the initial research proposal. These serve as a starting point to weave critical reflections from the vivencia of Home Coming on my positionality, the contextual experience, and theoretical notions from the descolonial turn that I have set out to explore as lenses for (dis)ability. I conclude this chapter with a review of the research question and methodological implications for the research. This is the structure of the chapter:

1. Initial Research Questions
2. How to engage in research on Decolonising (dis)ability In Latin America?
3. The descolonial Turn
   3.1. Resistance to Coloniality in Abya Yala
   3.2. Crossing the Borders of Knowledge Production

   The Theory of dependence

   The Theology of liberation

   Pedagogy of the Oppressed
   3.3. Some central conceptualisations of the coloniality/modernity/descoloniality projects

   The Coloniality of Power of Anibal Quijano

   Colonialism-decolonisation and Coloniality-descoloniality

   Postcolonialism and descoloniality

   The coloniality of gender

   Epistemic Justice and Pluriversal Thinking
4. Methodological Implications
5. Research Questions Review

Initial Research Questions

My initial research proposal was for the research to be carried out in Chile to explore the conceptualisations of (dis)ability in different sectors of education with some constituent members. My intention was to find or even create mini community research spaces in a handful of schools to reflect together with participants about various views on (dis)ability and what implications these may have on the inclusion of children with diverse needs in education. I had contacts with one inclusive school in the capital Santiago where my nephew and his sibling attend and with some academics and a government education official who work in the south of Chile in Mapuche communities. The research proposal set out to review conceptualisations of (dis)ability and proposed the use of descolonial theoretical lenses to uncover underlying hegemonic systems that 'other' children with diagnosed (dis)abilities.

The broad research questions focused on exploring the conceptualisations of (dis)ability from a descolonial perspective were:

- How is (dis)ability conceptualised in other cultures (Mapuche/Aymara/ Chilean/ Latin American)? Is it conceptualised?
- How are these conceptualisations a reflection of internalised colonisation? How are they similar to Western ideas? How are they different?
- How does the Chilean government conceptualise (dis)ability in their inclusion policies?

I had possible further questions such as What does it feel to be a disabled child in various settings in Chile? What do parents' lived experiences of their own and/or their child's (dis)ability reveal about (dis)ability conceptualisations? However, as I wanted to remain open to participants' contributions, I did not in the research proposal consolidate a set of wide and narrower question formulations. I was cognizant of coming into the research with a listening stance towards participants' ideas. In the research proposal I had written:

> To unstitch the universalistic cloak of Western conceptualisations around human diversity I may have to change the research question themselves during the research. From the perspective of Latin American DecoloniaIity I wonder about the validity of formuLating research questions without the research participants input, my hope is that I remain open to listening to the dialogue and to change these questions to what is collectively relevant. (Research proposal Arenas 2019)

In this homecoming trip I experienced a multitude of dissonances. I was back home in South America, I saw family members I hadn't seen for a decade, visited my father's small cobbled home village up in the coffee growing mountains in Colombia. I spent time with people very close to my heart and I saw the terrible hardship of Venezuelans everywhere I went in Chile and in Colombia. My encounter with Chilean researchers during this emotional time stripped me bare, put me in a conundrum. Everything they said reflected my understanding of methodologies that engage in decolonising approaches, this was in line with my notions of the rights of participants to cohabit and co-design research to create knowledge together. There was a contradiction I had to face and I hadn't seen. In my ethical desire to engage in descolonial

research on (dis)ability, in researching something close to my heart and within the borders of my continent, I had imagined a sense of belonging that I did not feel nor have when I arrived in Chile. As I said in the vivencia: "My internalised white-washed, European-labelled-Latina, mestiza-naivety slapped me in the face." I had arrived unaware that I was assuming some connection to a culture by generalising my 'LatinAmericanity' from Venezuela and Colombia to Chile? It took me months to grapple with this, I felt I had fallen back into the hegemonic stance of the researcher that comes to see, that presumes to create belonging with tenuous connections and comes to extract. How could I possibly have thought I was going to carry out some sort of dialogical research in the space of a month within a culture I didn't belong to and why would they see me as an insider? The reality of not belonging hit me from every angle from the Chilean accents to their views on the foreign Venezuelans that were migrating into the country. And then there was the impact of what was happening in the continent with the overwhelming exodus from my homeland, to Venezuelan families and children that were walking the continent: los caminantes- the walkers as they are known.

The questions proposed in the first ethics application for the research in Chile were broad and I was ever hopeful to remain open to hearing with participants about the relevance of the questions and be prepared to change them. And yet I realised that I was presuming to carry out participative research to address these questions, without having addressed my positionality in the context and having not considered how I was presuming to do participative research in communities where I did not belong. I have been northerned, as Anzaldua (1999) describes in her poem 'Because I, a mestiza,'. In Europe I have learned to think of myself as Latina, and I presumed a sense of being an insider. I have had to face the shame of unmasking a research intentionality presuming to disengage from the Western canon and embracing Latin American epistemologies whereas in reality what I was planning would result in a northerned extractivist gaze. I was coming home to explore (dis)ability from the lens of the Latin American descolonial turn, and the emotional troubling of my unexplored positionality propelled the weaving of disobedient fabric into the methodology of my research and the unravelling layers of self-decolonising I continue to experience today.

Maybe, dear reader, this was something that I should have picked up in my descolonial readings, but I didn't. After the trip I read and reread articles and books about decolonising educational research and I saw it all in black and white printed clearly. I think we read what we are ready to read, or I read what I was ready to read. In the abstract, in the imagined landscape of my research proposal I was enacting exploring descolonial methodologies. I thought I was already thinking outside of the Western psychological paradigm I was professionally trained in. But this is not a light switch, it is a weaving and unweaving, I now think peeling the layers of education and inculturation of internalised coloniality will be a lifetime process that permeates every area of my life.

The auto-ethnographic story of the exploratory phase of this research traces my growing awareness of the divide between my understandings of the descolonial turn, descolonial praxis and methodology, the realities of the socio-political present moment and my embodied syncretism of being Venezuelan, white, Latina, European, Welsh, professional of the psych sciences, feminist, rebellious and assimilated, mother of two women. Where to find a place of belonging within the research that didn't feel colonial? This was the start of my exploration on how to reformulate the research questions and I will continue to return to this in every chapter. To unravel these initial questions I turn to looking at why I am interested in descolonising (dis)ability and what are the central conceptualisations in the plurality of thinking within the Latin American decolonial paradigm.

How to engage in research on Decolonising (dis)ability In Latin America?

The initial questions for this research arose from the impetus of weaving together the threads of critical (dis)ability studies and the descolonial thinking. I found few readings with intersections in these fields at the start of this research (Angelino, 2012, 2014; Grech, 2011, 2015; Meekosha, 2011; Meekosha & Shuttleworth, 2009; Yarza de los Rios et al, 2019). Another advantage of the various research pauses is that I had both time to read more widely and more articles and books were published in Latin America on critical (dis)ability studies from descolonial standpoints in what is now a growing field of thought (Danel et al, 2021; Ferrari, 2020; Grech et al, 2023). The possibility of contributing to explorations for decolonising (dis)ability was the initial hope that

drove the research. To be candid, I still harbour that hope, however the articulations of my own self-decolonising from various spaces in the personal, political, cultural, professional and familial nodes of identities force me to unpack a basic tenet assumed within the original questions: the descolonisation by whom?

From my educational and professional experience in Venezuela, where I trained as a psychologist, my experience has been that (dis)ability is conceptualised and discussed broadly throughout Venezuela and Colombia within the same hegemonic theoretical frameworks of the Global North (Schewe and Vain, 2019). Historically in LatAm, we have looked to the North for everything scientific and professional, particularly in the mainstream medical, educational and psychological fields (Mignolo, 2018). The hegemony of knowledge production from the Global North is well established in postcolonial and descolonial literature. I will constantly return to the questioning of hegemonic modern knowledge throughout this thesis and leave it framed in the background of my writing with this striking visibilisation in the map below compiled by Pan et al (2012) using world citation databases to derive scientific publications by country.
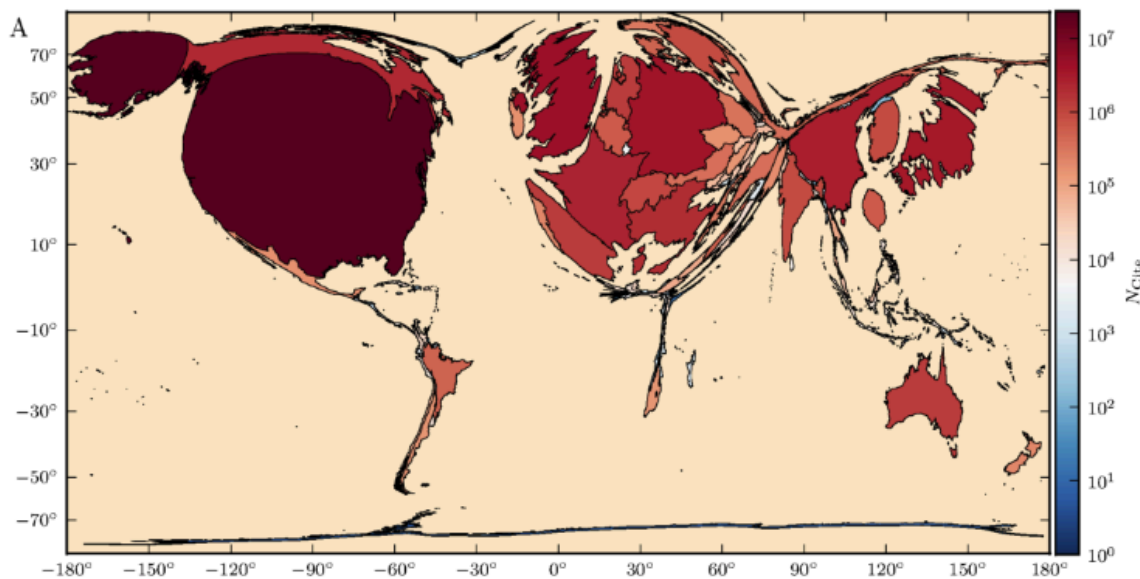
Illustration 1 | Citation map of the world where the area of each country is scaled and deformed according to the number of citations received, which is also represented by the colour of each country. (Pan et al, 2012).

I stepped into the Doctoral programme to explore what is formulated on (dis)ability that originates in the Global North of modern/colonial dominant epistemology and what is lost in the epistemicide of knowledge of the Global South. The conceptualisation of (dis)ability is used in numerous academic fields, health and psyche disciplines, education and therapeutic markets, including psychology, medicine, (dis)ability studies, education, special education, psychiatry, and sociology (Parker, 2007). There is a growing literature on (dis)ability from the descolonial turn contesting the pervasive hegemonic Western lens that places (dis)ability as centred in the individual and as a burden to society and their families. As a professional and especially as a mother and an aunt of children with disabilities I have set out to join the contestations of this deficit individualistic Western paradigm. The exploration of (dis)ability from a descolonial lens is the focus of chapter 4. What I want to establish is my starting point of understanding that the conceptualisation of (dis)ability is viewed in various critical perspectives, and this is increasingly more in mainstream narratives such as the social construction model of (dis)ability partially adopted in the International Classification of Functioning, (dis)ability, and Health (WHO, 2001b). That (dis)ability is also materialised in lives, in bodies, in communities and transgenerationally reproduced within the economic abuse, violence and extortion of the colonial paradigm (Meekosha & Soldatic, 2009) is not a mainstreamed narrative. The power dynamics of exclusion and oppression in (dis)ability are multilayered, complex, transversal and intersectional. Proposals for decolonising (dis)ability cannot be solely theoretical and must go beyond seeking representation of disabled voices, towards changing praxis and attitudes (Danel et al, 2021; Yarza de los Rios, 2019).

In my research proposal I wondered about my use of the term (dis)ability

> However, by naming this group as disabled am I not also staying within the modernity framework? And by discarding the use of the term disabled am I erasing the realities of people with impairments and ignoring the fields of (dis)ability studies and critical (dis)ability studies? To defragment the colonial within (dis)ability studies and to listen to the voices of all those othered, other frameworks of knowledge could be constructed which are not centred on divergence from some hierarchical arbitrary norm. Decolonising (dis)ability is a

project to decolonise what it is to be human and not to be seen as an outsider of humanity. (Arenas, 2018)

In the creation of knowledge about who is human we need to ask ourselves, who defines what it is to be human and who decides what are the categories to be used (Maldonado-Torres, 2016; Spivak, 2010; Curiel, 2021). How do these forms of knowledge affect the lives of people and their status within 'in/human' societies? From inside some descolonial projects more situated in praxis and less inside academia, Rivera Cusicanqui (2010) investigates not only the psychological colonisation of the vanquished native peoples, but also the unwitting collusion between the oppressive structure and racist framework permeating our mestizo psyche in Abya Yala (Latin America). "The internal enemy—colonisation—is within us all, from elites to the oppressed," she says. This articulation of colonisation from within is replicated by feminist decolonising authors. The questionings of the identities of alterity we carry within are fundamental theoretical issues in the descolonial turn: mestizos, non-white ethnic groups, the colonised, the poor, the indigenous, women and I suggest, too, those categorised as dis/abled as these are categorisations of the Global North paradigm of who is human (Espinosa-Miñosa et al, 2021). These are the questionings I needed to uncover in myself if I was to ethically engage in descolonial research.

What happened to me through this research planning trip was an awakening from a historic colonial amnesia, an amnesia that is transgenerational, cross-cultural and global and that is subsumed with layers of assimilation, resistance, rebelliousness, survival, anti-colonialism, internalisation, pro-Europeanism, feminism. I have carried all my life, probably due to my diverse heritages and having lived in different countries, an ever present preoccupation around my identities, my privileges, my invalidations and what spaces I belong in or am excluded from. The marginalised inhabited borderline spaces of human identities are preoccupations that have directed my research interests, and I have found in the descolonial turn a pluralistic lens to learn, but I have a lot more to learn and unlearn about the descolonial turn in Abya Yala, to decolonise myself.

The planning visit to Abya Yala turned my proposal on its head and forced me to review my understandings of what is the descolonial turn, the fundamental concepts of descoloniality and how these can critically inform the research on hand, the methodology and helping to shape my research identity and positionality. The vivencias from my trip were realisations of how hegemonic Global North epistemologies were permeating the design of my research plan, the lived experience of being in Abya Yala highlighted my insider-outsider imbricated positionality and the evolving research design demanded I re-examine in more depth the theoretical threads of descolonial thinking in the light of my embodied experience.

Descoloniality and critical (dis)ability studies are fields of study with conceptual and social justice synergies that are just beginning to be explored within both fields (Danel et al, 2021; Yarza de los Rios, 2019; Grech, 2015; Grech and Soldatic, 2016). In essence uncovering these synergy was the centre of my research project. These ideas are important to me as a mother of a child with a (dis)ability to make explicit the specific rationality of eurocentric thought that has permeated knowledge production and the social sciences, including psychology, education and their derivative fields of study such as special education. It is central to this research to contend that Western knowledge in the psyche sciences, apparatus about (dis)ability, is rooted in dominant white Eurocentric hegemonic knowledge that have dehumanised people.

The centrality of pluralism and the recognition of many other critical epistemologies is an attitude embedded in the fibres of the descolonial turn's insistence of looking for emancipation, change and forging spaces for human plurality, social justice and change of paradigm. It is in these spaces where I am searching for alternative epistemes for (dis)ability and contestations of what it is to be human. In Dan Goodley's (2013) article Distengling Critical (dis)ability studies he suggests that "while we may well start with (dis)ability, we often never end with it as we engage with other transformative arenas including feminist, critical race and queer theories." (pg 631). The terrain in critical (dis)ability studies is open to transdisciplinary paradigmatic troubling (Goodley, 2012; Goodley et al, 2019; Grech and Soldatic, 2016; Grech et al, 2023; Grech, 2015). Descolonial turn activists, teachers, writers and thinkers in Latin America (Danel et al, 2021; Ferrari, 2020; Yarza de los Rios et al, 2019) are exploring the conceptualisation of (dis)ability,

that has been imported into the health care and educational praxis, and asking who is the subject of (dis)ability within the coloniality/modernity frameworks.

To explore the underpinnings of the conceptualisation of (dis)ability through the lens of descoloniality thought (which I will engage in Chapter 4), it is necessary to first lay out the origins, evolution and central theses of The descolonial Turn. This review is important for this research to unpeel the layers of my own internalised coloniality as a researcher. This is the cornerstone of this chapter and a response arising from my planning trip to review my understandings on descoloniality, the methodological implications and next question reformulation.

The Descolonial Turn

In the 1990s, Latin American social thinkers working at universities in Latin America, Spain, and the United States were gaining traction in the effort to deconstruct Eurocentrism focusing on colonialism in social thinking (Lander, 2000). Since the emergence of Latin American descoloniality it has not been postulated as a unified theory but as a collective aim to create a plurality of altern epistemologies that do not answer or conform to the structures of Western thought created and produced in the corridors of academia. There are many lines of thought amongst academic descoloniality-modernity thinkers and social praxis movements that focus on problematising the certainties of the naturalised Eurocentric world premises and exploring the multiple dimensions of the legacy of colonialism in its modern form: coloniality.

Resistance to Coloniality in Abya Yala

At the start of this chapter the warrior chant of the Cuicas gives us a view into the resistance to the invaders of one group of original peoples who inhabited what is now known as the Andean and Plain regions of Venezuela. The Cuicas are part of the Chibcha cultural group and were known as peaceful agriculture communities. The poem is one illustration of the threads of resistance in Abya Yala that were ignited in 1492 in the politics, beliefs, and cultural lives of those of us born in the territory after that date.

Chía mi señora	
dame la chicha de tu valor inmenso	Chia my mistress
dame a comer en carne	give me the taste of your immense courage
el odio al invasor.	give me to feed in flesh
Canto Guerrero De Los Cuicas (López,	the hatred towards the invader.
2012)	Warrior Song Of The Cuicas (López,
	2012)

This last verse of a song from the peaceful agricultural Cuica Etnia in Venezuela is a time capsule of emotions. The song in the original Cuica language may be lost, the language of the Cuicas of Venezuela has not been spoken out loud since the early 20th century when it became extinct- it had survived in small pockets for almost 500 years of invasion. The song is repeatedly referenced in Cuica culture today and is visceral in its hatred of the conquistadores, a resistance to oppression and violence that was silenced in the textbooks throughout all my school years growing up in Caracas. These silences are red threads that run through my education and professional training, that I have been growing in awareness throughout my professional and personal life and that became the focus of this research. Resistance theory frames the narrative around power struggles by viewing resistance as a vehicle for social transformation and justice rather than only shining a light on injustice or resistance to a given authority. (Abowitz, 2000). Resistance to colonial violence in all its manifestations runs through the history of Abya Yala of the last 500 years.

Abya Yala is the name that captures my unexpected feelings landing in Brazil in Coming Home. Abya Yala instead of the term America or Latin America is the territorial name agreed in the World Council of Indigenous People, a name that announces a political and historical position that questions the namings of 'America' and 'New World' by European colonisers and invaders (Oberlin Molina and Chiaradía, 2019; Native Web, n.d). In the Kuna language it means 'land in its full maturity'. Abya Yala is a name that represents the unity of a multitude of diverse peoples across vast territories with a common positionality of resisting and rebelling against the European invasive colonial hegemony. An hegemony that robbed identities and gave a homogeneous label of Indians to over 60 million people in the Americas of thousands of different groups, with diverse cultures and languages.

Descoloniality in Latin America as it is conceptualised today in multiple forms has its roots in 500 years of resistance by the survivors of the indigenous genocide of millions and of the crime against humanity that was the Altantic slave trade. Resistance to colonialism is woven deeply into the fibres of Latin American societies, as deep and secret as our 'mestizaje' (Vargas, 2003). Imagine if you will the weaving of these threads onto the warp of our Abya Yala fibers of local beliefs, lost indigenous cultures and languages, forgotten histories of violence and rape, and the buried truths of genocide and exploitation of the indigenous peoples and the kidnapping of peoples of West Africa and the cultures they brought. This resistance is also woven with strong strands of assimilation and internalisation first to Spanish and Portuguese and later to North West European values of hierarchy, power, christianity, race superiority, patriarchism, rationalism and the enlightenment. The fabric of Latin America is one of imbricated identities of colonisers and colonised, conformers and revolutionaries, winners and losers. We always seem to be less developed, poorer, irrational, exploited, late. As Edoardo Galeano says: "we lost, others won."

Perdimos; otros ganaron. Pero ocurre que quienes ganaron, ganaron gracias a que nosotros perdimos: la historia del subdesarrollo de América Latina integra, como se ha dicho, la historia del desarrollo del capitalismo mundial. *Nuestra derrota estuvo siempre implícita en la victoria ajena; nuestra riqueza ha generado siempre nuestra pobreza para alimentar la prosperidad de otros: los imperios y sus caporales nativos. En la alquimia colonial y neocolonial, el oro se transfigura en chatarra, y los alimentos se convierten en veneno.*(Galeano, 2004, pg 16-17)

We lost; others won. But it happens that those who won, won thanks to the fact that we lost: the history of Latin American underdevelopment, as has been said, is the history of the development of world capitalism. *Our defeat was always implicit in the victory of others; our wealth has always generated our poverty to feed the prosperity of others: the empires and their native rulers. In colonial and neo-colonial alchemy, gold is transfigured into junk, and food is transfigured into poison.* (Galeano, 2004, pg 16-17, Author's italics)

Resistance to hegemony from the Global North in descolonial thinking has also had a strong influence and synergy with marxist thought in Latin America. However many descolonial thinkers have signalled that Marxist thought is also of Western origin, and the focus on the category of class has ignored other fundamental systemic categories. In the genealogy of

descolonial thinking multiple resistances can be found at its roots in the colonised of the hegemonic colonial world system: slavery emancipation revolutions (Curiel, 2021) cosmologies of the original peoples of Abya Yala (Rivera Cusicanqui, 2018), community based feminism to name a few. (Mendoza-Alvarez, 2016).

As Venezuelan and Latina I have been educated and lived in a patchwork knowledge of our colonial history and within a value system perpetuating colonial power hierarchies. Actually I didn't know I was Latina until I left Venezuela to live in the UK, and I didn't realise the extent to which my Welsh, Colombian and Venezuelan cultural identities were imbricated with colonial history.   We, so called Latinas and Latinos, are the mestizaje children of the original inhabitants of Abya Yala, of the kidnapped Africans, of the violent cristian conquistadors and of the mulatos, mestizos and criollos as the races mixed. Our heritage has been to delete our indigenous past, relegate and exoticise African culture and assimilate and look up to the knowledge of the Global North as universal; we have had to look up to the north to survive. I remember as a young teenager in Caracas, having some sense of what it was to grow up in a 'developing country'; returning from a trip to the UK, wondering what my life would have been like, what opportunities may have been different if I had grown up in the UK. I remember feelings of relief because I love my city and culture, but also of wondering what I may be missing.

Latin American and Caribbean histories are woven with forgotten horrific violence, continued oppression, a thirst for survival and powerful resistance. Many forms of resistance have left us indebted throughout our history and into present days. Suffice to name the first emancipatory revolution of the Americas, the first revolution to announce the equalities of all people: the Haitian revolution (Curiel, 2021). This first American revolution that abolished slavery and created the first black state in the Americas, was buried in the history books not as liberal revolution for freedom but as a non-event, a revolt squashed by an alliance of Western powers that incurred a historic debt for Hatians to France. This financial compensation debt continues to oppress Haiti, it has had to borrow over centuries from French banks to be able to pay reverse compensations to the French government for lands and slaves lost and firmly placing Haiti in the position of the poorest country in the world. A debt for freedom still being paid today (Boltax,

2021). The 'debts' and stealing from Latin America and the Caribbean are the economic foundation blocks of Europe and of modernity.

Anibal Quijano (2000), Peruvian sociologist, said we are the continent where Western modernity was invented, the pillage and oppression gave power to European empires that arose from the colonial enterprise. Edgardo Lander edited and published a seminal text in the year 2000 entitled: La Colonialidad del saber: Eurocentrismo y ciencias sociales; perspectivas Latino Americanas; in English The Coloniality of Knowledge: Eurocentrism and Social sciences: Latin American perspectives. The book arose from a collection of essays by the group coloniality/modernity that were written for the symposium: 'Alternatives to Eurocentrism and Colonialism in Contemporary Latin American Social Thought' which was organised in the context of the World Congress of Sociology held in Montreal in 1998.

The book's essays peel through layers of different historical moments of Latin American critical social thought and is one of the bases of the descolonial movement that has been named collectively as the modernity/coloniality group. This group of thinkers did not include many voices from the Latin American feminist movement, with the outstanding exception of Maria Lugones, still its publication opened a polyphony of critical perspectives from Latin America. The books last chapter is written by Anibal Quijano: The Coloniality of Power, eurocentrism and Latin America and is a culmination of his body of work and lays out his influential conceptualisation: The Coloniality of Power that is considered by many (Salgado et al., 2021) as the axis of what has become the Modernity/Coloniality/Descoloniality project (Segato, 2013) also known as the The Decolonial Turn (Maldonado-Torres, 2020). It is one of the few Latin American theories that has crossed the Global South/Global North border in the opposite direction of coloniality, from the south to the north.

Crossing the Borders of Knowledge Production

To make sense of what is the descolonial Turn, the pluralistic thought that has risen from centuries of resistance and its non reliance on one single author or theory, I would like to introduce the voices of Latin American descolonial feminists who have brought an

epistemological multiplicity to descolonial theories. In this section I have leaned on Rita Segato (2013), an Argentinian anthropologist and LatAm descolonial feminist, who is perhaps best known for her research and activism on gender violence in Latin America. Rita Segato posits the conceptualisation by Quijano of the 'Coloniality of Power' as an axis of transformation in global social sciences. She names three theories of resistance thought originated in LatinAmerica that have managed to migrate across the south-north global borderlines of knowledge production and that can be seen as the intellectual ground for Anibal Quijano's The Coloniality of Power. Segato labels these as the twentieth-century philosophical foundations for Latin America's descolonial project of the twenty-first century (Moreno, 2015).

These three significant strands of intellectual resistance in Latin America that Rita Segato (2013) refers to are the Marginal or Dependence Theory that broke with Development Theory in macroeconomics, The Theology of Freedom developed by catholic priests in central America and the Pedagogy of the Oppressed by Brazilian Paolo Freire. Clearly many other theories, ideas, literatures, social movements have formed and brewed in Abya Yala that are of radical importance within the Abya Yala territory to counter the histories and herstories that have laid the ground for descolonial thinkers.

I have chosen to focus on Segato's chosen three vocabularies of knowledge that have crossed borders from the Global South to the Global North as this contextualises the difficulties of knowledge production in Latin America and reminds us of the power hierarchies in global knowledge production. I briefly describe these three foundations that give context to the descolonial turn.

The Theory of Dependence

The theory of dependence, developed in the 1960s, critiques the modernist theory of development endeavour as a universal goal. Perhaps its best known author internationally, was the Uruguayan journalist and writer Edoardo Galeano. In the publishing of 'The Open Veins of Latin America' (Galeano, 1998) Galeano exposed to a wider mainstream audience the fallacy of how so-called underdeveloped countries might progress towards development by imitating the

example and programmes of self-named developed countries in Europe as well as the United States. This modernist progression was regarded to be accurate, despite the fact that the development initiative had begun during a historical period when the international economy was already organised under imperial rule, constructed by extracting riches from 'underdeveloped' nations that were oppressed, hierarchised and exploited (Lander, 2000).

Galeano says of the continuation of imperial rule in post colonial nations:

> We do not in these lands attend to the infancy of savage capitalism, rather to its bloody decrepitude. Underdevelopment is not a stage towards development. It is its consequence. The underdevelopment in Latin America boosts foreign development and continues to feed it. Impotent due to its function of international servitude, dying since it was born, the system has feet of clay. (Galeano, 2004, pg 363, My Translation)

Galeano (2004) explains clearly here that the modernist colonial paradigm was the source of subdevelopment, acting as a guide for exploitation. The veins of Latin America were opened in 1492 and are still being drained today. The open veins was a significant paradigm shifter in Latin America in the 1970s and is seen as one of the foundations of anti-globalisation movements and dependency theories in Latin America (Galeano, 2004; Lander, 2000).

The Theology of liberation

The second strand named by Segato (2013) is the Theology of liberation (Silva, 2009), another strand of intellectual opposition that crossed international borders. It was established by Latin American Catholic priests with varying degrees of influence of Marxist ideas and born out of the experiences of co-living with poverty. Its two main goals were to tackle poverty by serving the poor and to acknowledge the humanity of those living in poverty as subjects rather than objects. Theology of liberation as a theological and social movement arose in Abya Yala and was taken up around the world as a theology that questioned the social justice roots of poverty. It questioned from its beginnings the notion of "other", is rooted in perspectives of social solidarity and in praxis, it has given a political dimension to the Catholic Church's mission in Latin America (Mendoza-Alvarez, 2016; Gutierrez, 2002). The movement has questioned

government brutality, economic oppression and many of its upholders have been assassinated; six priests in El Salvador murdered by right wing extremists have been high profile cases. In the 60's Theology of Liberation took hold in the public imaginary of a devout Latin America, it is a theory rooted in a historical geo-political moment when globalisation, religious plurality and the increasing pauperisation of peoples in LatAm challenged the critical consciousness of religious groups working in communities (Gutierrez, 2002). It is a movement that continues to be reinvented in new currents of plurality and diversity in and beyond the borders of Latin America. The Black Theology of Liberation movement that arose in the 1960's civil rights movement is one example (Cone, 2012) amongst many more theology of liberation currents such as Latin American feminism, Intercultural theories, Indigenous theologies, Asiatic Theology of Liberation, Dussel's Ethics of Liberation (1997), Jewish, Palestinian and Islamic currents of Theology of Liberation (Mendoza-Alvarez, 2016). That catholicism itself is part of colonial conquest and theology of liberation stems from catholicism but also departs from its political structures and transforms to a hermeneutic theology, is just one example of hubris of hybridity that is Latin America (Fernandez Alban, 2015). This border crossing of the theology of liberation also highlights how paradigms can be questioned and are constantly critiqued from within hegemonic Western structures of knowledge, power and politics. Theology of liberation placed injustice, the marginalisation of groups of people and poverty firmly in a political social responsibility praxis not only a solidarity arena (Gutierrez, 2002).

Pedagogy of the Oppressed

The third strand that Rita Segato (2013) names as predating The Coloniality of Power and transcending borders in a global scope is Paolo Freire's Pedagogy of the Oppressed. Probably the most well-known Global South resistance to hegemonic knowledge within education has been Freire's (1993) pedagogy of 'conscientizacao', a critical thinking pedagogy originally developed for teaching adult literacy as a form of critical awareness and liberation. Freire set out a pedagogy where the people learning to read and write decided through reflective encounters with the teachers what knowledge, what transmission of culture they were interested in to inform the curriculum. Freire's Pedagogy of the Oppressed (1970) offers a Latin American lens in an overt political objective of democratising education and has been influential globally. Freire used dialogue as the

methodology of pedagogy, of educational research and as the means to achieve *conscientização* –that is awareness of contextual reality, awakening critical thinking between people to create political awareness (Freire, 2005, p52-59). Freire viewed the aim of traditional Western schooling as a pedagogy based on banking, depositing knowledge with the aim of normalising learners as the exercise of indoctrination to the views of the dominant elite. These elites can be political, economic, scientific, religious and/or cultural.

> "One cannot expect positive results from an educational or political action program which fails to respect the particular view of the world held by the people. Such a program constitutes cultural invasion, good intentions notwithstanding." (Freire, 2005, p 95).

I have quoted these words by Freire in multiple moments in my professional life and writings. They were ringing in my ears during my trip to Chile and Colombia with the plans I had made from Europe giving me a growing unease. He also tells us that we are oppressors at the same time that we are oppressed, when we see the contradictions between our actions, our intentions and our thoughts and words this is the point of transformation of self and of action (Freire, 1996). My internalised coloniality was coming to the surface, uncomfortably gnawing at my assumed descolonial attitude towards the research. Freire's (2005) insistence that researchers and pedagogues search for the meanings that are important to the community of learners, is the foundation of curriculum, democratic education and dialogic pedagogical practice. They are also the building blocks of participatory research pioneered in Colombia by Fals Borda (Fals Borda, 2009; Rappaport, 2020) and theatre of the oppressed of Augusto Boal (Tolomelli, 2016) that have subsequently also become influential beyond Latin American borders and spread around the world. The continued influence of Freire's pedagogical thinking, his concepts of conscientizacao and of transformation for liberation have permeated critical pedagogy globally and when his legacy has been questioned or as O'shea (2013) says misunderstood, the continued relevance and new currents of Freirean philosophy resides in the hope for transformation through an ethics of community agency that infuses Freire's thought (O'shea and O'Brien, 2013).

Segato (2013) posits these three strands of thought as the Latin American theoretical predecessors of Anibal Quijano's powerful conceptualisation of the coloniality of power that I describe in the

following section. These three theories or movements erupted in Latin America during the decades of the 1960s and 1970s highlighting a historical moment on the continent seeking epistemic disobedience and alternatives to the strategies of development coming from the north (Fernández Albán, 2015). Segato's (2013) argument of these three theories within the vast repertoire of Latin American thought within the social sciences are of the very few that have crossed global knowledge production borders, highlights the persistent dominance of the eurocentric paradigm that dissolves and dissipates knowledges created outside of the anglo-european scientific borders. The breaking down of the contained borders of global knowledge production by fragmentalising and problematising the certainties of the naturalised Eurocentric world paradigm is precisely what Quijano's Coloniality of Power demands and does.

Some central conceptualisations of the coloniality/modernity/descoloniality projects

Reviewing the wide and diverse literature on descoloniality produced in LatAm or by Latin Americans in Global North universities, I think there are two fundamental notions that need grounding before delving into descolonial concepts. Firstly, descoloniality and the descolonial turn is not one theory, there is not one single movement and crucially there is not an intentionality to place descoloniality as an epistemology on the other side of a binary of coloniality. This is not a bilateral thought process of one epistemology confronting another. There are clear differences, ruptures, tensions, commonalities and pluriversality within descoloniality. To reduce descoloniality to some binary opposition to coloniality would be on the one hand simplistic and reductionist and on the other hand would be ignoring the very pluralism of thought that descolonial thinkers are calling for in their turn away from modern/colonial thought. Secondly, it is important to recognise that descolonial thinkers tap into many alternative critical perspectives that have arisen from within the Global North. Just as there are Global North powerful elites and enclaves in the Global South, and Global South lived experiences in the Global North equally there are epistemic ruptures, critical thinkers, theories and activist movements from within the Global North hegemonic knowledge system that explore descolonial thinking. There are a plethora of oppositional critical resistances to modernity as established by the Western paradigm within the West. Although as befits a pluralistic descolonial thought paradigm there are some descolonial thinkers who are less inclined to align themselves with altern critical stance from the north (Mignolo, 2021) there are those who see dialogue as essential for transformative paradigms (Castro-Gomez, 2005, Lugones, 2003). Next I outline a few essential descolonial terms as reference for myself and for the readers that I will make reference to and develop throughout this thesis in my process of self descolonising.

The Coloniality of Power of Anibal Quijano

Anibal Quijano's notion of The Coloniality of Power is central to the conceptualisations of the coloniality/modernity/descoloniality project; it is seen as a paradigm shift in the social sciences in Latin America and beyond. His article 'Colonialidad del poder, eurocentrismo y América Latina' (Lander, 2000) is the culmination of a body of work that went beyond a transdisciplinary

view to a macro, interdisciplinary, systemic, historically situated pluralistic vision of the constitution of the modern globalisation paradigm born in the Americas. His conceptualisation has creatively captured and condensed resistance thinking in Latin America and triggered a change of paradigm that is now known as The Decolonial Turn as coined by Maldonado Torres (Castro-Gómez, 2008).

> Therefore, this lengthy essay (Quijano 2000a) establishes itself as a hinge, not only representing a new stage in Quijano's thought, but also as the first opening point of an entire agitating movement in the social sciences and humanities, not only in our Latin America and the Caribbean, but also elsewhere, thanks to the work of Latino intellectuals attached to northern academia and of others who attend gatherings of greater global impact (Salgado et al., 2021, pg 200)

Radically Quijano places the racial codification of difference at the centre of the social power relations in the "discovery" of the Americas. For Europeans, the New World was a separate world whose peoples were codified and negated. The history of inequality is as old as the history of humanity. However Quijano, and Decoloniality thinkers, states that the differentiation of humans not based on their history or culture or political structures but rather described as 'natural', 'biological', beyond the realism of history, as a universalising scientific categorisation was new. Anibal Quijano says the colonisers didn't ask: Who are they? rather What are they?

The construction of race was not based on a history of power relationships but rather on an anthropocentric rationalist epistemology, an indigenous European rationalism that hierarchises peoples in a dualism of nature-rationalism. The creation of hierarchy of 'otherness' and negation of the humanness of the 'other' was reified in all spheres of political, social, scientific, ethical, moral, economic, religious, and aesthetic realms of human relationships. Thus it is the start of a new world order, collaborating with the 'modern world-system' of Wallerstein (Wallerstein & Núñez, 1999) in the social sciences, Quijano (2000) charters the history and establishment of the Colonial-Modern world system. In the previously mentioned and most widely read article 'La Colonialidad del poder, eurocentrismo y América Latina' (Quijano, 2000) starts with the words:

La globalización en curso es, en primer término, la culminación de un proceso que comenzó con la constitución de América y la del capitalismo colonial/moderno y eurocentrado como un nuevo patrón de poder mundial. Uno de los ejes fundamentales de ese patrón de poder es la clasificación social de la población mundial sobre la idea de raza, una construcción mental que expresa la experiencia básica de la dominación colonial y que desde entonces permea las dimensiones más importantes del poder mundial, incluyendo su racionalidad específica, el eurocentrismo. Dicho eje tiene, pues, origen y carácter colonial, pero ha probado ser más duradero y estable que el colonialismo en cuya matriz fue establecido. Implica, en consecuencia, un elemento de colonialidad en el patrón de poder hoy mundialmente hegemónico. (Lander, 2000, pág 201)

The current globalisation is, first of all, the culmination of a process that began with the constitution of America and that of colonial/modern Eurocentric capitalism as a new model of world power. One of the fundamental axes of this power pattern is the social classification of the world's population on the idea of race, a mental construct that expresses the basic experience of colonial domination and that has since permeated the most important dimensions of world power, including its specific rationality, Eurocentrism. This axis is thus colonial in origin and character, but it has proven to be more durable and stable than the colonialism in whose matrix it was established. It implies, therefore, an element of coloniality in the pattern of power that is now globally hegemonic. (Lander, 2000, pg 201)

Quijano (2000) puts forward European colonisation of the Americas and the European colonial invention of race as the essential preconditions to understand the globalised modern world system. The emergent dynamics of power and hierarchy at the start of the spanish and portuguese colonisation of exploitation of resources, production by means of exploitation of labour and slavery, created a new pattern of social hierarchies, division of labour, social relations based on capital and domination that Quijano contends was a structure that is historically and economically new. The conquistadors, those in the future to be known as Europeans, correlated unpaid work with the dominated races, because they were inferior races: the indigenous peoples, the Africans, the mestizos. Unpaid work was naturalised. This new pattern of social domination that imposed a systematic division of labour based on race is what Quijano names the coloniality of power. Simultaneously, it also forged new patterns of social resistance.

Quijano, throughout his work, extensively dives into the historical processes and creation of the new rationality and the justifications for social dominations on peoples who were categorised "objectified' with a universal rationality. He expands on the moments when the Iberian peninsula was the central control of power, he labels the Spanish and Portuguese Empires as the first modernity moments that failed, and how the empire and power was transferred to northern occidental Europe with the installation of the empire of the Hamburgs that sweeps Iberia into a backwards spiral, and of course the British empire that gets a firm grasp on trade throughout the continent and the Caribbean. Quijano goes on to argue how the modern/colonial world system that was eurocentric redefined global capital relations where the coloniality of relations of power redefined the identities of Orient, Africa and Oceania.

In his essay Quijano also states an idea that is striking and to me speaks of the state of the globalised modern world today more succinctly than I have read or heard elsewhere. He said that the impossibility of the modern world is based on the paradox of inequality-freedom. The Western democratic episteme of equality and freedom for all and the creation of various charters of human rights are in stark contradiction to the episteme of the industrialised capitalist extract, produce, sell, consume on demand model of the global modern world. The extractivism of coloniality persists today in the trade, banking, industrial and information systems that characterise the global economy we live and work within. Modernity as we know it exists on a bed of redefinition of relationships in the colonial episteme based on the naturalisation of racism and a justification of inequality that is a modern paradox when confronted with the notions of freedom and human rights. Quijano labels this epistemic conflict as probably the most important conflict of our times. If I look at the big themes in critical (dis)ability studies, such as (dis)ability rights, right to take decisions, right to dignified lives, questioning what it means to be human, all of these seem to find a place within this paradox of inequality-freedom that Quijano shines a light on. Themes I will expand initially on more extensively in chapter four: Decolonising (dis)ability.

To contextualise these ideas I remind myself of Quijano's conceptualisation of the coloniality of power as a description of the modern world system as being rooted in colonial structures: the flip side of modernity is coloniality. A coloniality of power that perpetuates modes of social and political relations in the modern world that are based on the racialisation of labour, the associated

relationship of unpaid labour, oppression and violence on those categorised as 'other'. I recourse to Quijano's own words to prescribe the regionality of the Eurocentric knowledge system with its universaling impact around the world:

"No se trata, en consecuencia, de una categoría que implica a toda la historia cognoscitiva en toda Europa, ni en Europa Occidental en particular. En otros términos, no se refiere a todos los modos de conocer de todos los europeos y en todas las épocas, sino a una específica racionalidad o perspectiva de conocimiento que se hace mundialmente hegemónica colonizando y sobreponiéndose a todas las demás, previas o diferentes, y a sus respectivos saberes concretos, tanto en Europa como en el resto del mundo." (Lander, 2000, p. 219)

"It is not, therefore, a category that involves the whole of the knowledge of history in the whole of Europe, nor in Western Europe in particular. It does not refer to all the modes of knowing of all Europeans and in all ages, but to a specific rationality or perspective of knowledge that was made globally hegemonic by colonising and overpowering all other forms of knowledges, previous or different, and their respective concrete knowledges, both in Europe and in the rest of the world." (Lander, 2000, p. 219)

Colonialism-decolonisation and Coloniality-descoloniality

Maldonado-Torres (2016) in his seminal and passionate article 'Outline of Ten Theses on Coloniality and Decoloniality' published by the Fondation Frantz Fanon states the importance of differentiating between colonialism and decolonisation from coloniality and descoloniality. He clarifies that colonialism and decolonisation are concepts that specifically refer to particular episodes of social, historical and geopolitical empires and their termination. From the stance point view of modernity and the epistemology of rationality, colonialism and decolonisation are in the past, they are history:

"They become objects for a subject that is considered to be already beyond the influence of colonialism and the imperative of decolonisation. In like manner, from this perspective, those who make the questions about the meaning and significance of colonialism and decolonisation inevitably appear as anachronic—as if they exist in a different time and therefore can never be entirely reasonable." (pg 10)

Not only does Maldonado-Torres (2016) clarify the epistemological rationality of how modernity views colonisation and decolonisation as firmly in the past, he also firmly uncovers the hierarchical damnation stamped by modern northern eyes on viewing colonisation as anything but in the past. Inspired by Frantz Fanon's Black Skin, White Masks, Maldonado-Torres writes about the fear and anxiety imbued in modernity which covers a hypocritical form of rationality when colonialism is brought to the fore. Quijano's concept of coloniality of power shakes the certainties of rational modernity.

So moving on to distinguish colonisation and decolonisation from coloniality and descoloniality, the latter refer to the matrix of power relations and of economic structures, the matrix of European epistemologies and the logic rational thinking that remain beyond independence and decolonisation of the Americas. When Quijano coined the term coloniality he was bringing attention to the continuity of colonisation and denied the idea of so-called postcolonialism. Quijano (2000) and Maldonado-Torres (2016) assert how Western eurocentric knowledge and Western civilisation itself were also born in empire and colony, they did not exist before and their very existence today relies on the continuation of its universaling, hegemonic, rationalistic extractivist practices and discourses to maintain the modern Western eurocentric civilisation model. Coloniality encompasses the naturalised premises of what is knowledge, coloniality implies that colonial knowledge and structures are the dark side of modernity. In other words, coloniality is the flip side of modernity.

If coloniality refers to the hegemony of modern Western culture originated in colonisation in all its manifestations economic, political, administrative, scientific, judicial and cultural then descoloniality refers to all resistances and movements away from coloniality.

"If coloniality refers to a logic, metaphysics, ontology, and a matrix of power that can continue existing after formal independence and desegregation, decoloniality refers to efforts at rehumanizing the world, to breaking hierarchies of difference that dehumanize subjects and communities and that destroy nature, and to the production of counter-discourses, counter-knowledges, counter-creative acts, and counter-practices that seek to dismantle coloniality and to open up multiple other forms of being in the world." (Maldonado-Torres, 2016)

It is clear from these contentions that descoloniality is not a simple idea, it is a re-reading of history and present knowledge systems, it is a way of life, a way of singing, it is broad, it is about anti-oppression of peoples and living creatures and the territories we live in, it is all encompassing, brave, confronting, compassionate, relational, it is related to many models of living, spiritual practices, aesthetics and to many epistemologies (Lugones, 2003). Descoloniality is many perspectives that speak to lives all round the world, it is not pre-modern knowledge but non-modern and includes practices that are counter to modern practices and that in Lugones (2010, abstract) words propose 'not an added reading to modern life', not an addition on the checklist of decolonising at our workplaces but a re-reading of modernity. Many of us think this is an essential re-reading of life that our survival and that of our planet desperately need. This is a rereading of my life and positionality I am engaged in coming into the research.

Postcolonialism and descoloniality

Another important distinction is between the terms postcolonialism and descoloniality, their alliances and differences. Postcolonialism is a term very familiar within Western academy, Edwards Said's Orientalism marked an important moment in Global North social sciences Castro-Gomez (Moraña et al., 2008) in his chapter "(Post)Coloniality for Dummies" says that Latin American Coloniality group have approached coloniality/modernity differently than postcolonial theory. He argues extensively that postcolonial thinking does not address the particularities of colonialism in Latin America. Using Dussel's notion of Epistemic Colonialism (Dussel, 2005), Mignolo's (2011) ideas on Occidentalism and Quijano's Coloniality of Power

(2000), he tracks a historic re-reading of postcoloniality and coloniality. Castro-Gomez (2008) acknowledges Said's clarity in Orientalism by establishing that one of the characteristics of colonial power in modernity is that of dominance and subjugation based on the ontological discourse of the "Other". This alienating and assimilated discourse both in the minds and cultures of the colonisers and the colonised is what gave Europe's power over colonies during the Western Empire. The othering discourse also created the myth of the orient.

However descoloniality/modernity group theorists argue that Orient came into existence as a mental exoticism created by Occident in the 18th century. Whereas, they argue, the conception of the West itself, of Europe as the supreme empire came to being after 1492, in the extreme West, in the Americas. That Western civilisation, with Western europe as the nucleus of power and hierarchy, is what will give rise later to orientalism. There is no orientalism without the creation of the West, there is no Western civilisation or Europe without the colonisation of Abya Yala (Castro-Gomez, 2008; Moraña et al., 2008)

Both fields of thought Descoloniality and Postcolonialism share the critique of modernity and Western thought as 'othering' and place racism at the root of the power dynamics between East (Orient), West (Europe) and extreme West (The Americas). The fields complement each other in their unmasking of oppression and domination based on othering, however they depart on the geographical and historical origins of Western othering. For descoloniality thinkers *t*he origin of coloniality is therefore placed firmly in the invasions and conquest of the Americas, historically situated; they call this the first modernity that defines the European hierarchisation of humans.

There is another more fundamentally radical difference between postcolonialism as represented by Said, postcolonial thinkers in Asia and Africa, and the descolonial turn represented by the Latin American coloniality/modernity group (Castro-Gomez, 2008; Moraña et al., 2008). This is that Latin American philosophy formulates a critique of colonialism that emphasises its epistemic nucleus. It is a colonisation of economic, social and political structures but it is above all an epistemic colonisation. It is the episteme of rational technological science that offers value free, naturalised and universal representations of the world that are objective and hence are true knowledge (Dussel, 2005). It is this omnipotent god's view of reality of objective Western

science which Castro-Gomez (2005) calls the hubris of zero degrees. The Greenwich line of knowledge reference.

What is of interest to me in particular as Latin American women researching 'othering' is this notion of epistemological critique. To uncover that the knowledge funds of the enlightenment have their roots in racism and colonisation has been for me an awakening, my own anti-enlightenment. What are the implications of this epistemological critique for understanding (dis)ability? One particular distinction relevant to my explorations of 'othering' is something I wish to put at the centre of this thesis so I would like to introduce now in this first chapter: The coloniality of gender.

The coloniality of gender

In his description of social colonial relations based on race, and the naturalisation of race as the bases of the domination of a white superior race, Quijano (2000) names previous social relations that can be said to form the historical backdrop to racial hierarchy, the previously well rehearsed gender hierarchy; patriarchy.

Históricamente, eso significó una nueva manera de legitimar las ya antiguas ideas y prácticas de relaciones de superioridad/inferioridad entre dominados y dominantes. Desde entonces ha demostrado ser el más eficaz y perdurable instrumento de dominación social universal, pues de él pasó a depender inclusive otro igualmente universal, pero más antiguo, el inter-sexual o de género:los pueblos conquistados y dominados fueron situados en una posición natural de inferioridad y, en consecuencia, también sus rasgos fenotípicos, así como sus descubrimientos mentales y culturales. (Lander, 2002, pg 203)

Historically, this meant a new way of legitimising the old ideas and practices of superiority/inferiority relations between the dominated and the dominant. It has since proved to be the most effective and enduring instrument of universal social domination, for on it came to depend another equally universal but older one, the inter-sexual or gender one: conquered and dominated peoples were placed in a natural position of inferiority and, consequently, so were their phenotypic traits, as well as their mental and cultural discoveries. (Lander, 2002, pg 203)

Many descolonial feminists argue that the coloniality/modernity project excluded women's views and Latin American feminist perspectives and that Quijano and others did not explore the connections between race and gender within coloniality. Maria Lugones (2010, 2007) introduces the concept of 'the coloniality of gender' starting from the framework of Quijano's central conceptualisation of 'the coloniality of power'. In her initial presentation of the "coloniality of gender" Lugones states that it is politically important to make clear that many who have taken the coloniality of power seriously have tended to naturalise gender, inadvertently re-enacting and entrenching the very oppressions of patriarchal colonial naturalised categorisation they are contending to contest. This moment marks a significant tension within descolonial perspectives highlighting how elements of the colonial/modern world system persist even in the creation of altern perspectives. Her thinking highlights the entrenched mesh of coloniality within descoloniality, our internalised coloniality and is an important red thread throughout this research: what does it mean to decolonise knowledge and ways of producing knowledge, who needs decolonising?

Lugones (2010) argues that the coloniality of gender and the patriarchal system that she places as originating in the colonial project highlight the profound fusion of race and gender in the dehumanising episteme of coloniality. She writes extensively of the generation of these categorical logics that subsume the rationalistic episteme of the eurocentric knowledge production of the Global North and in the power relations that women experience in social, interpersonal and intimate realms of daily life.

> I understand the dichotomous hierarchy between the human and the non-human as the central dichotomy of colonial modernity. Beginning with the colonization of the Americas and the Caribbean, a hierarchical, dichotomous distinction between human and non-human was imposed on the colonized in the service of Western man. It was accompanied by other dichotomous hierarchical distinctions, among them that between men and women. This distinction became a mark of the human and a mark of civilization. Only the civilized are men or women. Indigenous peoples of the Americas and enslaved Africans were classified as not human in species - as animals, uncontrollably sexual and wild. The European, bourgeois, colonial, modern man became a subject/agent, fit for rule, for public life and ruling, a being of

civilization, heterosexual, Christian, a being of mind and reason. The
European bourgeois woman was not understood as his complement, but as
someone who reproduced race and capital through her sexual purity,
passivity, and being homebound in the service of the white, European,
bourgeois man. The imposition of these dichotomous hierarchies became
woven into the historicity of relations, including intimate relations. (Lugones,
2010, pg. 743)

An important departure between Lugones and another descolonial feminist Segato is the debate
around the origin of gender and the patriarchal hierarchical system of power and knowledge.
Lugones (2010) firmly places the origin of this particular patriarchal paradigm in the
colonisation of the Americas and the development of categorial thought of race and gender to
justify oppression. Segato (Segato and Monque, 2021) contends that no anthropologist can deny
the existence of gender inequality in societies barely touched by colonisation and previous to the
colonisation of the Americas. However, where she does agree with Lugones is in the scope of
patriarchy. Segato contends that pre-colonisation the patriarchal ideology that varied throughout
many societies was of "low impact", that is women's role in society was deemed important and
often also they were seen as inferior. For Segato (Segato and Monque, 2021), the crucial
difference is that the patriarchy of modernity, born in colonial America, is of high impact
because it became femicidal and genocidal. She contends it was the rationality of modernity that
brought the factory of death. Historically, Segato's argument makes sense when we put it
alongside the European witch hunts that started in the 15th century and lasted well into the
1800's (Chollet, 2022).

This origin of patriarchy story has wide implications in viewing gender as the first root
discriminatory category of 'othering' that in colonial thought was used as an epistemological
rational basis for hierarchical discrimination and oppression. If we follow Segato, the well
rehearsed discrimination and inferiorisation of women is a foundational practice and defining of
an epistemology of 'othering'.

The Coloniality of Gender became the foundational notion of descolonial feminism in Abya
Yala, enclaved with the notion of descoloniality and questioning the Eurocentric definition of
who is eligible to be human. As well as Quijano's foundational concept of the coloniality of

power, Lugones (2010) draws on other essential descolonial concepts. Firstly, the coloniality of being posited by Maldonado Torres developing Fanon's zones of being and non being, where the damned of the earth inhabit spaces of violence and enslavement denied of humanity due to their inferior status in the construction of who is human (Curiel, 2021; Miñosa- Espinosa, 2021;). Secondly, Lugones and descolonial feminists have drawn from the development of the concept of the coloniality of knowledge outlined by Castro-Gomez (Curiel, 2021; Castro-Gomez, 2000). The traditional Western eurocentric modern positivist paradigm proposes that knowledge should be universal and objective. This modern episteme of thought has been positioned as neutral, impartial in what Castro-Gomez (2005) names the 'zero-point hubris' and is itself localised European ethnic knowledge with a penchant for dualisms and an arrogance favouring of rationalism over 'emotionalism'. The questioning of Western cartesian knowledge is well rehearsed within European philosophy (Escobar, 2018), however the location of the knowledge producers as privileged male European thinkers with privileged lives who can afford to produce abstract universal knowledge from the god eye position is the genealogy at the centre of the coloniality of knowledge. The place and the who enunciating local knowledge as universal runs parallel to the socio-economic political seats of the empire in the geographies of the Global North. So the discourse of modern science is a colonial discourse where the naturalisation of superiority of some men over others and of some knowledge over other constructs a cognitive hegemony and an epistemicide of other forms of knowledge (Castro-Gomez, 2005).

The final concept I wish to present here that Lugones leans into is intersectionality developed by black feminist in the United States, Crenshaw (1991) and Collins (1986). This pivotal idea has become central to Latin American feminists in afro-caribbean, indigenous, marginalised, lesbian and queer, afro-Latino and indigenous mestizo communities of praxis and thought. I will return to intersectionality in great depth in chapter four but it is relevant to keep as a backdrop the imbricated complexities of (dis)ability within the Latin American context as I will contend that descolonial feminists in all their multiple thinking have perhaps the most to contribute to understanding (dis)ability from descoloniality perspectives.

Epistemic Justice and Pluriversal Thinking

In the descoloniality paradigm, descolonial projects and peripheral border thinking there is a call for plurality, a rescuing and construction of epistemologies that not simply counter the hegemonic positivist rationalist form of Western knowledge which has been globalised as universal and true, but opens epistemic spaces for confronting and collaborating various altern paradigms (Mignolo, 2021; Escobar, 2012.) As Escobar (2012, 2018) says, in a world that is increasingly wounded by social and ecological crises, new discourses are emerging in response to the need of transitioning to other pluriversal models of social-natural worlds.

Maldonado-Torres (2016) Tenth thesis: Decoloniality is a collective project points also to the notion of pluriversality. Emancipatory projects arising particularly in groups that have been denied basic human dignity with dialogues amongst cultures and social groups (Maldonado-Torres, 2016).

According to Escobar (2018) social groups working for emancipation and subaltern cosmopolitanism are well placed to define their own forms of modernity in a pluriversal framework. Rivera Cusicanqui (2018) in her exploration of the notion of "ch'ixi" -loosely meaning imbricated, non homogeneous mix of identities- talks of heterogeneous, confused, polychromatic, variegated societies where local histories, practices and technologies are interlaced to define various new localised modernities. All these authors in a variety of conceptual forms point to the diversity of living forms that have been denied a seat at the table of policy, decision making and rights agendas (human rights, ecological rights, animal rights). Spivak (1988, 2010) proposed the term epistemic violence to refer to this silencing. There is an inexhaustible diversity calling for and creating new epistemologies. Epistemologies for global justice.

The notion that is repeatedly found throughout descolonial writings is the insistence on the production of many epistemes, not one alternative to the dominating Western episteme but many options. Mignolo (2021) says to think of options, a pluriverse of altern epistemes, gives the space to understand that the hegemonic Western eurocentric paradigm has been the dominant option but it is but one option. Escobar (2018) says: "we are facing modern problems for which there

are no longer modern solutions" (pg 67). To propose one altern episteme would take us down the same route of hegemonic and discriminatory practices.

I would like to close this section with the notion of relational worlds or ontologies following from the pluriversal and epistemic justice concepts. There is a clear direct line from pluriversality to cooperation between emancipation struggles of all kinds (Maldonado-Torres, 2016). Struggles and movements are often reduced to specific demographic constituencies in 'interest groups' by neoliberal practices (Roshanravan, 2014) and consequently the knowledge production arising in these movements remains exoticed, marginalised, devalued and silenced. Escobar (2018) talks of relational worlds, and I wish to name a few examples of relational coalitions or geo-body-political knowledges that embody epistemic delinking and justice (Mignolo, 2009) in that they have migrated to other movements, geographical or social imaginary spaces. The Bantu's philosophy of Ubuntu, the Quechua and Aymara cosmovisions of 'Buen Vivir'(Good Living) incorporated into the national constitutions in Ecuador and Bolivia with rights for the environment are all philosophical stances that have travelled to other movements around the world (Torres-Solis and Ramírez-Valverde, 2019). The (dis)ability movement's slogan 'Nothing about us without us' (Charlton, 1998) adopted by other social justice movements like the refugee movement. In LatAm descolonial feminism, black feminism conceptualisation are central points of reference and theory construction (Espinosa-Miñoso, 2021), in queer studies and critical race studies are weaving with and into critical (dis)ability studies (Goodley, 2013), indigenous knowledge used as reference in ecological movements (Escobar, 2007); there are multiple pluriversal forms of knowledge producing groups and coalitions delinking from the Western episteme (Mignolo, 2021) and engaging in epistemic disobedience in relational forms and worlds.

The epistemic relational world I am interested in and that concerns this research are the recent growing explorations on descolonising (dis)ability in Latin America. During the various pauses of my research intellectual, academic and pedagogical movements interested in (dis)ability and descoloniality have grown. I will explore what can be understood about the conceptualisation of (dis)ability as it is described in the mainstream dominant theories of the Global North and from the lens of the descolonial turn in Chapter 4 (Dis)ability: The descolonial hope of being. How are

resistant ideas from the majority Global South world in cognitive solidarity with critical (dis)ability studies? Where are the overlaps in these movements and fields of study? Humanising peoples through alternate counter- hegemonics that strive for cognitive and social justice in a recognition of the plurality of forms of life is, I suggest, a common ground between critical (dis)ability studies and the descolonial turn and descolonial feminism in particular. However, given the ethical issues on insider/outsider and positionality arising in Vivencia Coming Home, I first need to address the methodological redesign of the research, an ethical and responsible research.

Methodological Implications: Critical Self-Reflexivity for Self-descolonising

What I learned during my trip, what I saw and felt made me realise that having a descolonial research intentionality of listening was not enough. From descolonial perspectives, from critical theories and now from my lived experience, questions about belonging, privilege, authorship, motivation, insider-outsider positions, and who was going to benefit from the research came to the forefront. Critically I was starting to realise that coming with a research design with formulated themes and questions into spaces where I was not invited and did not belong was troubling, uncomfortable, unauthentic and perpetuating of the very notions I was attempting to question. The flip side of my methodology was colonial. The methodology was not as straightforward as coming in with good intentions of listening. Freire's words ringing in my ears. I realised as a researcher I had to deal first with methodological and positionality awareness. Is this research more relevant and authentic as the story of my personal learning of designing descolonial research? Can this be relevant to others, how and to whom?

Maldonado Torres (2021) says decoloniality is a verb, descoloniality is action, is constant movement, it is not a metaphor (Tuck and Yang, 2012). In this sense the fundamental methodological principle I adhere to is a call to action, to awareness, to critical self-reflexivity, a self-descolonising life and to descolonise the methodology.

The descolonial turn in epistemology has laid bare an understanding of the modern Western global world system by stating that 'the flip side of modernity is coloniality' (Mignolo, 2011).

This phrase became an anchor for my thinking throughout this thesis, and it is a foundational notion to think through the methodological design. It is also foundational to the structure I have played with for this piece of academic writing where I have chosen to not follow the traditional thesis structure. The writing of this research as a narrative of my vivencias is a procedural attempt intrinsic to the descoloniality learning I have gone through during this research and itself is part of the de-methodology I explore. In engaging in self-reflexivity I have used autoethnography as Dutta describes:

> "... as a site for interrogating the coloniality inscribed into the very production of knowledge, working through the reflexive turn inward to imagine subversive communicative structures for knowledge production that challenge the contemporary organizing of political, economic, cultural, and social colonization."
> (Dutta, 2018, pg 96)

I have started this thesis writing with autoethnographic narratives before I make explicit the methodology I have engaged in. I will address descolonial altern methodology in the next chapter.

Research Question Review

I came to this research as a mother looking for altern forms of understanding (dis)ability and have been confronted with unpacking my own internalised colonisation. I initiated this research motivated to explore what the descolonial turn can offer as critical lenses for understanding (dis)ability? I asked:

- How is (dis)ability conceptualised in other cultures (Mapuche/Aymara/ Chilean/ Latin American)? Is it conceptualised?
- How are these conceptualisations a reflection of internalised colonisation? How are they similar to Western ideas? How are they different?

After my trip witnessing first hand, in Chile and in Colombia, the exodus of Venezuelans in the continent and realising my presumed belonging in Chilean culture was my own northerned internalised Latina colonisation I shifted the context of my research to a space where I already

had some participation in, namely NGOs I had been supporting in Bogota working with Venezuelan migrants. In the ethics application (Appendix One) I requested to carry out the research in Bogota with Venezuelan migrants where I had NGO, cultural and family connections, I reformulated the main conceptual question as:

> "How do Venezuelan children and their families, embodying the intersections of forced immigration and (dis)ability, experience migration and inclusion into communities and schools in Colombia and back in Venezuela?" (Arenas, 2020)

The methodological revised questions that I needed to answer to be able to engage in any exploration of (dis)ability research as I aspire to were a review of what descolonial research is and how to enact it? These methodological questions included:

- How do I design ethical descolonial research?
- How can I delink from the methodologies I have been trained in to enact?
- What do descolonial methodologies look like in action?
- Do I need to descolonise myself, and how?
- How do I decolonise this research?

Coming Home led me to question the location of my research and search for a re-location to which I was genealogically, geographically, culturally, emotionally and epistemologically connected to. Fundamental methodological and ethical questions about my positionality were raised.

Chapter One Summary

Dear Reader,
My positionality is a constant sentipensar reweaving you will encounter throughout your reading of this thesis. I cannot authentically write in the first person and attempt some academic rigour of

knowledge that purports expertise without the nitty-gritty unpicking and disentangling of the weave and threads that are the heirloom of my education and training.

In this chapter, I have addressed some of the fundamental conceptualisations of descolonial thinking in Abya Yala. Descoloniality/Modernity/Coloniality thinking permeates every chapter and, returning to resistance, it is in descoloniality that I wish to explore other understandings of what it is to be human, to resist the Western Globalk North paradigm on (dis)ability.

Looking to explore (dis)ability from descolonial lenses in Abya Yala has brought up methodological questions and a self-decolonising unravelling. The trip to Chile and Colombia uncovered the need to change the context and the methodology, in fact to redirect the research itself as a methodological research that required a review of the research questions. The reformulation of research questions, the resetting of the research and the focus on experimenting with descolonising methodologies, is where I turn to in the next chapter, as well as dealing with the impact of the global COVID pandemic.

Chapter Two Tent Research and 'Metodologías Otras'

<div align="right">

Because I, a mestiza
Continually walk out of one culture
And into another,
Because I am in all cultures at the same
Time,
Alma entre dos mundos, tres, cuatro,
Me zumba la cabeza con lo contradictorio.
Estoy norteada por todas las voces que me
Hablan

(Gloria Anzaldua, 1999, pp. 256–257)

</div>

Prelude

This chapter is a continuation of the autoethnographic story of my research. In the first chapter, planning to carry out the research in Chile gave me pause to rethink my research intentions, my internalised colonialism and my positionality. In the vivencia of this second chapter: Tent Research, the methodological doubts and questions of chapter one are suspended above the void of the pandemic. Dear reader, maybe you are thinking, is this another autoethnographic story of how the research unfolded? When are we getting to the substance of this research? Indeed what is the substance of this thesis? I am aware of the unconventional writing style and structuring of the thesis.The descolonial 'escrevivencia' of this thesis is the intention of sharing my vivencias with you as they unfolded to communicate the process behind my struggles and endeavours to learn how to carry out descolonial research with the people I have worked with and for. This vivencia tells of a huge shift in the whole research and doctoral process for me with the setting up of a not-for-profit RLO in collaboration and coalition with Venezuelan women. This experience focused critical reflections on descolonising methodologies which is the theme of this chapter.

Vivencia Tent Research

I am online at night, sitting safely in a tent somewhere on the border between The Netherlands and Germany. My instagram account for a fundraising border walk is exploding, 500 plus followers is bemusing for someone who didn't have an instagram account two weeks before. Some people are contacting me about how to donate, but most messages are from Venezuelan people in Colombia, intimate private messages constantly searching for solutions through as many avenues as possible to desperate moment of life:

a family without any legal documents asking for legal help in Bogota,

a mother who hides her children in a room while she goes out to work

a mother who has walked for days to arrive in Bogota with her two children,

a man who had received no pay for a week's work

a mother whose disabled daughter is being excluded from school

a family who want to walk back to Venezuela who had arrived last month before lock down and were desperate for their next meal

a mother whose child has an autoimmune disease and they are sleeping on the streets

an evicted family with three children under ten paying for daily rental accommodations

a mother whose 19 year old down syndrome son is depressed because he can't work in mechanics as he had done in Venezuela

a mum whose teenage autistic daughter is being excluded from school

a family living on the street with a baby

a mother desperate to know if I can help her find work

My research plan had been to spend the summer of 2020 in Bogota with one of the Refugee Led Organisations I had been volunteering for remotely and collecting funds for their work supporting Venezuelan *caminantes* arriving into Bogotá. I had reviewed my research proposal and ethics and moved the research location to Bogota. I intended to immerse myself in the work of the RLOs for a two month period and conduct group interviews with staff and the families they supported focusing on those who had children with or without a diagnosed (dis)ability. Now the pandemic has come with extremely harsh impacts on the continent and an unexpected and unwelcome obstacle to the research visit. Worryingly the RLOs I have been in contact with and

collaborating with at a distance are losing funding resources, they are crumbling whilst attending to multiply impacted Venezuelans who have lost informal incomes and have no health care access.

Frustrated that I could not travel to Colombia, I started an online funding project to raise awareness and money for Venezuelan refugees in Bogota during the pandemic. I decided to walk the borders of the Netherlands and Germany, where outdoor movement was still allowed. I have been walking for Venezuelan caminantes who walk the whole of the Abya Yala continent looking for new places to rebuild their lives. And hence I find myself in a tent in the summer of 2020 receiving instagram messages.

It is striking for me during this border walk that although the instagram page is asking for donations a great majority of the messages I receive are not for donations, they are requests for services, for sharing a story, for connecting. In the middle of one Dutch night I have a conversation with a mum looking for medical help for her child in Bogota. I refer her to one of the RLOs for Venezuelan refugees in Bogota with whom I have contact, this midnight scenario is repeated every night of the 12 days I walked. However, many of the refugee RLOs in Bogota I was referring to were struggling during COVID with a disintegrating volunteer workforce just when the people they attended most needed their services. Equally they reported that the large international NGOs seemed paralysed. The reality during this pandemic is that the small RLOs are working tirelessly but do not have the resources to deal with the overwhelming issues at their doorstep.

I began to reflect on the inadequacy of the questions I had initially set out to explore on the conceptualisations of (dis)ability and inclusion in education whilst here I was encountering people who were being excluded from all areas of society and dis-abled to live dignified lives owing to global definitions of citizenship. I couldn't imagine interviewing people about these ideas when they were in desperate moments of their lives. How was my exploration of western conceptualisation of what it is to be human from a (dis)ability and descolonial lens relevant to people's lives?

I had to decide what to do next regarding the research . Take a break? Reformulate the research? Ethics amendments again? I entered into contact online with various groups of people, people I had planned to meet and work with in Bogota, refugees and forced migrants, some who are volunteers and create networks to support fellow refugees. All the COVID obstacles that blocked my research trip led to unimaginable online connections and led to actions that I could never have foreseen.

After my border walks and funding collection I kept in daily contact with a couple of the Venezuelan women I had collaborated with online, a human rights lawyer and an administrative accountant. We had, through previous international fundraising, made contact with a human rights advocacy group that was forming a new international alliance of Refugee Led Organisations. They invited us to join the alliance, which implied funding for Venezuelan refugees in Colombia, if we could legally form a Refugee Led Organisation in Colombia, which we decided to go ahead and do.

It would be an understatement to say that the process of starting a nonprofit Refugee Led Organisation (RLO) as an outcome of our connection and activism has been a monumentally huge task. For me it has been the most beautiful outcome of entering this doctoral program. Our collective action responded to my research doubts and questions by opening an activist route away from the planning of research that felt more like an extractivist exercise. The question that had kept me awake in the tent was: How could I ethically interview people who were asking for help? Collaborating on the start of the RLO has given me a sense of direction, of purpose, of working with a community. It has moved me away from the sense of research exploitation, privileged positionality and betrayal that I had been feeling and instead moved me to a collective, towards acts of love, of connection and re-imagining my presence in the world differently. Silvia Rivera Cusicanqui, Paolo Freire, Ochy Curiel, Rita Segato, Katherine Runswick-Cole, Nelson Maldonado Torres, Maria Lugones, some of my favourite thinkers and writers, all talk about epistemologies and practices in pedagogy and research based not only on intellectual curiosity but on love, solidarity and social justice. This joining with Venezuelan women felt right. An entry in my journal highlights how the RLO took over my research space and how right that felt:

The context of my research is far away from where I live at present. I am
from Caracas and am living in Amsterdam. From afar, together with over 6
million displaced Venezuelans, we watch the disintegration of our
homeland. My privileged days are filled with the normality of a professional
life in Europe and my nights by stories in the news, social media, from
friends, family and colleagues about the Venezuelans who are fleeing in the
largest human migration ever known in the Americas. In Colombia and with
the people I am working with remotely, the stories are of work exploitation,
premature deaths, xenofobia, hunger, sexual exploitation, exclusion, of loss
and grief, of walking thousands of kilometres, and of the will to survive to
make a better life for theirs and their children's future. Setting up the RLO is
the only action that makes sense to me now, the research would be self
serving.

The pandemic has been the backdrop of my research time. It has made more visible the
inequities in the world between richer and poorer countries, between people with privileged lives
and full access to human rights and those who are denied this access, between rich and poor,
citizens and non citizens, young and old, those seen as 'normal' and those who are categorised as
not 'normal', those who have access to health and safety and who do not. In Venezuela people I
knew and in my family succumbed to the pandemic. In particular we witnessed as an RLO how
forced migrant Venezuelan children who had been in schooling in Colombia had severely limited
access to digital learning during the pandemic. In this sense they joined the many already
excluded children from school due to poverty, (dis)ability exclusion, lack of school placements
and refugee/migrant status exclusion amongst many other reasons. The structural inequities that
Venezuelan forced migrants had been struggling to survive within worsened and the gaps in the
social support networks they relied on became gaping holes. The previously ignored
precariousness of their lives became during lockdowns totally invisible, silenced and often fatal.
My interests and readings on descoloniality, critical disability studies, critical theories and
learning about migration influenced the decisions I took, but it was the pandemic and the
injustices I witnessed that have impacted the direction of my life in unpredictable ways. A few
months into the RLO set up I wrote in my research journal:

For some time I have dwelled in a warped research space where every
time I was poised to write, the weave has become a knotted mess of
threads of ethical doubts, of global pandemic practicalities, and of feelings

of despair, betrayal and solidarity for people of my home country
Venezuela.

I had by this point written five assignments, a research proposal, and was re-applying for ethics
to turn to online research. But I had uneasy feelings. As Venezuelan novelist Karina Sainz Borgo
has described, many of us who could get out of Venezuela and make lives elsewhere thanks to
dual citizenship or financial or professional privilege carry a 'survivors' guilt on our shoulders.

I requested a leave of absence from the university in September 2020 that I was unsure about
ever returning from, as I grappled with a day job in The Netherlands and an online night time
work volunteering with a group of Venezuelan refugees organising ourselves to build support
networks in Colombia and form a RLO. I requested the leave of absence citing both personal and
academic reasons. Personally, I am a full time carer for my elderly mother who has some chronic
conditions and is well into her 80s and the pandemic required adjustments to our home life to
keep her safe. On the academic side, I wrote in the leave of absence request:

> Due to Covid, the nature of my research work in Colombia is not possible
> as previously planned and I am in the process of redesigning what it looks
> like online and I am establishing contacts and a network that I can
> collaborate with online. Plus the RLO I work with remotely in Colombia
> and was doing the research with, are in COVID crisis with the refugees and
> I am supporting them with an international campaign to help alleviate some
> needs. It is not the moment to focus on the research.

My choice was to move towards epistemologically, ethically and practically prioritising the
community over my research. Surprisingly, the pandemic also gave me space to do new work in
collaboration with a collective of women and to rethink the purpose, need and methodology of
this research if indeed I would return to it. After some months of working with the RLO I did
come back to the research, there were stories I felt were important to tell and it could be useful
for the RLO to explore a methodology for us to collect and retell stories. This placed the research
as an act that could be done within the frames of social justice praxis and academic activism. I
decided that I would interview women who already had received help through our RLO or whom
we had referred to other civil society organisations for support. In these interviews the idea of
how to co-write narratives of lived experiences became the methodological question. These

explorations gave rise to the narratives of Esperanza, Xiomara, Angeles, Mariana, Rosemary all of whom are based on conversations with women I talked with. They said these are things that we will never forget, we cannot forget them.

In the safety of my tent I thought of Esperanza, standing between traffic lanes with her children, waiting for the lights to change to red to ask for money. In my mind she embodies the fears, the struggle and the inner strength of people excluded and ostracised. Her firm stance of resistance and survival is a statement that separates her from definitions of victimhood and oppression, rather she is calling out from the borders: we are alive, we are human, we are capable, we have rights.

Chapter Overview 'Metodologias otras'

This chapter investigates descolonial altern methodologies or 'metodologias otras'. Exploring my identities of being a mestiza living in Europe, and through the notion 'The personal is Political' I explore descolonising myself and this research. Through understanding the impact of my experiences as an activist-academic I put forth a shift in the research questions away from exploring conceptualisations of (dis)ability towards experimenting with 'methodologias otras'(Ortiz Ocaña et al, 2018), that is altern methodologies that can enable a descolonial exploration of (dis)ability.

In exploring the where and the how to do the research during the pandemic, the previous methodological notions of participation and positionality, that were already a challenge owing to the erratic precarious lives of Venezuelan forced migrants, became more difficult to achieve through online interviews. A methodological review and redesign were needed. Therefore, this chapter should be read as the heart of the methodological exploration of this research. I thread the theoretical literature on descolonial and qualitative methodologies with critical self-reflections from Tent Research to describe an emergent research design, responsive to the research experience. These are the sections of this chapter:

1. Descolonial Methodologies: paradigmatic shifts
    1.1. Descolonising myself
          Borderland Identities
          The Personal is Political
    1.2. Descolonising the research to engage in descolonising (dis)ability matters
2. Activist scholarship
    2.1. The Context and Activist Scholarship
    2.2. Ethical Considerations
3. Methodological Implications
4. Research Questions Review

Descolonial Methodologies: paradigmatic shifts

In the growing descolonial literature on methodologies (Barnes, 2018; Curiel, 2021; Darder, 2019; Ferrada y del Pino, 2017; Ortiz Ocaña, 2017; Patel, 2016; Thambinathan & Kinsella, 2021; Tuhiwai Smith, 2012) there are many complex and rich explorations of multiple epistemologies from the Global South. In Latin America these explorations have their origins in the participatory methodologies developed in Latin America by activist academic Fals Borda (2009) in Colombia, influenced by Paolo Freire (1974) in Brazil, both of whom focused on participation and collaboration as methods focused on pedagogy and activism for social change and justice. Explorations of descolonial methodologies expose tensions between the traditional western methodological canon and altern collective forms of knowledge production that respond to 'epistemologias otras' that is 'altern epistemologies' (Ortiz Ocaña, 2017; Barnes 2018; Tuhiwai Smith, 2012; Patel, 2016). The work of dismantling western epistemology together with recognising a pluriverse of epistemologies (Escobar, 2012; Mignolo, 2009) is to acknowledge practices and collective knowledge production that are in favour of historically oppressed groups of people taking control of their lives (Maldonado-Torres, 2016). According to Espinosa-Miñoso (2014) descolonial feminists cultivate a practice that roots knowledge production in historical and geographical spaces, laying the intention of providing alternative perspectives on the world and de-centering dominant knowledge. Curiel (2009) places the descolonising of knowledge firmly in the space of questioning the relationship between knowledge and power.

Mignolo (2009), one of the founding members of the colonial-modernity group (Lander, 1993), calls for epistemic disobedience and that descolonial methodologies need to question the sacred traditional western scientific precepts of objectivity, neutrality and universality and labels these notions as the 'ethnic European enlightenment western code'. In his book The Darker Side of Western Modernity he calls for breaking this 'western code' of knowledge (2011), following Quijano's (2000) precepts of the modern world knowledge system as colonial and racist, Mignolo (2011) proposes descolonial epistemologies that must lay bare the western code of knowledge production by questioning it, delinking from it and acknowledging altern knowledge epistemes. The unifying themes of descolonial epistemologies and methodologies are to move away from one dominant and hegemonic knowledge world system towards a pluriverse of

epistemologies (Escobar, 2020) with the express purpose of making visible the lives of those historically oppressed and enable them to move towards dignified lives. The notion 'colonialidad del saber' (coloniality of knowing) is at the heart of the descolonial project (Lander, 2000)

> "Whereas the work of decolonizing is, on one hand, to mark, name, and pull apart this often-obfuscated, secularized politics of knowledge production, on the other hand, decolonizing work actively participates in the production of knowledge that resists the forms, processes, and effects of contemporary forms of cultural, social, spatial, economic, and political colonization." (Dutta, 2018)

Descoloniality questions the roots of knowledge, resists being included in one broad discipline of thought and equally probes the methodology of knowledge production (Anzi, 2021). Formulating what a descolonised methodology could look like in my context I have looked principally, but not exclusively, to descolonial feminist praxis and thought in Abya Yala (Curiel, 2009; Lugones, 2011, 2021; Medina Martin, 2018; Paredes, 2017; Rivera Cusicanqui, 2010; Villalón, 2024), to Latin American descolonial methodologies in educational research (Ortiz Ocaña, 2017; Ortiz Ocaña et al, 2018; Pereyra, 2021; Tolomelli, 2016; Torres, 2006), to critical (dis)ability methodologies (Acevedo, 2022; Goodley et al, 2019; Grech, 2015; Gronvik, 2009; Minich, 2016; Schalk, 2017), to critical decolonising methodologies (Barnes, 2018; Cannella & Lincoln, 2018; Chawla & Atay, 2018; Dutta, 2018; Harari & Pozzebon, 2024; Hernandez, 2019; Patel, 2016; Pelias, 2005; Thambinathan & Kinsella, 2021; Tuhiwai Smith, 2012) and to a lesser degree critical migration studies (Eastmond, 2007; Jacobsen & Landau, 2003; Landau, 2019).

The growing realisation of the centrality of how I implemented the methodology to perform descolonial research shifted the research focus and questions from conceptual to methodological, something I will expand on throughout this chapter. The impact of my positionality and privileges in the research relational spaces refocused my attention to the uneven power dynamics I naively thought I could circumnavigate in collaborative activist intentionalities. As I connected with people and became active in working in collectives in the RLO I questioned my research objectives and it became clear that the only route I felt was ethical was focusing on methodology. As a mother and a Venezuelan I knew that the choices I made in the methodology had to be in harmony with my values of social responsibility and a caring research stance. Descolonial

feminism starts with the fundamental premise that in knowledge production we must recognise the place from which we start, from where we produce knowledge and how this knowledge is produced from our intersectional identities (Collins, 1986; Haraway, 1988; Leyva Solano, 2018). In this epistemic localisation positionality is a space of knowledge production as much as the geo-political contextual space (Anzaldua, 1999; Leyva Solano, 2018; Mohanty, 2003). Hence, the knowledge we produce is a representation of our positionality within a given context.

Entering into and working in the spaces for the research I felt the binary insider/outsider didn't fully describe the complexity of my identity role within the research. Moving away from doing research in Chile, as described in chapter one, was certainly a straightforward feeling of being an outsider but in Colombia this was different. I came to the online research in Colombia as a Venezuelan woman who was labelled 'latina' when I left my continent but also -although I squirm to write it in black and white on this digital paper- I came back home to Latin America dressed up as a privileged latina that looked like a westerner. Navigating my 'mestiza borderlands' (Anzaldua, 1999) and growing in awareness of the multiple and contradictory threads of research epistemology I was pulling from is not fully resolved in this thesis, I will continue to unlearn for the rest of my life. What became clear was that my personal and professional history also needed excavating and descolonising if I was to learn how to perform ethical descolonial research and to do ethical collaborative work in the RLO. Developing a critical consciousness moving towards a descolonised methodology I have found it essential to descolonise myself (Fanon, 1963; Maldonado Torres, 2020; Rivera Cusicanqui, 2010; Tuck and Yang, 2012). Samuel and Ortiz (2021) interrogating how to descolonise psychology, weigh out Tuck and Yang'(2012) contention that decolonisation cannot be used as a metaphor to absolve western epistemic colonisation with Maldonado-Torres and Fanon's emphasis on the developing of a descolonial attitude. They conclude that:

>   …"decolonizing the mind" is about more than developing a critical consciousness… and may indeed be an essential piece of descolonial praxis in psychology(Samuel & Ortiz, 2021, pg. 4)

So, by placing the decolonisation of self at the centre of the research reformulation, it becomes clear that more is required than simply exploring the *mestiza* genealogies of my imbricated positionalities. What's crucial is examining how this critical consciousness is enacted in

practice—that is, focusing on the praxis of the methodology itself. Tuvali Smith (2012), Barnes (2018), Tuck and Yang (2012), Ortiz Ocaña (2017), Maldonado Torres (2020) and Bell (2018), amongst others, alert about the importance of interrogating descolonising methodologies to avoid inadvertently reinforcing the very systems that it critiques. Rivera Cusicanqui (2016) firmly voices her concerns from Bolivia regarding the re-enacting colonial hierarchies and of knowledge production by Latin American descolonial authors who inhabit northern academic spaces. To attempt to learn and enact methodologies within a descolonial turn, it is essential to imagine what this means in the context of the research in Colombia with Venezuelan forced migrants and the relationality with which I enter into the space.

Engaging in self-descolonising and developing a critical consciousness, how am I avoiding absolving my northern-southern mestiza identities and northern professional training and falling back to colonial research methods? I have found relevant themes in the literature that informed the research design to investigate descolonising methodologies. I now explore the following themes: descolonising myself and how to descolonise the research.

Descolonising myself

In his influential article 'Delinking', Mignolo (2007) invites all of us involved and committed to the Decolonial Turn to think about how to descolonise the mind (knowledge) and the imaginary (being). Despite having read, planned my research and felt I was within critical perspectives, I realised that I had planned research enactments if not with western eyes, definitely with western internalised colonial mestiza lenses. Or as Anzaldua (1999) poses, I have been 'northerned' in my education in Venezuela and in my professional experiences in Europe. To perform a descolonial methodology I am committed to self-decolonisation, therefore I explore critical reflection on my borderland identities.

Borderland identities

My personal and professional identities within which I stand in this research are coloured by my professional and academic experiences and interests in Critical Disability Studies, Early Childhood, and Critical psychology. I am reading within these fields as a Latina mother of a diagnosed child and through multiple descolonial concepts, particularly latin american descolonial feminism. Exploring my identities and positionality has signified engaging in reflexivity as to who I am, what am I doing in this research space and why am I doing it? Bell (2018) in her designing of pedagogical responses to descoloniality asks the researcher to consider: What is motivating me to ask my questions? Who do these questions serve? and What are the politics behind the questioning? Tuhiwai Smith (2012) and other descolonial feminists and disability critical researchers pose similar lines of questions which I will expand on further ahead in the research questions section.

Critical reflections on my identities signified understanding the genealogy of the various socio-historical spaces I grew up in, have been educated in and those I now inhabit. (Medina Martin, 2018; Ciriza, 2015; Espinosa 2014 y 2016; Segato, 2013; Jofré, 2012; Anzaldúa, 1999; Lugones, 2011). My pluri-cultural identities, my motherhood and critical perspectives learning have placed me at odds with my western based education in a Global South context and have opened up spaces to explore epistemology from an intercultural pluriverse perspective (Escobar, 2018; Mignolo, 2018; Lugones, 2003). Gloria Anzaldua in her book Borderlands/La Frontera (1999) shines a light on living interculturally, between cultures, on embodying multiplicity.

In the last lines Anzaldua says in Spanish that she is a soul between many worlds, embodying and buzzing in contradictions "I have been northerned by all the voices that speak to me" (Anzaldua, 1999, p 194, my translation) and she puts centre stage the radical importance of recognising the projection of history in our mestizo Latinx lives. That is a mestizaje that is imbued in a historicity of resistance, adaptation, survival, subversiveness, and a tolerance for ambiguities. This is a notion of mestizaje not as a rich fusion of multiculturalism but rather about identities on cultural 'borderlands' (Anzaldua, 1987) filled with antagonism and ambiguities. Mignolo (2007), describes Anzaldua's underlining the awareness of being mestiza as a break away from the universalising epistemology of social sciences discourse of othering. Anzaldua places knowledge production from within our lived ambiguous lives, as a tolerance for ambiguity and to transcend subject-object duality, to reinterpret history rupturing oppressive epistemologies. This notion of 'mestizaje' in border zones of culture is deeply explored by the Bolivian Aymara sociologist Silvia Rivera Cusicanqui (2010) in her descriptions of the Aymara notion of 'ch'ixi'. In Aymara culture, 'chi'xi', is something that is and simultaneously is not. Rivera Cusicanqui uses 'ch'ixi 'to describe what mestizaje is not: not a harmonic fusion of internalised colonisation nor is mestizaje a celebration of multiculturalism. She calls it a logic of the 'othered', the third that is not described but is present. Rivera Cusicanqui uses 'ch'ixi' to describe mestizo culture as:

… la co-existencia en paralelo de múltiples diferencias culturales que no se funden, sino que antagonizan o se complementan. Cada una se reproduce a sí misma desde la profundidad del pasado y se relaciona con las otras de forma contenciosa. (Rivera Cusicanqui, 2010, p 70)	… the co-existence in parallel of multiple cultural differences that do not fuse, rather they either antagonise or complement each other. Each one reproduces itself from the depth of the past and they relate to each other in a contentious manner. (Rivera Cusicanqui, 2010, p 70, My translation)

In the research I found myself navigating a multiplicity of cultural identities as well as professional identities, at the same time belonging to the psyche apparatus and navigating '(dis)ability' as a family, being privileged with a descolonial view and migratory allyship with underprivileged families. I am a mother searching for altern spaces of knowledge production that afford the children in my family and those I work with, access to their rights to education and to self determination.

I am a mother of two women, one with a diagnosed (dis)ability,
I am a mother of two women, one with a sibling with a diagnosis
I am a woman born and educated in the (ex)colonial territory of Venezuela, labelled as latina in Europe
I am a daughter of a Welsh mother from a mining valley community in The Rhondda, labelled as British
I am a daughter of a Colombian father who fled to Venezuela due to political persecution during the Colombian ten year civil war (1948-58) known as La Violencia, labelled as a foreigner
I am a daughter of a medical doctor and an academic, the first in their families to go to university
I am a professionally trained psychologist in Caracas, in the Global South but within the western hegemonic scientific psych paradigm of the Global North,
I am learning about the history of my continent
I am a co-collaborator with Venezuelan refugee women in Colombia
I am a professional living and working in a system of privilege in Europe as an expat,
I am navigating Europe as a Latina
I am a carer for my elderly mother
I am a Latin American crossing cultural borders living globally

I am a sister, cousin, aunt whose family live nostalgically globally

I am a researcher within a UK university: Early Childhood MA and now a Psychology and Education DEd candidate, looking at my home country with mestiza westernised eyes

I am a professional supporting parents and children who are labelled as different

I am a professional working within early years community

I am a Venezuelan filled with nostalgia for my homeland and weekend dancing

The Personal is Political

The emblematic 1970s feminist slogan 'the personal is political' attributed to Hanisch (1970) alludes to the recognition of how women's daily lives are shaped by inequitable systemic patriarchal structures. Although there have been arguments as to how this slogan is diversely interpreted by second wave, third wave and intersectional feminisms and which feminist activist practices can be labelled as political, it remains a powerful idea that permeates diverse feminist movements and thinkers (Schuster, 2017). In her seminal text 'Under western Eyes' Mohanty (1988) drew attention to what was left out of critical feminist thinking in the North, namely the personal lives and political realities of third world women; she called out northern feminism as ethnocentric universalism. Listening to localised and contextual lives within the notion that 'the personal is political', I agree with Schuster, is a common ground for Global South and north feminisms. This is exemplified by the group Iniciativa Mesoamericana de Mujeres Defensoras de Derechos Humanos (The Mesoamerican Initiative of Women Defensors of Human Rights) who place their Self-Care as Political Strategy in this fundamental and guiding question:

"¿La forma en la que nos relacionamos con nuestras/os compañeras/os de lucha es la que creemos que ayuda a la transformación social?, es decir, a través de este tipo de reflexiones intentamos concretar en lo cotidiano nuestros discursos a favor de la vida de las personas." (Cárdenas & Méndez, 2017, p. 181)

"Is the way in which we relate to our companions in the struggle the way we believe helps social transformation? In other words, through this type of reflection we try to make our discourse situated in daily life for the welfare of people" (Cárdenas & Méndez, 2017, p. 181)

The IM Defensoras frame 'the personal is political' as a first principle within a collective care perspective, reflecting on the community as political subjects and as well as critically reflecting on how to be activists by working with others in the same way they expect for themselves and in favour of the changes they are advocating for in the communities.

The feminist notion of the personal is political, of how everyday experiences reflect and are part of the political reality we live within, can be connected to the struggles of representation and self determination that disability rights activist groups have articulated in the key notion: " Nothing about us without us". (Charlton, 1998). This slogan has been central to disability rights groups and it has been replicated in various rights movements from Mapuche's fighting for their ancestral lands rights in Chile and Argentina, to the Network for Refugee Voices Refugee Rights networks (Mustafa, 2018) and children's rights to be heard in the (O'Donnell, 2009). "Nothing about us without us" encapsulates not only a call to self determination but also a reminder of the reality not being historically included in decisions at personal and political levels, that the lived lives of those who are oppressed are a reflection of the systemic silencing of voices.

What does the 'personal is political' look like for me in this self-descolonising mestiza stance? In genealogical anthropological excavations, descolonial latinx feminists in the North (Lugones, 2011; Anzaldua, 1999) and descolonial feminists in Abya Yala (Curiel, 2009; Espinosa, 2016; Segato, 2015) have worked on a reinterpretation of history to uncover in the modern world the genealogy of the domination of patriarchy and its systemic perpetuation in societal structures and knowledge production institutions. Transversally, while I read latina feminists and (dis)ability thinkers from both sides of the Atlantic, while I meet and work with Venezuelan women on the borderlands of forced migration, activism and motherhoods of (dis)ability, I am on a personal level reinterpreting my history and simultaneously I am seeking reflexive dialogues in activism. In carrying out my own personal descolonial excavation, unveiling my own epistemic privilege in bringing a plan to the community, the realisation I have is that this first planning step is already colonial. I cannot carry out a descolonial methodology alone. To be the researcher that brings the terms to be investigated to the community I am already deciding the terms to be researched, I am bringing a methodology of interviewing, of observing, of coloniality (Ortiz

Ocaña & Airas Lopez, 2019). So in reality, if this research seeks for descolonial disruption of the methodologies, it cannot stay on these pages or else it becomes another colonial attempt to objectify the 'other', the (dis)abled, the forced migrant, the mothers. As I worked with colleagues at the RLO, the work took over, and that was the ethical anti-research stance I took. Reflexive descolonising myself would have to be my anti-methodology in this research, to turn the lens on myself. To do anything else would mean staying in epistemologies that reify the very forms of knowledge and attitudes I set out to question. I initiated this doctorate on a quest to explore how disability is conceptualised from non-western perspectives, specifically latin american descolonial feminist perspectives and question how has disability been constructed and exported within the modernity/coloniality global paradigm we inhabit now. I will explore this in chapter four descolonising disability, but what I was faced with was to do research that was descolonial, I had to start with imbricated ambiguous mestiza self.

The point I am hoping to make here is that I have painfully realised that, despite having read and believing I was firmly situated within critical perspectives of Critical Disability Studies and of the descolonial turn, despite planning the research thinking of relational ethics and methodologies; what I had set out to enact was actually if not with western eyes, definitely with privileged mestiza-internalised-colonised eyes. Self-reflexivity and the awareness of my history, privilege and education focused my attention on knowledge production, how my personal 'mestiza borderlands' history is a reflection and enactment of colonial political geohistory. This awareness contributed to the shifting the focus of the research questions towards a methodological exploration. So how to engage with the intention of finding altern emancipatory epistemologies as a mum for my daughter, and as a professional for the children and families I work with?

Descolonising the research to engage in descolonising (dis)ability matters

As a psychologist, I was trained to assess and describe children in terms of who they are not, what they cannot do and what needs fixing. I have spent many years now disentangling myself from that academic knowledge machine, and contesting oppressive praxis while inhabiting spaces both professionally and as a mother that operate within modernity/colonial knowledge

paradigms. Reviewing the literature for this research, reflecting on my training in Venezuela, my professional life and the experiences at the RLO, my understanding of disability shifted to a see it as a colonial conceptualisation of human categorisation that has been born in the western hegemonic psych discipline. Whilst examining ableist notions of normality rooted in the coloniality of being (Danel, 2021; Ferrari, 2020) and from Critical Disability Studies lenses (Goodley et al, 2019; Grech, 2015; Mallett & Runswick-Cole, 2014; Yarza de los Rions, 2019) I have dissonantly been part of a psyche apparatus that oppresses some children into deficit positions of dysfunction focused on assessed needs, that ignores and silences the historic geo-socio-political conditions that disable children.

Understanding my personal and professional history in the light of descolonial thinking has confronted me with re-imagined possibilities of the 'how' to be in this research space. The original research questions I had proposed were regarding conceptualisations of (dis)ability in the context of Latin America. I had planned to research the conceptualisation of (dis)ability in indigenous and urban settings in Chile, then moved the research to the intersectionality of forced migration, children and(dis)ability in Colombia. As described in Tent Research, the pandemic shifted the research online and only with adults at the intersectionalities of disability, forced migration and motherhood. In the meantime, I joined a coalition of Venezuelan refugee women and we set up the RLO. Shifts and pauses in the research also became a gift for slow thinking. The realisation of the ethical conundrum in how I approached understanding disability from a descolonial lens required to enact research that was methodologically descolonial. In other words, to descolonise this research focusing on methodology feels like a necessary imperative that precedes the examining of conceptualisations.

The exploration of how to do the research during COVID and the experience of working at the RLO awoke the realisation and understanding that although I didn't set out with the intention I was in fact designing a methodology that would presume to represent 'others' voices. Spivak(1988) cautions us in her challenging and provoking essay "Can the subaltern speak?". Spivak confronts us with our possible complicitness in epistemic violence by the construction of a homogenous 'Other as the Self's shadow' (Spivak, 2010, pg 35). What I decided I could do was write about how people's sharing their stories affected me academically, emotionally,

professionally and why this changed the methodological choices, the course of the research and created a goal for the research. These reflections prompted an unlearning process, a self-descolonising that could help me be a better listening activist and be an ally. Essentially, I ask the reader to read the vivencias and stories I share as a disobedient methodological change of attitude as Fanon states in his critique of method:

> "It is good form to introduce a work in psychology with a statement of its methodological point of view. I shall be derelict. I leave methods to the botanists and the mathematicians. There is a point at which methods devour themselves."(Fanon, 2008, pg 5).

I don't have the intention to be derelict in describing my methodology, it is the theme of the next chapter, but I am taking from Fanon the urgency of attitude change. I am endeavouring to understand the implications of methodological routes as central to the investigation itself by looking at "metodologias otras' (other methodologies) with overt epistemic disobedience (Mignolo, 2021; Ortiz Ocaña et al, 2018) as routes to avoid being co-opted by familiar methodologies that devour the descolonial intentionalities of dialogue and unmask coloniality. In both autoethnographic vivencias in these first two chapters the questioning of ethics, the growing awareness of the complexity of my 'mestiza' identities (Anzaldua, 1999; Rivera Cusicanqui, 2010) and my positionalities in the research, the acceptance of power dynamics in the relationships in the RLO work, the activist stance I have taken and the context of the pandemic for forced Venezuelan migrants in Colombia; completely shifted the methodological enactment of the research to centre stage. I have stopped to listen, to rethink, to unlearn and to shift many times. In the pauses I had to explore and experiment how to descolonise myself and the research in the particular context of the RLO's work in Bogota.

The shift in this research from focusing on conceptualisations towards how the methodology is enacted in these thesis, is informed by descolonial thinking as well as from Critical Disability Studies (CDS). Indeed many CDS thinkers have extracted (dis)ability as an subject-object, and while focusing on the political-cultural contextuality of (dis)ability have rooted the conceptualisation in history, including histories of coloniality. Schalk (2017) published an article

entitled Critical Disability Studies as Methodology, where she cites Minich (2016) as a voice that clearly articulate Critical Disability Studies as a methodology, Schalk concludes:

> The methodology of disability studies as I would define it, then, involves scrutinizing not bodily or mental impairments but the social norms that define particular attributes as impairments, as well as the social conditions that concentrate stigmatized attributes in particular populations. (Schalk, 2017)

Minich (2016) argues that it is the mode of analysis that should be the focus of Critical Disability Studies rather than place disability or disabled people's lives as the objects of study (Minich, 2016). So for instance, Runswick-Cole & Hodge (2009) clearly describe the focus on needs rather than rights as a discriminatory lens in education in their exploration of the educational language around special needs and educational rights. The critical stance of placing the focus on collective rights and not on individual deficits or needs is a call for re-humanisation and shifts the focus of analysis on (dis)bility to the context. Focusing on a mode of analysis that includes the social conditions of (dis)ability resonates with the descolonial latina feminists work of reinterpreting history to uncover in the modern world the genealogy of the domination of patriarchy and its systemic perpetuation in societal structures and knowledge production institutions (Curiel, 2007; Segato, 2015; Lugones, 2008) that have excluded some people by questioning their humanity.

Goodley et al (2021) in the first issue of the International Journal of Disability and Justice also posit how Critical Disabilities Studies is poised to "to consider how human beings – those often living at the margins of society – can inform their inclusion through the development of transformative ideas, theories and practices" (Goodley et al, 2021, pg 32). In descolonial studies Maldonado-Torres (2016) coined the term the 'la zona del no ser' (the zone of non-being), inspired by Fanon's 'The wretched of the earth' (1963). This zone of non-being human flattens down what it means to be human, or rather not-being human by creating ontological naturalised hierarchical differences. This ontology is the legacy of colonisation that defines modernity's classification of people into categories. From a descolonial turn, acknowledging that histories of oppression for different groups (gendered, racialised, disabled, sexualised, ethnicized) have their own unique genealogy is crucially important alongside considering the epistemic communalities

in these historic exclusions. In particular, the episteme that has normalised the objectification of others is an epistemological line of inquiry that I pursue. Decentering the ideology of "normality" in the episteme of the west is a contested area explored in (dis)ability research and praxis (Danel et al, 2021; Yarza de los Rios et al, 2019; Campos, 2019). These turns of viewing (dis)ability not as an object of study but as a conceptualisation that is intersectional with other subjects in its epistemic origins is where (dis)ability can be a methodological approach to understand what it means to be human (Ferrari, 2020; Goodley, 2013; Minich, 2016; Schalk, 2017).

Thambinathan and Kinsella (2021), have outlined four critical practices to push the limits of "paradigmatic boundaries and imagine possibilities free from colonial roots" (n.p. end of 9th paragraph). These practices are useful guides to consider in the methodology. They are exercising critical reflexivity, reciprocity and respect for self determination, embracing Other(ed) ways of knowing and embodying a transformative praxis or activist scholarship. The notion of critical reflexivity is what I have been embracing in the methodological ponderings in this chapter as well as in my professional praxis and moving towards making spaces that embody ethical praxis of descolonisation I turned to activist scholarship.

I am no longer looking to Latin America for resistance to western understandings of (dis)ability as if Latin America is somehow 'outside' hegemonic frameworks of disability. Hence the other self-descolonising moment has been realising that to descolonise the conceptualisations of disability is not a monolith of Global North/Global South differentiation of conceptualisations. It is an epistemological urgency looking into nodes of dialogue between critical fields of thinking.

From this critical stance of reflexivity as a professional and researcher I 'sentipienso'-feelthink (Lomelli & Rappaport, 2018; Fals Borda, 2009) an academic responsibility and ethical commitment towards radical questioning of how we create knowledges in research. Reflecting, delving in descolonial methodology literature, critical disability studies as a methodology (Schalk, 2017) and talking to my tutor have shifted tensions to embrace activist scholarship during the writing. Acevedo (2022) asserts that scholar-activism through

contemplative inquiry has an important place in research methodologies for a liberatory disability politics and indeed other oppressed communities.

All knowledge is partial and contingent to the geohistorical space it is produced within and our representations are a product of the positionality we adopt towards those we represent. In this sense, as I write, I realise that the academic and the activist in my experience are spaces that collide and where the representations I narrate in the thesis have been forged.

Activist scholarship

This research initiated within the disciplines and fields that I have a professional and personal connection with: critical disability studies and descolonial feminism. Along the way, in the literature review, I have delved deeper but mostly wider into other fields, such as migration studies. This is a response, in great measure, to the issues arising in the daily realities of the RLO work where people's lives are bound in the systemic intersectional (Carbado et al, 2013) and imbricated (Lugones, 2008) boundaries of gender, (dis)ability, xenophobia, poverty, violence, forced migration to name a few. The need to delve into so many fields of study speaks to the modern hegemonic division of knowledge that cannot fully describe the paradoxes, richness, oppressions and messiness of real lives.

One of the avenues of research in the literature that I delved into late in the writing process was activist scholarship. Talking to my tutor changed the discomfort I had with writing about the RLO I co-founded as I had felt that was not part of the plan of this research. It was something that happened as a result of connecting with others to do the research. But then not much of what I am writing about was part of the original plan I had. My tutor opened my eyes into reading about activist scholarship. I cite Harari and Pozzebon (2023) who point to challenging Eurocentric knowledge production in the search for descolonial methodologies by looking at the challenges and the alternate paths that emerge as opportunities to unlearn, and to generate '*Metodologias Otras*'. During the pandemic I felt that thinking and researching is important, but I felt what I did with the thinking/feeling and researching was more important. My pausing of the research for a period of time in favour of activism and advocacy was an alternate path that arose

due to the pandemic as well as due to my sentipensar response to the planned research. During this period I put the research to one side and focused on the work of the RLO.

Ochy Curiel (Villalón, 2024), a descolonial feminist, in a conversation with Roberta Villalón asks: how can we conceive of a descolonial feminism in academia without a praxis? She argues that if we are doing research for social justice we necessarily have to be rooted in a collective political praxis that is articulated to many other movements at the same time. Indeed research by itself cannot, and historically has not, enacted social change (Rivera Cusicanqui, 2018; Barnes, 2018). However, activist scholarship can support grassroots movements where change has historically been enacted such as in the disability rights movement (Oliver & Barnes, 2012). Embarking on starting a Refugee Led Organisation (RLO), run by Venezuelan refugees and allied women, I found a collective project I could get involved in that felt ethical, purposeful, and where we had to articulate imbricated and intersectional issues of migration, women's rights, children's rights, health access rights, school inclusion rights. In an interview with Villalón (2024), Curiel says she does not believe in projects that only centre themselves on identity politics, instead she has been working with other descolonial feminists:

…combatir toda la matriz de opresión colonial, que se expresa fundamentalmente en la colonialidad, y que afecta a los grupos que no tienen privilegios. Por lo tanto, es imposible no pensar en puentes epistemológicos, políticos, subjetivos, organizativos, de coaliciones, porque la realidad no está nunca fracturada, está siempre articulada, imbricada. Esto me ha dado la posibilidad de pensar y actuar no desde *una* posición o identidad política particular, sino desde *todas* esas posiciones que forman parte de un proyecto político, que es de hecho, colectivo. (Villalón, 2024, p 114)

...to combat the whole matrix of colonial oppression, which is fundamentally expressed in coloniality, and which affects groups that do not have privileges. Therefore, it is impossible not to think of epistemological, political, subjective, organisational, coalition bridges, because reality is never fractured, it is always articulated, intertwined. This has given me the possibility to think and act not from a particular political position or identity, but from all those positions that are part of a political project, which is in fact collective. (Villalón, 2024, p 114).

In scholarly activism, social movements are recognised as spaces for the emergence of co-constructed knowledge (Berghs et al, 2019; Kagan, 2022; Nguyen et al, 2019). Exploring the tensions between activism and scholarship and questioning the purpose of the research has given birth to an idea. The notion I have set for myself arising from my learning in the research is to share my learning process by generating a draft of methodological principles or ideas to be co-constructed within the RLO. Maybe this could be helpful in producing knowledge from within the community. This brings me to the other essential critical reflection I wish to outline is regarding the context of this research which is the forced migration of millions of Venezuelans and the impact of the COVID pandemic on their migration experiences.

The Context and Activist Scholarship

The Venezuelan mass migration of the last decade has totally altered the migratory landscape in South America. The Venezuela I grew up in was a major destination of South American and international migration, and it is now a country of emigrants. Neighbouring countries who had big populations emigrating (often to Vzla) such as Colombia, Ecuador, and Peru are now net immigration countries for the first time since records began in 1950 (Rosas & Zapata, 2024, pg 252) due to the Venezuelan exodus. Latin America has some of the most progressive laws regarding migration including the 1984 Cartagena agreement (ACNUR, 1984) with its expanded definition of refugee status that goes beyond the 1951 International protection for refugees of the UN. Local regional agreements also include the right to free mobility, social and healthcare rights, that most LatAm and Caribbean countries have signed up to (Rosas & Zapata, 2024). One of the most salient clues of the attitudes and legal policies on mobility in LatAm is that overall, and up to now, there are no refugee encampments or detention centres for migrants without documents. Whereas in other parts of the world refugees and forced migrants live an average of 17 years living in refugee encampments or 5-10 years to have asylum processes in LatAm the great majority of migrants whether or not they have residency papers live in cities and towns. In LatAm integration is the challenge, not containment and imprisonment -as it is in Europe and the USA (Eastmond, 2007). And whereas the root of the other two large migrations of the last decade have been wars in Syria and Ukraine; the Venezuelan exodus has resulted from other types of violence: hunger, food insecurity, insecurity on the streets with highest murder rates in the world (Reliefweb, 2020).

The pandemic made it impossible to travel to carry out the originally planned research, and required a rethink of the methodology, a re-application for ethics approval, and a review of the context as the pandemic made the lives of the people I had intended to participate with even more precarious than they already were. The pandemic reified the inequity of the poverty of Venezuelan forced migrants' lives in Bogota, there was an absence of social and governmental protection systems as well as growing xenophobia where before there had been some tolerance and solidarity (Guerrero & Graham, 2020; R4V, 2021; ReliefWeb, 2020; UNHCR, 2021). The exposure of inequities by the pandemic has been reported around the world (Danel et al, 2021; Kagan, 2022; Guterres, 2020) while simultaneously the impact of these inequities on people's bodies and lives happens mostly invisibilized.

In Latin American countries where public services are already stretched and not reaching many (CEPAL, 2019; Molina, 2019; Galeano, 1998), the pandemic exposed social discrimination and the lack of support for those already underserved and living on the borderlines of society with growing gaps in the access to basic services of education, health and food security. There was catastrophic loss of life and ever more precarious living for millions across the continent (Schwalb et al., 2022). For Venezuelan refugees in Colombia the lockdown meant the loss of informal work, no income, evictions from informal rental agreements, no family or community support network, no access to medical services and hunger. (Guerrero Ble & Graham, 2020). In one swift stroke their survival dependency of selling coffee on a street corner, or selling household cleaning products on the buses or doing informal daily cash work in a restaurant evaporated as severe lockdown rules hit Bogota like the rest of the country and continent.

The statistics about the number of Venezuelan children affected by forced migration and the pandemic lockdowns are hard to find. The records are bureaucratically not reliable and the statistics do not reflect the non-registered, informal, so called 'illegal' border crossings and non registered residents. (Infobae, 2024). Statistics regarding (dis)abled refugee and migrant Venezuelan children are following my research of Colombian and international humanitarian agencies non-existent as I exemplify below.

Colombia is the largest recipient of the global Venezuelan exodus, the most extensive migratory phenomenon in the Western hemisphere, in Jan 2024 estimated at over 8 million Venezuelans. Colombia also has one of the highest internal displacement in the world and is considered one of the countries with largest south to south migration (Courtheyn, 2023). According to the Interagency Coordination Platform for Refugees and Migrants from Venezuela ((Plataforma de Coordinación Interagencial para Refugiados y Migrantes de Venezuela, R4V, 2023) in December 2020 there were around 1.7 million Venezuelan refugees and forced migrants in Colombia alone, this has surpassed the 2.8 million in the latest estimations of the Colombian government (Migracion Colombia, 2024) . The statistics of Venezuelan migrant minors in the territory vary between 23-28% depending on the source, it is one of the unique features of this migration that the percentage of children on the move are higher than any other migration in modern times (UNICEF, 2023). On the news page of the Instituto Colombiano de Bienestar Familiar (ICBF) Colombian Institute of Family Wellbeing in 2020, it reports that of the 1.7 million Venezuelan refugees and migrants in the country at that date, 389,244 are under 18 years of age, that represents 22.33% of Venezuelan population in Colombia (ICBF, 2019). The ICBF (2019) recognises that the migration phenomenon during early childhood is not a visibilised one, and this is accentuated when children are separated from guardians and/or are in the legal limbo of Statelessness. A review of the ICBF publications on their website between 2019-2024 that describe their Programs and Strategies for child migration has no mention of migrant children with (dis)abilities. Equally on the ICBF (2021) web pages on (dis)ability there is no mention of migrant (dis)abled children.

A 2022 report from the above mentioned platform about the situation of refugees and migrants with physical and sensory disabilities in Latin America, starts by saying "Las personas refugiadas y migrantes con discapacidad se encuentran en una situación en la que se cruzan dos procesos de invisibilización." (R4V, 2022) "Refugees and migrant people with disabilities find themselves in a situation where two processes of invisibilisation crossover" (my translation). Children are not mentioned in this report and again invisibilized, children with (dis)abilities are not accounted for and not planned for in this context of migration in Colombia.

There are multiple intersectional barriers for Venezuelan refugee and forced migrant disabled children and their families in Colombia that are invisibilized, underreported, and hence this

group is underserved, their lack of access to basic human rights is not being explicitly named or planned for. These invisible intersectional discriminations and gaps in knowledge, service and representation spurred me back into the research to give evidence of the stories that were being shared with us in the RLO and to learn how to build an understanding about the issues families and children were living with. I explore these invisibilisations further in the next chapter descolonising Disability. What I wish to highlight about the contextual reality of the pandemic is that children who were already affected by malnutrition, precarious living conditions, lack of access to health and educational inequalities, now became more susceptible to prolonged interruption of education, food scarcity and being further invisibilized as a group with unattended rights (UNHCR, 2021).

I have been engaged in the unveiling of my mestiza positionality in the research enmeshed with activism and advocacy. The way I dealt with the tensions I experienced between the research and the work was to keep these apart. I had certainly not planned to write about my experiences at the RLO. Perhaps partially this separation was an adherence to some subsumed understanding of scholarship as abstracted from the real world, perhaps it was a commitment to focus only on activism due to survivor's guilt as enunciated by Karina Sainz Borgo (2019) in her Venezuelan diasporic novel "La Hija de la Española" (In English published as The Spanish Woman's Daughter).

"Era la culpa del superviviente, algo parecido a lo que padecieron los que se marchaban del país, una sensación de oprobio y vergüenza: darse de baja del sufrimiento era otra forma de traición." (Karina Sainz Borgo, The Spanish Woman's Daughter, 2019, p 48)

"It was survivor's guilt, something akin to what those who left the country suffered, a sense of dishonour and shame: to withdraw from suffering was another form of betrayal." (Karina Sainz Borgo, The Spanish Woman's Daughter, 2019, p 48, my translation)

Karina encapsulates a feeling so many of us more privileged Venezuelans carry thanks to another passport, or a professional job opportunity abroad, or other privileges that enabled us to leave comfortably. While many of us left by plane with access to integrating in other countries, most of the south to south Venezuelan migration in Latin America has been mixed migratory flows of people whose legal rights disappear as they cross the borders between Venezuela and Colombia

or traverse the continent. These include people I know, family, friends as well as people I have come to know through the RLO, and so my personal story is part of a collective story that has become political in its focus on activism through the work of the RLO.

However, in the work in the RLO I found myself confronting the same challenges I have had in the research. For example, how to design programmes that were not top down and that responded to people's needs, rights and wishes. Other challenges included working with communities where many people owing to their legal status are often itinerant, fearful of any institutionality that may lay their situation vulnerable to deportation, challenges in maintaining ongoing relationships with people with levels of poverty that render them invisible even to the RLO because they cannot afford to travel or keep communication with us, hence we often simply lost touch and had no way of knowing what had happened to them. Within these challenges we have managed and continue to make an impact on some people's lives, sometimes it is as simple as petitioning for their right to a hospital appointment thanks to the legal team or helping parents to access some form of means of living or listening to a mother's concerns and guiding them to find the institutional support available.

Starting with the feminist and descolonial notion that knowledge is situated in geohistorical spaces (Curiel, 2021; Haraway, 1988; Leyva Solano, 2018; Spivak, 2010) and that it is not neutral nor delocalised, then questioning the hierarchical privileging of knowledge produced in academia over knowledge created in activist spaces is a relevant area of questioning within social research. In many activist- academic spaces in Abya Yala from theology of liberation (Baró, 1994), pedagogies for conscientizaçao and transformative social work (Freire, 1974) and Latin American participatory community work (Fals Borda, 2009), the western dichotomisation of academic knowledge versus activist knowledge has not found a foothold. Participatory action research with the objective of social equity has a firm hold on the continent (do Mar Pereira, 2016; Fals Borda, 2009) "Where there is no dichotomy between theory and practice, reflection on our actions reveals the theory- without which the action(or practice) is not a real one" (Freire, 1974, pg 103).

The tension between being an activist and a researcher flows in many directions. It is not only the tension usually referred to of the position of an academic in relation to activism (Kagan,

2020; do Mar Pereira, 2016;), but equally how activists working outside of academia engage in research. The binary insider/outsider can complicate the hierarchical relationships that academic activists inhabit with those they are advocating for in the context of the research. Working in the RLO, advocating for the access of basic human rights for Venezuelan forced migrants I find myself straddling multiple grey areas of the outsider-researcher, insider-activist. And yet I also have a 'sentipensar' (feelthinking) that these binarisms do not reflect the hybridity of my positionality, nor am I able to address them without recognising that these essentializing binarisms are rooted in what Castro-Gomez (2000) calls "the invention of the other".

I would like to add to this section an autoethnographic reflection with regards to activist movements, academia and my initial motivation into this research to explore descolonising (dis)ability in Latin America. (Dis)ability movements originate within disability lives. Academia and professional practices have in multiple ways colluded with hegemonic structures to perpetuate the non/human deficit view of dis/ability while simultaneously some academic movements have been an important part of the membership of disability movements in Global North pockets. Under the present conditions academics and professionals, work within the present order of knowledge production in universities, and work within clinical, social and educational settings with structured professionalised protocols. Expressing dissatisfaction with the professional modern structures, seeking new readings of the past and promoting altern ideas within the modern structures of work and education as hugely problematic. The work of contesting dis/ability is fraught with survival. This was another of the reasons I had sought to do my research in my continent rather than in Europe where I work. Both searching for alternate understandings of disability, looking for this within my own culture and also in an environment far away from my daily job that maintains my daughters, my mother and myself.

Ethical Considerations

I explore the ethics of the methodology of the conversations I held with Venezuelan women in the next chapter where I fully describe the design and implementation of the research. I would like to highlight the contrasting and enmeshed intentionalities of enacting the research in the context of the RLO and Venezuelan forced migration, from a place of critical reflexivity.

Enacting activist-academic research with the intention of having 'conscientizacao' about my privileges, having clarity of non-representativeness whilst having the urgency from the context to action has many layers of complexity.

I have thought deeply about my connections to the women I work with and the women we serve. Whereas we share internalised histories of Venezuelan culture, accents, Venezuelan slang and other common cultural funds of knowledge and identity, we equally have identities rooted in many layers of differences. Thinking with Stuart Halls' (2019) cultural identities in mind, the layers of connection and differences we share as Venezuelan women are also firmly rooted in power structures that we may or not remain aware of in moments of dialogue- I suspect that the very notion I write on the paper that we may not be aware of belies my privilege of being a white, professional, middels class researcher. This reinforces the notion of explicitly laying out my positionality not only in terms of methodology but also in the research purpose of solidarity and action within academic research of feminist refugee leadership movement.

In the Global South and critical feminist movements many thinkers (Haraway, 1988; Lugones, 2011; Mohanty 2003) have posited that the knowledge we produce are representations of our positionality in relation to those we represent, looking at others as part of ourselves. An epistemology/ethics of relationships as Torres (2006) calls it, inspired by Anzaldua's 'La Conciencia de la Mestiza' in her book Borderlands (1999). In the light of this 'epistemologia otra' of relationships, from a descolonial turn and an activist-research stance I next summarise the methodological implications of this chapter and reformulate the research questions from conceptual explorations to a methodological exploration.

Methodological Implications: Research for transformative activism

My intersectional positionality and growing awareness of the threads of my privilege in every step of the methodological design have been central to the realisation that my research was not methodologically descolonial. The need to adjust the methodology to a digital context during the pandemic required an amendment to the ethics application (Appendix One and Two) so the

research could be carried out online and participants could not include children in this format. The ethics amendments, the ethical and pandemic pauses in the research plus the complexities of the precarious circumstances of the community and my role as activist -researcher, all gave me a space to review why I wished to do the research and who was I serving? I changed direction and dedicated myself to collaborative activism.

This process of recognising in my personal research process the systemic hegemonic learnings I was educated within moved me from worrying about navel gazing and impostor syndrome to understanding I could not do descolonising research if I myself do not recognise the weave of coloniality and descoloniality in my identities. The notion of leading a research changed to who is the research answerable to. The 'personal is political' is relevant as a researcher because it exemplifies the social systemic structures I operate within, I am assimilated to at the same time as I am gaining the tools to resist it. Descolonial feminists like Ochy Curiel (2012) remind me about the need to dissent from the hierarchy of knowledge production by uplifting the power of communities and non academics to conceptualise, as well as bringing a descolonial imaginary to the fore of knowledge production. This is an imaginary that unravels the hidden threads of those who have been silenced and those who have been silenced, the threads of subjectivity that the rational western has ignored and violently suppressed. So I take with me back to the RLO the importance of self-reflexivity to enact research for transformative activism, always centering that the personal is political and our presence in a collective is political.

Research Question Review

Descolonial research methodology at its core is about shifting the power and voice away from the single researcher. To design research from the emotional-rational whole, to allow yourself to be affected, impacted, to be vulnerable; to unlearn and to be of service, an ally for change towards social justice for those of us who have been historically marginalised in a myriad of ways. So my questions shifted to ethical and methodological ones, and the interviews were learning moments with ethical redirectioning.

Conceptually I wondered:

- What is it that I am questioning about (dis)ability and now forced migration through a descolonial lens?
- If I include the notion of (dis)ability in my line of questioning, am I questioning the ideological normative base of (dis)ability, of oppression and subalterity as it has been developed in the western hegemonic knowledge?
- Am I questioning the labelling I use and assign to people I am engaging with?

These conceptual questions I will return to in Chapter 4. Focusing on research as transformative activism, based on the feminist notions that the personal is political and recurring to descolonial, feminist, critical tools of inquiry for the design of the methodology the questions emerging were:

- Am I exoticising Venezuelan migrants' pain for my research benefit?
- Who has the power in this research design?
- Do the potential participants have power in the research story?
- Whose voice am I attempting to represent?
- Can I truly represent the voice of those I interview?
- Who has the voice in a data analysis of interviews?
- What methods can I use, create or recreate to make lived experiences of historically silenced people visible and audible?
- What can descolonial research look like in the context I am participating in, remotely and online?
- How can I ethically interview people in the most precarious circumstances? Does that equate to do no harm?

I have felt I could not investigate my original conceptual research questions before answering these ethical and methodological questions. These methodological, ethical and epistemological questions have been asked in other contexts (Acevedo, 2022; Gigena, 2022; Patel, 2016; Tuhiwai Smith, 2012; Minich 2016; Haraway, 1988) with a stance of disobedient epistemology (Mignolo 2007, Curiel, 2021; Rivera Cusicanqui et al, 2016). These questions are explorative, methodological and inform my stance, and my research attitude.

Chapter Two Summary

Dear Reader,

In this chapter I have set out the changing research questions in response to the context in Colombia, to the particularities of doing research during the pandemic, to my growing awareness of the impact of my positionality and activist role from the perspective of critical thinking from Descolonial Turn and CDS. I have explored how these issues of descolonising myself and the methodology required ethics amendments with reformulated research questions and positioned me to seek other ways of investigating (metodologias otras) and how to enact socially just participative descolonial methodologies. I hope to have been able to keep you engaged in my descolonising that is after all personal and political and embedded in a community. In the next chapter I set out my methodological choices arising from the ethical convergence of my researcher-activist experience: autoethnographic writing. The chapter starts with the vivencia of Esperanza's second arrival into Colombia from the perspective of a professional who works in a refugee NGO and their chance meeting on the routes of the caminantes- the walkers.

Chapter Three Vulnerability: Autoethnographic Writing

"In autoethnography, writing is not an activity that stands apart from the rest of the research process. Autoethnographers want to twist and turn readers' heads and make their hearts skip a beat now and then. We want to evoke feeling and induce readers to make a personal connection to the stories we are telling. Our writing is not simply academic; it's personal and artistic too."

Bochner and Ellis (2016, pg 80)

Prelude

Methodologies from the Global South, with a descolonial turn are open and emergent (Gigena, 2022). The search for 'metodologias otras' (Ortiz Ocaña et al, 2018), that in English translates to 'methodologies others' is not conclusive, it is disobedient, counterhegemonic and transformative (Walsh, 2018). In previous chapters I have situated the questioning of the methodological of this thesis in a self-reflective decolonising positionality and activist intentionality. In this chapter I lay out my methodological choices of autoethnographic writing and the emerging research design that was implemented in conversations with Venezuelan women migrants and professionals working in NGOs and the RLO I work with. It is relevant here to retrieve the notions of methodology in Complexity Thinking, (Morin, Ciurana and Motta, 2005), where method is seen as an ever-constructing path, method is constructed as it progresses within the relationships we are committed to and in a shared construction. 'Metodologias otras' are also self-constructing in this sense, and we come out of the process changed. This chapter starts with a story I have written based on my vivencia of conversations with professionals working in NGOs and the RLO I work with and Esperanza, whom I last saw with her children at the traffic lights in Cucuta in Chapter one.

Vivencia: Vulnerabilidad

Tuve miedo porque hay muchas historias de asaltos y crímenes pero igual me detuve, nuestras miradas se rozaron al ella voltear cuando oyó mi carro cerca, cargaba a un bebe y llevaba una niña de la mano y ya no pude arrancar de nuevo.

Pensé: debe ser Venezolana. Llevó la mayor parte de mi vida profesional trabajando con personas desplazadas internamente por el conflicto armado aquí en Colombia. Desde hace pocos años eso ha cambiado, no es una escogencia trabajar con la población migrante Venezolana, es la realidad, es lo que te trae el trabajo en el campo y es la vulnerabilidad. Mi motivación es la persona que tengo enfrente y de qué manera puedo conectarlas con ayuda, en estos momentos las personas con más vulnerabilidad son personas de Venezuela que llegan con historias muy duras y con otras costumbres. Y por la vía profesional los aprendizajes son empíricos en el campo de acción. La verdad no me gusta usar esa palabra: vulnerable. Es un rollo por el tema de derechos humanos.

Manejaba sola ese día y le había prometido a mi papa que no me detendría por nadie en la carretera. Era tarde e iba manejando hacia Tunja en la carretera que es ruta de los caminantes que van a Bogotá. Los ves por la carretera, grupos grandes con personas de todas las edades, grupos más pequeños, trios de jóvenes, personas solas, lo más duro de ver es los grupos con niños.

Al dar una curva la vi a Esperanza, iba cargando un bebé, llevaba una niña como de cuatro años de la mano y en la otra mano un maletón de ruedas. Me detuve sin pensar, ella me vio y me acordé de mi papá. "Yo no le echo la culpa a los venezolanos porque sé que muchos de ellos son víctimas también de estos asaltos en la carretera, pero vas manejando sola y no es seguro, no te vayas a parar".

Con la mano le hice un gesto a la mama para que se acercara y le abrí la ventana: ¿Para dónde vas? Mientras me respondía que su destino era Bogotá sus ojos cavernosos me miraban, una cara joven envejecida. Se montaron en el carro. Luego no se lo conté a mi papá para no

preocuparlo, ya suficiente angustia tiene con mi trabajo diario en comunidades en zonas peligrosas de Bogotá.

Mis primeros acercamientos a los colectivos comunitarios cambiaron mi sentir profesional al salir de la universidad. Mi aprendizaje fue muy empírico y diferente al aprendizaje académico. Yo no era parte de las comunidades donde entre a trabajar pero el trabajo comunitario me enseño que yo también participaba dentro de las metodologías y yo no llegaba a imponer ó a no imponer mi saber. No soy parte de la comunidad pero soy parte de los procesos con una escucha activa en la construcción de saberes. No es trabajar sobre las personas o para las personas sino que entre a ser parte de la comunidad. Y por eso me cuesta decir las palabras 'son vulnerables' pues no es un término que yo manejo eso de población vulnerable. No me gusta como encasillar a la gente como por el tipo de vulnerabilidad porque siento que una no puede medir eso en una persona, claro hay herramientas en el quehacer profesional del trabajo social y psicológico para llevar a cabo acciones. Pero epistemológicamente encasillar a las personas como vulnerables, ¿que implica?

El uso profesional del término vulnerable es más una utilidad práctica, lo práctico es nombrar algo que la persona no elige sino que es a lo que llega o a lo que queda después de enfrentar algunas barreras en instituciones, en la falta de medios, en los silencios de la sociedad. Lo vulnerable no reside dentro de la persona sino que es una dinámica compleja. Cuando llamamos a una población vulnerable entonces surgen temas de culpabilidad tanto en el voz a voz de la calle como en la academia, pasan por encima de la realidad y se enfocan en las fallas de las personas, se les califica dentro de unos parámetros.

"¿A dónde te vas a vivir?" Le pregunté a Esperanza.
"Voy a Bogotá, ya tengo unos meses allá" me contestó
"Ah estás ya viviendo aquí en Colombia con tus niñas?"
"No, yo me vine primero sola con la bebe, tenía apenas cinco meses. Yo me vine y yo la dejé a la niña mayor con mi mamá porque realmente los recursos que tenían no eran suficiente para traérmela. Ahora la fui a buscar porque realmente allá ... bueno se iba al colegio sin comer"

Pensé que esta es una familia en un estado de vulnerabilidad, vienen de vulnerabilidad y llegan a más vulnerabilidad. Ya sabemos que a grupos familiares como Esperanza se les están negando el acceso a unas cosas que son básicas, que son necesarias. No son regalos lo que necesitan, ni caridad, no es una bendición por la que oran, son derechos básicos, es algo que se necesita para vivir y que debería ser garantizado. En términos prácticos llamar a alguien vulnerable es simplificar un proceso social complejo a una palabra que reside en un cuerpo. Yo diría entonces que el cuerpo llamado vulnerable es el reflejo de una sociedad. Pues como se entiende la vulnerabilidad depende mucho del profesional y de su posición política ante lo que hace.

"Y te viniste sola con la bebe de Venezuela? Pues si
"¿Cómo decidiste venirte?"
Salí de Venezuela como quien dicen con sangre fría, es que yo dije no tengo más opciones es ya o ya, o es echarme a morir aquí en Venezuela decía yo."

A Esperanza la van clasificar como 'vulnerable' en cualquier organismo estatal o ONG con el que le tocara entrar en contacto. Una madre sola, dos niñas, una en edad temprana, recién llegada, sin medios de vida, sin familiares a quien recurrir en Colombia, son muchas sus necesidades de protección. Esperanza contaba:

"La niña me llegaba con dolor de cabeza del colegio buscando algo de comer, y no tenía nada que darle entonces ya esa situación a mí me tenía muy mal porque yo decía de que se me va a morir la niña de hambre. Porque bueno la bebe todavía la podía alimentar yo pero igual mi alimentación no era la adecuada tampoco. De hecho ella nació baja de peso por eso claro porque no no tuve la alimentación adecuada."

Encasillar a las personas como vulnerables debido a la falta de acceso a unas necesidades básicas a sus derechos que no deberían ser negociables va más allá del encasillamiento. Es una estigmatización, la persona que se categoriza como vulnerable queda encasillada pero detrás de eso se esconde una falta de garantías de derechos y se establece una estigma de su ser ya sea como migrante o como mujer o como madre o por ser menor de edad o por su identidad sexual o

su supuesta discapacidad o su nacionalidad y queda sujeta de ser segregada y excluida. Ni el Estado, ni las instituciones ni las barreras sociales están descritas detrás de esa palabra vulnerable, entonces yo siento que la palabra vulnerabilidad es como decirle ay pobrecitos vamos a ir a solucionar el problema a estas personas pobres que no tienen nada. Entonces vamos a solucionar el problema de la gente vulnerable como si el problema es de ellos o sea como si fuera por el tipo de persona como una descripción de su identidad. Igual tenemos que funcionar dentro de las posibilidades que hay, así que le digo a Esperanza:

"Te puedo llevar a una ONG en Tunja, y allí te conectan con otras fundaciones que te pueden ayudar. ¿Te parece?"
"Sí señora, gracias, muchas gracias. ¿Con cuál me dejas?"

Mi posición política y profesional tanto hacia la vida como hacia las personas con quien trabajo es de entender que aun sin derechos garantizados esa persona sigue estando en la capacidad de decidir por su vida. Entonces en ese sentido la persona que tengo enfrente es lo que motiva mi trabajo, qué fuentes de información y ayuda se pueden brindar para que esa persona elija sus rutas de vida. Es decir yo hago el trabajo de una escucha activa, de entregar mi información, de crear un contacto, de planear una acción yo sé que esa persona no está en la obligación ni de agradecerme y está completamente libre de tomarlo, dejarlo, cuestionarmelo. Respetarlos y como que no ir con la cultura del pobrecito yo veo personas capaces de tomar sus propias decisiones.

Bueno, no le conté a mi papá acerca de aquella noche que lleve a Esperanza y sus niñas a Tunja, ni de los fragmentos de su vida que ella me contó con voz silenciada en el carro. Pero si le cuento a mi papá algunas historias de los caminantes a quienes conozco por el trabajo, le cuento de mis reflexiones sobre nuestras responsabilidades como Colombianos hacia los Venezolanos que nos rodean ahora en todos los ámbitos de la vida. Porque ya están aquí, es una realidad y sus historias no son historias de personas vulnerables sino historias políticas, de fronteras donde el robo de sus derechos humanos se subsume en el lenguaje clasificatorio de vulnerabilidades, de personas con necesidad de protección donde se silencian las

responsabilidades políticas y sociales. Después de dejar a Esperanza mas nunca supe de ella, ojala que encuentre buen camino. No la puedo olivar.

Vivencia: Vulnerability in Translation

I was afraid because there are so many stories of muggings and crimes but I stopped anyway, our eyes met as she turned around when she heard my car nearby. She was carrying a baby and holding a young girl by the hand. I couldn't drive off.

I thought she must be Venezuelan. I have spent most of my professional life working with people internally displaced by the armed conflict here in Colombia. It is not a choice to work with the Venezuelan migrant population, it is the reality, it is what working in the field brings you and it is because of the high levels of vulnerability. My motivation is the person in front of me and how I can connect them with help. At the moment, the most vulnerable people are people from Venezuela who arrive with very difficult histories and with other customs. On the professional side, the learning is empirical in the field. I really don't like to use that word: vulnerable. It's a bit of a mess because of human rights issues.

I was driving alone that day and I had promised my papá that I wouldn't stop for anyone on the road. It was late in the afternoon and I was driving to Tunja on the road that is the route of the caminantes going to Bogota. You see them on the road, big groups with people of all ages, smaller groups, trios of young people, single people, the hardest thing to see is the groups with children.

As I rounded a bend I saw Esperanza, she was carrying a baby, she was holding a young girl by the hand and in the other hand a wheelie suitcase. I stopped without thinking, she saw me and I remembered what my papa says: "I don't blame the Venezuelans because I know that many of them are also victims of these assaults on the road, but you're driving alone and it's not safe, don't stop."

With my hand I gestured to the mother to come closer and I opened the window: "Where are you going? She answered that her destination was Bogotá, her cavernous eyes looking at me, an aged

young face. They got into the car. I didn't tell my dad afterwards so as not to worry him, as he was worried enough about my daily work in communities in dangerous areas of Bogotá.

My first contact with community collectives changed my professional feeling when I left university. My learning was very empirical and different from academic learning. I was not part of the communities where I went to work but the community work taught me that I also participated in the methodologies and I did not get to impose or not to impose my knowledge. I am not part of the community but I am part of the processes with active listening in the construction of knowledge. It is not about working on people or for people, but about becoming part of the community. And that is why it is difficult for me to say the words 'they are vulnerable' because I don't use the term 'vulnerable population'. I don't like to pigeonhole people by their type of vulnerability because I feel that one cannot measure that in a person, of course these are practical tools in the professional work of social work and psychology to carry out actions. But epistemologically, what does it imply to pigeonhole people as vulnerable?

The professional use of the term vulnerability is used to name something that the person does not choose but that is what they arrive with or what they are confronted with after facing barriers in institutions, in the lack of means and in the silences of society. Vulnerability does not reside within the person but is a complex dynamic. When we call a population vulnerable then issues of guilt and blame arise both in the street and in academia, ignoring reality, the focus is on people's faults, they are qualified within certain parameters.

"I'm going to Bogotá, I've already been there for a few months," she had replied.
"Ahh you are already living here in Colombia with your children?
"No, I first came alone with the baby, she was only five months old. I came and I left the older girl with my mother because really the resources I had weren't enough to bring her with me. Now I went to pick her up because she was going to school without eating".

I thought to myself: this is a family in a high state of vulnerability, they come from vulnerability and they arrive into vulnerability. We already know that family groups like Esperanza are being denied access to things that are basic, that are necessary. It's not gifts that they need, it's not

charity, it's not a blessing that they pray for, it's basic rights, it's everything that is needed to live and that should be guaranteed. In practical terms to call someone vulnerable is to simplify a complex social process to a word as if it resides in that body. I would say then that the body called vulnerable is a reflection of a society. For how vulnerability is understood depends very much on the professional and their political position towards their profession.

"And you came alone with the baby from Venezuela the first time?"
" Yes, I did."
"How was your decision to come?
"I left Venezuela in cold blood, as they say, I said to myself I have no other options, it's either now or now or I'm going to die here in Venezuela,"

Esperanza will be classified as 'vulnerable' in any state agency or NGO she comes into contact with. A single mother, two girls, one at an early age, a newcomer, with no means of support, no family to turn to in Colombia, her protection needs are many. She went on talking.

"In Venezuela the girl would come home from school with a headache looking for something to eat, and I didn't have anything to give her, so this situation made me very upset because I thought my girl was going to die of hunger. Because I could still breastfeed the baby, but my diet was not adequate either. In fact, she was born underweight because of that, of course, because I didn't have the right food".

Pigeonholing people as vulnerable, due to lack of access to basic needs and rights that should be non-negotiable goes beyond pigeonholing. It is a stigmatisation, the person who is categorised as vulnerable is pigeonholed but behind this is hidden a lack of rights guarantees. A stigma is established as a migrant or as a woman or as a mother or as a minor or because of their sexual identity or their disability or their nationality they are subject to being segregated and excluded. Neither the state, nor the institutions, nor the social barriers are described behind the word vulnerable, so I feel that the word vulnerability is like saying 'awww poor people, we are going to solve the problem of these poor people who have nothing'. So we are going to solve the problem of vulnerable people as if the problem is theirs, that is to say, as if it were a description of the type of person or their identity.

My political and professional position, both towards life and towards the people I work with, is to understand that even without guaranteed rights, that person still has the capacity to decide for his or her life. So in this sense, the person in front of me is what motivates my work. What are the sources of information and help that can be provided so that this person can choose his or her life path. That is to say, I do the work of active listening, of giving my information, of creating contact, of planning an action. I know that this person is not obliged to thank me and is completely free to take it, to leave it, to question me. Respecting them and kind of not going with the culture of the 'poor thing', I see people who are capable of making their own decisions. I tell Esperanza:

"I can take you to an NGO in Tunja, and there they connect you with other foundations that can help you. Does that sound okay to you?"
"Sí señora, gracias, muchas gracias. Which organisation will you take me to?"

Well, I didn't tell my dad about that time I picked up Esperanza and her girls and took them to Tunja, nor about the fragments of her life that she told me in a hushed voice in the car. But I do tell my dad some bits of the stories of the *caminantes* I meet through work. I tell him about my reflections on our responsibilities as Colombians towards the Venezuelans who surround us now in all walks of life. Because they are already here, it is a reality and their stories are not stories of vulnerable people but political stories, of borders where the theft of their human rights is subsumed in the classificatory language of vulnerabilities, of people in need of protection where political and social responsibilities are silenced. I never heard from Esperanza again, I hope she found some good pathways. I cannot forget her.

Chapter Overview: Autoethnographic Research

This chapter outlines the methodological choices of this research and its implementation.
In the first section of this chapter I describe autoethnographic writing and storytelling and in the second section I describe the emergent research design and implementation. The reflexive nature

of this thesis with critical self reflexivity, reviewing the methodology, and the investigative nature of self-decolonising have opened the possibility of writing in a non-conventional structure and writing style. I have been experimenting and proposing a structure to redefine a mode of research that starts from 'sentipensar' and 'escrivivencia' as outlined in the preface. Hence each chapter has its starting point in a vivencia. I intend through this chapter to elaborate the relevance of these storytelling vivencias as a methodology of descolonising myself. Dear reader, that I will now explain in this third chapter the implemented methodology of autoethnographic writing after you have already read two autoethnographic pieces, may seem topsy turvy to the conventional order of theory, methodology, qualitative data (in this case autoethnographic), analysis and conclusions. On the one hand, this disorder follows my experience of implementing and writing the research in the order in which I have lived it. On the other hand, this order has functioned for me as an experimentation to find a new form of writing the research outside of the borders of western rationality and challenging the modern structures of knowledge production I was trained in. My attempt at subversive academic writing supports a quest for storytelling as a community learning and engagement project to take back to the RLO. These are the sections of this chapter:

1. Methodological Choices: Autoethnography and Storytelling
    1.1. Autoethnographic Writing
    1.2. Autoethnographic Storytelling
2. Research design and emergent ethics
    2.1. Research Design and Ethics
    2.2. Research Methods and Participant Invitation
    2.3. Interviews Approach
            My privileged position
            Their previous experiences of interviewings
            Their present day needs
            Beyond do no harm
    2.4. Vivencias Writing Process
    2.5. Quality in Qualitative descolonial Research

Methodological Choices: Autoethnography and Storytelling

First, I put forth the autoethnographic storytelling methodology I have chosen to carry out in the research as the ethical convergence of the research-activist relationships I have experienced while carrying out this research. The methodology of this thesis is within a qualitative critical theory paradigm (Denzin & Lincoln, 2018) and within the growing field of descolonial methodologies in Abya Yala (Mignolo, 2009; Maldonado Torres, 2006) and particularly descolonial feminist approaches to research and praxis (Curiel, 2021; Lugones, 2021; Patel, 2016; Tuhiwai Smith, 2012; Tuck & Yang, 2012; Walsh, 2021).

El proceso decolonizante debe ser ético, respetuoso, sociable, solidario y útil. Decolonizar la investigación implica no sólo investigar desde metodologías "otras", sino también cuestionar el contenido de dicha noción y cuestionar incluso el propio término. Implica develar otras formas de hacer ciencia sin subalternizar, sin dominar las acciones humanas ni los ideales de una comunidad. Implica vivir en/por/para la propia comunidad que pretende decolonizarse. Es por ello que todo proceso decolonizante es una auto-decolonización. (Ortiz Ocaña et al, 2018, p182).

The decolonising process must be ethical, respectful, sociable, supportive and useful. Decolonising research implies not only research based on "other" methodologies, but also questioning the content of this notion and even questioning the term itself. It implies unveiling other ways of doing science without subalternising, without domineering the human actions or the ideals of a community. It implies living in/by/for the very community that seeks to decolonise itself. That is why every decolonising process is a self-decolonisation. (Ortiz Ocaña et al, 2018, p182).

'Othering' is what the RLO workers were questioning in their conversations with me that I have related in this story 'Vulnerability'. In the story writing process, which I describe further ahead in the chapter, I explain how I have taken words from participants as I heard them and weaved them into vivencias that reflect what they made me think about and question. In the vivencia Vulnerability, an RLO worker meets Esperanza, in her professional role and she knows Esperanza will be placed in the category `vulnerable' in all the organisations she will come into contact with. She challenges this notion of labelling people as vulnerable as an erasing of Esperanza as the 'other' and erasing the conditions that have rendered Esperanza 'vulnerable'. The narrator's challenge reminds those of us working in the field to responsibly critique the

knowledge within which the structures of support operate - governmental and non-governmental-even as we work within them. I will further explore categorisations of 'othering' in the next chapter on (Dis)ability. The continuous questioning of how we work within communities and do research with and by the "othered' in Abya Yala (Danel et al, 2021; Fals Borda, 2009; Hernandez, 2019; Spivak, 2010) has the enormous potential and huge necessity of rethinking how we explore and design descolonial methodology.

The choice of autoethnography emerged from the ethical self-questioning and doubts as described in the previous two chapters. Self-reflexivity and the awareness of my history, education and the geopolitical-historical context focused my attention on questioning how I was seeking knowledge, who produced this knowledge and how would that knowledge be used. Did I have a right to be asking for dialogue with people during harsh moments of their lives from my privileged stance as a doctoral candidate? The continuous exploration for the research questions have taken me to reformulate them to: Is this research what they want and need? How do I decolonise myself to be able to be an ally? How do I decolonise this research? How can we produce collaborative knowledge in the RLO I work within and with what purpose?

Spivak (1988) warns us in "Does the Subaltern Speak?" that the "other," cannot be authentically represented, as every representation has already been absorbed into the dominant discourse. So every attempt to speak for another is impossible as we cannot help but use the language of the familiar and hegemonic matrices of knowledge we are trained in. She refers to postmodernist Derrida's notion of "continuous deferral or suspension", which questions the idea of representations. This line of thought puts forward that representations of others and/or on their behalf are always suspended in ever changing subjective meanings. So while representation of the voices from the Global South and of those who have been historically oppressed is a necessity, the possibility of representation is always speculative and I argue must remain constantly, dialogically and iteratively in question. When navigating the notion of unequal power dynamics in the research relationships (Thambinathan and Kinsella, 2021), this iterative questioning becomes central to the ethical decisions around participative research. The articulation of representation and the 'other' in this research became central to my descolonial

intentionality of 'methodological disobedience' (Mignolo, 2007) and to the experiences I have within the RLO.

It is necessary to acknowledge and simultaneously question the imperative of articulating the 'other' in Abya Yala to be able to 'delink' from the rhetoric of modern sciences and the logic of coloniality (Spivak, 2010; Mignolo, 2007). The exploration of how the 'other' and 'othering' are constitutive of the modern world paradigm (Castro-Gomez, 2000; Lugones, 2011; Quijano, 2000; Maldonado, 2016; Curiel, 2009) is a central theme of relevance in the descolonial turn. These themes are also reflected within the field of critical (dis)ability studies in the explorations of identity politics and the questioning of who is human? (Danel et al, 2021; Goodley et al, 2021).

My choice for autoethnography and storytelling my vivencias resides in my positionality to grow in continuous awareness of the geopolitical history of the conceptualisations we use (Espinosa-Miñoso, 2014), while focusing to learn how to do co-research in this moment in time in the context within which I collaborate in Bogota. As Patel (2016) says: "Attending to context, to place, to temporality, is perhaps one of the strongest ways that educational researchers can interrupt coloniality" (pg 61).

Autoethnographic Writing

Chawla and Atay (2017) position autoethnography as a postcolonial turn in ethnographic methodology that traditionally is posited in a colonial discourse whereas autoethnography they say "re-centers the researcher (the Other) and her story as subject/participant and context in the field" (Chawla and Atay, 2017, pg 4). Working alongside colleagues in the RLO we focus on how we could support people through participative methods so people could formulate what they needed and could achieve for their lives. I recorded in my journal "I cannot ethically carry out interviews that feel extractive". Ellis, Adams and Bochner (2011) say that "autoethnography is one of the approaches that acknowledges and accommodates subjectivity, emotionality, and the researcher's influence on research, rather than hiding from these matters or assuming they don't exist." (pg 2)

Does creative auto-ethnographic writing embody being a descolonial researcher? Retelling what I have experienced, from the lens I have listened with, is it really of interest and of use to anyone? Is this really contributing to a descolonial knowledge production? Is it not just a personal autobiography, subjective and self reflective? Grappling with these questions brings me full circle to my wonderings about what it is to write a doctoral thesis, what the scope can be for a professional like myself with naive and limited research experience. I am after all a professional psychologist working full time in education in Europe, working part time as a RLO volunteer online in Colombia, part time researcher, a full time carer and mum. This research is connected to all my identities, however the research itself is possibly the smallest part of my life timewise given the brief daily time I have to write and contiguously it is emotionally a huge part of my life in that it has infiltrated and transformed my thinking in all aspects of my daily life.

Boylorn at al (2016) define autoethnography as a cultural analysis through the use of personal narratives, while encouraging critical reflection both inwards and outwardly, to understand our positionality in our research and lived contexts. To expand on the centrality of subjectivity and self-reflection in experimenting with methodology with a descolonial turn I look to Maldonado's (2016) ten theses on Coloniality and Decoloniality. In his fifth theses he places the subject and subjectivity itself at the crux of the knowledge production figuratively drawing subjectivity at the centre of the colonialities of power, of being and of knowledge. He centres subjectivity as the space of struggle within which to question the normative oppressive knowledge production of the hegemonic west. I have experienced autoethnographic writing as an epistemic inquiry into making meanings within the relationality with those I have spoken with. It has allowed me to explore my changing positionality and develop critical awareness within the relationalities of the RLO and the communities we work within, as well as within the research. The autoethnographic descriptions I have engaged in to tell the story of the evolving research design have helped me make sense of the insider/outsider experience that I think reveals the ethical tensions to disrupt my researcher 'authority' and question the coloniality of the researcher position (Ellis et al, 2011).

As a 'privileged mestiza' and a mother, with all the colonial implications the mestiza and female identities have of being othered, of internalised colonialism, of my privileges as white latina, of

externalising assimilations of western hegemonic thought, I have experimented with performative writing as a methodology where I could experiment with critical self awareness and 'sentipensar' as a route to understand not my only personal experience but as a way of interpreting and witnessing the political and cultural normativity (Spry 2018) that oppresses Venezuelan forced migrants lives in Colombia. Diversi et al (2021) inspire us to look at autoethnography as a way to destabilise what we know, and highlight the interweaving of our personal histories with the histories of oppression, the personal is political. Holman Jones, Adams & Ellis (2013) say "Autoethnography creates a space for a turn, a change, a reconsideration of how we think, how we do research and relationships, and how we live" (Holman Jones et al, 2013, p. 21).

Activism, inward-outward gaze, positionality, emotional solidarity, fear of recreating systemic discrimination have all come together in my research mind to use autoethnography as a way to avoid colluding with the colonial oppressive system while holding a light to the strength of a people's survival in the face of barriers and injustices. Esperzanza, in the professionals' story, embodies my perception of the many amazing strong women I have met whose voices I cannot represent but who changed my life direction towards activism as well as my research questions and methodological objectives. Rather than hiding my subjectivities in the experience I look to autoethnography as an approach that acknowledges my subjectivities and their impact on the research (Ellis, Adams and Bochner, 2011). Autoethnography offers the possibility of a descolonial intercultural research (Walsh, 2018) through critical personal reflection (Harari and Pozzebon, 2024; Thambinathan and Kinsella, 2021) and embodying transformative praxis through activist scholarship based on solidarity (Acevedo, 2022). Autoethnography has helped me find a form of speaking from, for, and to the margins, using my voice and not presuming to represent others; and also with a hope of learning to build collaborative tools for future storymaking within the RLO. This moves the autoethnographic exploration further on from self-reflexivity towards an activist positionality exploring power relations that are socially and geo-historically located and towards praxes of unlearning and relearning collaboratively.

Dutta (2018) positions autoethnography as inhabiting a liminal space full of creativity and imaginaries where other knowledges can be generated, particularly knowledge production that resists normative use by linking academia and activism in ethical positionalities for social

injustice. To avoid colluding with the system I could not stay in the objective distant interview and report mode I have been trained in traditional psychology. The realities of Venezuelan migrant families and the systemic barriers they face continues to be the core experience that changed my methodology. The need for action and the emotional connections forged, are my subjective and emotional responses, my 'sentipensar' and define my presence in the research and my story writing.

Throughout the thesis, I have engaged in critical analysis through a narrative style that diverges from canonic academic style and structure and I hope without losing internal consistency and coherence. I have endeavoured to communicate my personal descolonisation through an embodied descolonial feminist methodology of personal genealogy, an autoethnographic self descolonising. I hope through this disruptive and narrative discourse to put ethical responsibility and reflective positionality at the centre of the research to do justice to the trust given to me by the women who gave me their time and stories.

Autoethnographic Storytelling

> "As an autoethnographer, I am both the author and focus of the story, the one who tells and the one who experiences, the observer and the observed, the creator and the created. I am the person at the intersection of the personal and the cultural, thinking and observing as an ethnographer and writing and describing as a storyteller." (Ellis, 2009, pg 5)

Pelias (2018), argues that performative writing , in which he includes autoethnography, is one of many alternative critical forms of scholarship knowledge production. That these forms of writing can bring into the social science fields greater alignment with human lived experience and open the notions of what is considered academic knowledge while seeking to honour the complexities and oppressions in human life. "The performative writing fracture may help all academic houses settle into greater align-ment with human experience." (Pelias, 2018, pg 417). Everyday experiences, then, are not scholarship, but the shaping of everyday experience into telling, reflexive and moving stories can be.

Autoethnography implies treating the stories we hear and tell ourselves as whole stories, not to

be deconstructed or analysed as data (Denzin & Lincoln, 2018; Ellis, 2009). I grappled with how to ethically analyse the "data" and to tell the stories shared with me. I asked myself, how to avoid what Mignolo (2021) describes as producing meanings about others as if we are subject and object; the holder of reason beholding the being in nature?

> "The positivist project failed when it tried to answer the question about what it means to be a human being, about how we are to live our lives. The subject-object, mind-body, human-world, and researcher-researched dichotomies that defined modernism were found lacking." (Herrmann and DiFate, 2014, pg 5-6).

Referring to the literature on representation of the "other" (Spivak, 2010) I have already questioned the presumption of representing other's voices. Framing the question of representation based on the false dichotomy of 'I' and the 'other' - false in that the 'I' is always constituted by the 'other'- Spry (2018) questions: "What more may be learned about our 'strange dialogues' when autoethnographic praxes are as profoundly focused upon the sociocultural representations of the Other as those of self?" (Spry, 2018, pg1092,). In the story 'Vulnerability' I focus on the shared preoccupation with colleagues of how we need to represent 'others' in a certain language (vulnerable) so people can access services. Highlighting the coloniality in the language of 'othering' and the coloniality of power that it sits on, is a focus of the sociocultural representations I have tried to listen for in the interviews and dialogue with the participants through the transcripts and stories.

Creative autoethnographic storytelling is the messy space I have chosen to experiment with to embrace "other(ed)" ways of knowing (Thambinathan and Kinsella, 2021) and to embrace relationality as the space to hopefully co-produce meanings (Lugones, 2003). For me to understand what another is saying to me as we dialogue, I cannot leave behind my history, I cannot extract myself from my explicit and unconscious positionalities of hierarchy, hence I am explicitly saying these are the stories as I heard them, as well as these are the stories where I could engage in 'relational reflexivity'(Spry, 2018) when I was able to engage in feedback with participants. I also cannot extract my meanings from the geosocial history we are immersed in and the relationality involved in the meaning-making during and after the conversations. Spry says "...autoethnography situates the methodological nexus of meaning making within the body

and being of the critically reflexive researcher for the purpose of offering narratives transgressing normative and oppressive performativities." (2018, pg 1092-1093).

I have chosen also in the writing not to attempt a full story of someone's migration or a family's (dis)ability diagnostic story. I have often been marked by one small gesture or moment or image or a small detail someone has chosen to share with me or that I have witnessed or from my own personal story. These images have ingrained in me a wondering on how that person came to be in that moment or what that gesture means to me within the geo-political social history we are immersed in.

Witnessing a young child sitting immovable for hours in the dust between traffic lanes whilst her mother begs for money.
A professional pondering the meaning of vulnerability as a human category.
A woman standing at a bus stop crying because she cannot bring herself to get on the bus to beg.
My child saying to me: Mama, I'm afraid. Am I not normal?
A young child being ignored by adults because she is a Venezuelan migrant.
A professional asking a mother to choose if she wants an autism diagnosis for her child or not.

Each one of these moments have become stories in my mind that I make meaning from given the modern/colonial/gendered world systems particular genealogy in that geo-socio-political moment and space. Some of these moments have been the ones where the research was suspended in attendance to the need for activism whilst all of them have marked the changing direction of the research. These moments point to the omnipresent wounds in the modern/ colonial system and prompted moments of reflection on anticolonial alternatives of solidarity activism to research.

Given the impossibility of online participatory research in groups or with children, given the activist work required to attend to people's needs and rights first, given the extreme barriers of inequity owing to the pandemic, given that many wanted to tell their stories and have them retold, given that Spivak (1988) teaches us that we cannot authentically represent the 'other' without misrepresenting and betraying them, autoethnographic storytelling became my choice of action as a descolonial methodology.

In a Decolonial Summer School I attended in the summer of 2021 Maldonado-Torres said something that has stayed with me: 'decolonising is a verb' playing on Tuck and Yang's essay "Decolonising is not a metaphor" (Tuck and Yang, 2012). The storytelling writing based on the conversations I have had is my descolonial experimental action. The practice of oral storytelling, of community whispers, of generational history, of artful expression, of retelling and sharing stories runs through human history and is embedded in the Amerindian cultures of Abya Yala (Baquero Montoya & de la Hoz Siegler, 2010). There is a tradition of story as methodology within critical research methodologies (Strom et al, 2018; Rice and Mundel, 2018) and critical (dis)ability studies (Rice et al, 2015).

As I write the stories based on the interviews and get feedback (when it was possible), in an iterative process, I am placing myself to look outwards (systemic knowledge and others) and inwards (self-reflexivity), centering my responsibility in the telling as well as decentering myself (Strom et al, 2018).

The story 'Vulnerability' is based on a conversation with two professionals working with Venezuelan forced migrants in Bogota and a separate conversation with a Venezuelan migrant woman. The story uses their words as I heard them and weave them into the story of Esperanza. The professional participants' feedback contributed to rewriting the story through a few drafts where they requested that I eliminate informal word fillers but in particular they suggested ideas where I could make their story more vibrant by interlacing the conversation with Esperanza and the internal conversation her presence and responses elicit. They relayed that they felt well represented in the highlighting of the uncomfortable feelings they have professionally and ethically with the term: 'Vulnerable'. The forced migrant mother I conversed with who was a main inspiration for Esperanzita, was not re-contactable, this is very common in our experience with forced migrants. Contact can be erratic due to many barriers from financial constraints, phone functionality to continuous mobility within the city or beyond. Curiel (2021) states about descolonial methodology that: "In this history (she refers to Western Modernity history) people come to be at the colonial difference and the colonial wound, which are terrifying positionalities from which coloniality is vivid…" (pg 14, Curiel, 2021). I have witnessed at every step the vulnerable position that Venezuelan women and their families living on the margins are placed in, as Curiel (2021) labels it: in the colonial wound, and I am aware of how their experience

contrasts with my privilege. I have felt this in how we relate to each other, in the (im)possibility of maintaining communication, in the stories of their encounters with the institutionality of government and non governmental organisations, and in the narrative of the professionals who inspired the story: Vulnerability

Research design and emergent ethics

In this next section I lay out the methodological design and procedures as they emerged during the research and the writing. The emergent research did not follow the preconceived outline, it emerged from the context and my responses to the relationships I engaged in, it has been an unlearning/relearning process (Espinosa-Miñoso, 2014). A participative research design was what I had initially imagined I would carry out in the research. I have had to go through a long unlearning and continuous self decolonising process to realise that I was not only naive but presumptive of using participative research in communities I didn't fully belong to. In the following sections I will describe:

> 2.1 Research Design and Ethics (Approval)
> 2.2 Research Methods and Participant Invitation
> 2.3 Interviews Approach
> 2.4 Vivencias Writing Process
> 2.5 Quality in Qualitative descolonial Research

2.1 Research Design and Ethics (Approval)

The research design I outline here responded to two pilot online interviews that gave me pause to reflect on my ethical relationships with the women I was speaking to. In these pilot interviews I found myself in conversations witnessing desperate life situations, my ethical research intentions unravelled in the complexities of people's lives. The start of these interviews felt extractivist-notwithstanding my good intentions. I saw myself as a research spectator, I was inviting people to relive their pains and frustrations and I felt I was enacting my ethics in the exact terms I was

intending to oppose, I was complicit in a gazing of the other as 'vulnerable'. I stopped the research interviews and used the time to fill the family's application for support at the foundation. I referred the women within the RLO so they would be assigned to a case worker who could start supporting them with health, educational, work and legal solutions to their situations and refer them to organisations where they can get the help we cannot offer. I told both women I was not comfortable listening to their stories without being able to offer some ideas of support. Both women wanted just that, support in any form it could take.

I adopted a different stance, accepting that it was highly likely that most participants perceived me as a person in a position of power being a researcher and positioned in the RLO. Not wanting to transgress the emotional and relational space the women were offering me I decided I would only interview women who were already registered in the RLO and had a support plan in progress.

Regarding the university ethics application process I have had mixed feelings. On the one hand it felt secure as a naive researcher to have guidelines to follow, to know my application was being reviewed by experts in research ethics. In the questions and comments that were returned anonymously in the ethics form I was asked relevant thoughtful questions regarding the safety of the participants, whether debriefing sessions would be offered and would children be missing out on school time. These questions did make me think carefully about the logistics of my process with participants.

In the Potential Harm to Participants section I was asked at what stage post migration is this study going to take place, which struck me as a valid caring question, and goes to the point of my uncomfortable sense when stopping the interviews with people in desperate need and moving into activism.   I wondered who should decide what is post migration, what are the stages when it would imply 'no harm', and who decides this? I also wondered at the finality of the phrase post migration, when is a forced migration completed?

These questions made me wonder about the extent to which the practice of informed consent is established to protect and honor participants or researchers or academic institutions. I wonder if

by the institution and the individual researcher determining whether there is a risk, or whether we can protect participants with 'No Harm' intentionality, are we already taking away participant agency and following patriarchal hierarchical regulations? How is it that we can decide for others? (Iphofen and Tolich, 2018). The regulations that academic institutions' ethics requirements oblige us to comply with remain within a status quo of knowledge production that privileges colonial northern centric criterias of ethics (Castro-Gomez, 2007).   "Nothing about us, without us" comes to mind regarding the absence of participation in how these ethics are determined (Mackenzie et al, 2007).

The history of codes and guidelines of ethics used by academic institutions and organisations approving and funding research does not involve participants in research communities in the ethics guidelines designed with equal voice to the university ethics committees. The ethical guidelines that institutional ethics boards use to regulate research are originally not from the social sciences but from biomedical research (Guillemin & Gillam, 2004; Iphofen and Tolich, 2018), and now still remain as the core of ethics we need to subscribe to. Returning to the previous point on power and participation, I wondered what is the measure of good ethics, and who measures it? What and who is absent in the regulatory frameworks is worth understanding but beyond this research.

University ethics are focused on procedural compliance with Voluntary and Informed Consent; Confidentiality and Privacy; and Minimising Harm. These are ethical considerations that are important but are all established prior to the research, by the institution and the researcher. These ethical choices include the participants only a posteriori when they sign the consent and there is an assumption that participants are individually autonomous in this consent. I also remain aware that ethical applications cannot capture all the possible situated challenges that researchers can encounter in the practice. However I felt ill prepared for the ever present concern that ethics would become. The ethics guidelines seemed to me to assume a neutralising of the power hierarchies that may be involved. Once I had university approved ethics the messy reality of social relationships and status became clear as I realised in the pilot interviews. The two women readily accepted the interview and consent because I am a professional working at an RLO and they were keen to sign without having fully read or heard the consent form. I had to slow down

the consent process. They were so eager. I was perceived as a professional, of higher social class and status. They were delighted to have direct contact with me. This did not feel ethical and had the potential of false hope even when it was not my intention hence I changed the interviews to intakes with the RLO. It was a reflective moment for me and I did go ahead with more interviews with new precautions first ensuring the women already had started their support process at the RLO as well as being prepared to refer them to supports where I could at the end of the interviews and be clear when I did not have a possible path to offer (Hugman, 2013)

As a naive researcher how could I make sure I was not replicating the power imbalances of the Global North-South realities, of authoritative hierarchies? During successive interviews with women already involved in the support routes of the RLO, I wished to practise an iterative shared relational ethics, whilst remaining aware of the systemic inequalities. Relational ethics compels researchers to seek an answer to the questions of consent in our dialogues and relationships with others, to adopt reflexivity in our ethics rather than only performative form applications. Jacobsen and Landau (2003) speak of the dual imperative in refugee research on producing knowledge for research and/or for advocacy with the intention of making people's lives better. Spivak (1988, 2010) also talks of the tension in the impossibility of representation in contrast to the urgency of highlighting inequalities and oppressions through research. By asking myself questions in the background during my interviews it helped me focus not only on a 'do no harm' attitude but also on a 'do as much good as possible' attitude.

- What is the situated relationship between myself as the researcher and the participants?
- Does the relationship continue to feel mutually consented during the conversation?
- Is there a shared vulnerability?
- Can I share my vulnerability to make them feel more comfortable?
- Does the other person continue to feel comfortable?
- Are they still engaged, attentive? Do they want to be here?
- What should I do if I sense potential false hope that could lead to harm and distress?
- Ensuring they had support from the RLO or other entities I could refer with issues they brought up

Reflexivity may not be a hard measure of ethics compliance but I felt it important to remain continually engaged in these questions, thinking about how my positionalities and identities influenced how I was present in the research, what I was interested in, how did the participants show up and and how did they perceive themselves in the relationality of the research. As Guillemin and Gillam put it:

> "Adopting a reflexive research process means a continuous process of critical scrutiny and interpretation, not just in relation to the research methods and the data but also to the researcher, participants, and the research context. (Guillemin & Gillam, 2004, p. 275).

Regarding confidentiality, I was surprised that all the participants, every single one, manifested their wish to have their name used and not keep confidentiality in a first reading through the consent form. I was taken aback that this happened each time. In the cases of the women with children it was clear that they were sharing stories about their child who could potentially be identified at some point without their child having consented, this explanation was accepted and everyone's names anonymised.

This also became a consent process I had to engage in personally when I choose to write autobiographically and mentioned two children in my family, particularly I have talked in detail about the diagnostic process for my daughter - as you will read in the next chapter- in self reflective writing regarding my positionality as a mother of a child with a disability label. My daughter who has a diagnosis and her sister who lived through the process are both now adults, and both were keen to give their consent. However I asked them both to read the whole section before they committed their full consent. In all these cases it is unlikely these children will ever be impacted by this research being read further afield but it was an opening conversation with all the mothers that made them feel respected, one mother thanked me for pointing this out as she wouldn't have thought of it. Finally regarding consent and confidentiality I focused on these practices:

- reminding the participants during the conversation that they could leave at any time,
- spend time explaining consent and came back to it during the conversations
- shared the consent form before and during the conversations

- Front pages of consent form were a simple table with easy to read tabs on the consents given

Once I had the university ethics approval amended for online interviews due to the pandemic (Appendix One and Two) I contacted my fellow co-founders and workers from the RLO for permission to approach families for interviews. My requests were always met with positive responses, the idea was to use this research as a base to consider what research we could do that furthered the mission of the RLO. However at that point we had no protocols in place for consent apart from data protection policies for people who registered with us, so the university ethics was the central guide.

The ethical concerns I have grappled with have been focused on how to tell other people's stories, could/should I be the one representing the stories and crucially questioning the morals and ethics of engaging in interviews at very vulnerable moments in their lives. As I describe above I experienced the start of the pilot interviews as an exploitative mining operation I could not engage in. I stopped the interviews and registered the two people in the RLO to direct them to services. I came to autoethnography as a means to avoid the ethical pitfalls of interviewing people in desperate situations when what they were asking for was support to generate their own solutions to living. I continued with interviews but with the explicit and explained intention of not engaging in analysis based on the interviews but rather storytelling in the form of critical reflexivity autoethnographic writing.

I am also wary in the process of autoethnographic writing that the 'Other' is inherently engaged, represented and can be unacknowledged (Spry, 2018). As I describe in the following sections I have endeavoured, and not always succeeded, in bringing in the participants' opinions to the stories I was writing. In one sense, this is a failure of this research, and the best learning space to consider how to focus on the sociopolitical, philosophical, and material representations of the Other with the Other.

2.2 Research Methods and Participant Invitation

The call for Participants came from within the database of the RLO, where people had subscribed to be registered and had given approval for their data to be used within the foundation. I shortlisted around thirty women. The fundamental reason for them all being women is that over 90% of the people registered with us at that point were women and this trend continues today at the RLO. This in itself is an issue worthy of research to understand how this reflects the role of Venezuelan women in the migratory process to Colombia, the understanding of motherhood in the migratory process and in conjunction with disability. The conceptualisation of motherhood was not something I had foreseen in my initial research proposal or question formulations. Realising I was in dialogue fundamentally only with women, and that I have come to the research motivated by my own experience of mothering a child with a disability points to another novice research overlook, motherhood has been imbricated in this research from the start and the context where I now work and do the research is a community of women and mothers. I will turn to motherhood in the next chapters, suffice to lay here the seeds of this gap I need to attend to in the questions formulation if I am truly responding to the context.

The group of thirty women had all marked the presence of (dis)ability in a member of their family on their intake registration to the RLO. The common traits the women shared were that they were Venezuelan, forced migrants, who had come to Bogota with children and registered for support with the RLO in one of the localities we work in. They are in a process of support that could include: legal support, psico-social community support, child nutrition support, small grants for startup initiatives, or training for job seeking. In the first contact I asked if they would be interested in having conversations with me around the themes of their own migration stories and their children's. When they showed an interest they were given the information sheet (Appendix Three) to read and take home.

As I engaged with women who were showing an interest in participating and deciding, it became apparent that their notions of what is disability were widely diverse, they were sometimes unsure if their child qualified as having a disability because they did not have a diagnosis. They asked, is a stutter a disability? Is having difficulties at school a disability? Is a physical chronic illness a

disability? My child is disabled by this illness so does that qualify? And does joining in this conversation and maybe the research help me? I felt that the mothers themselves were asking what is (dis)ability and who determines that?

Many women did not respond to the call out, indeed many also did not respond to offers of services in general from the RLO. We know that often Venezuelan forced migrants don't have money to pay for data on their phones, or they share a mobile phone, in some cases people's phones are lost, stolen, or are not functioning. Often Venezuelan migrants with the highest needs for support have highly itinerant lives, moving around the city, or to other areas of Colombia or another country and even in some cases go back to Venezuela. In 2022-23 for example, Venezuelans in transit through Colombia going towards other countries (going south to Peru, Ecuador and Chile or going north through Central America to the USA) represent the largest percent of transient migrants nationalities: 65% (R4V, 2023a, pg 94).

In Table 1 below I describe the participants. From the initial call out I received responses from five mothers who volunteered to take part. They were asked to sign (See Appendix Three) the consent form. I received positive responses from three of the women, and within the ethical boundaries of the university consent process, we confirmed dates to talk.

I also received positive responses to engage in conversations within the ethical boundaries of the university consent process with five colleagues from the RLO and other foundations working for Venezuelans in Bogota (See Table 1). Three of these women are professional Venezuelans who are themselves forced migrants and are working to support the Venezuelan diaspora in Colombia, the other two women are Colombian professionals also working to support Venezuelan forced migrants specifically in Bogota. Two of these conversations were carried out in dyads, that is myself and two professionals together. The fifth participant was an individual conversation.

Table 1: Participants

People	No. of Interactions	Types of Interactions
5 NGO workers of different professions (social worker, psychologist, lawyer, administration)	1-3	Individual and Group, Online (Google suite) and Face to face conversations and interviews
3 Mothers	1-2	Individual Online (Google suite) conversations and interviews
Researcher- writer	Ongoing	Journaling, messaging to family and friends, emails, personal photos, vivencia writing

In Table two below I lay out the other central sources of data and information throughout the thesis and in the Vivencias writings have been policy documents from the Colombian government regarding Venezuelan refugees, families, education and disability. I have also sourced information from international organisations research, policies and reports regarding humanitarian issues and disability. Finally, given the impact of the Venezuelan migration on the continent of LatAm news reports have also been a source of information.

Table 2: Secondary Information Sources

Source Type	Information
Policy documents	Migración Colombia Ministerio de Relaciones Exteriores (GOV.CO) Instituto Colombiano de Bienestar Familiar (ICBF) Politica de Educacion Inclusiva para Colombia MIN.CO United Nations Convention On The Rights Of Persons With Disabilities Diagnostic and Statistical Manual of Mental Disorders 5 International Classification of Functioning, Disability and Health (ICF)
International and National Non-Governmental Organisations Reports	Humanity & Inclusion IDA International Disability Alliance UNICEF Migration in Latam reports OIM Colombia (International Migration Org of UN in Colombia) Regional Inter-Agency Coordination Platform for the Response for Venezuelans (R4V) UNHCR The UN Refugee Agency Global Refugee-Led Network Resourcing Refugee Leadership Initiative

| News Sources | El Tiempo (Colombia) |
| | La Voz de America |

2.3 Interviews Approach

To give the reader a sense of how the interviews proceeded I outline below the steps of the process for preparation, implementation and feedback.

Table 3: Interview Steps

Steps	Process
Preparation	Participant Selection process carried out together with colleagues using the criteria of (dis)ability having been marked in the registration with the RLO Design of conversation guide: a long list of open exploratory questions that I could dip in and out of during the conversations listening to what was important for participants, guided by solidarity and sensitively worded (Appendix Four.in Spanish and with English literal translation)
Initial contact and invitations	Invitations sent out to 30 people Research information shared (Appendix Two) Five women responded positively, and finally three engaged in agreeing a date Five colleagues from the RLO accepted to participate Consent form shared (Appendix Two)
Conversations with consent agreed	Consent agreed in writing or oral consent in the recordings Conversation Guide on hand (Appendix Four) Audio Recordings
Transcript Summary share	I used the voice to text app on google docs (Google Suite) to start the transcripts, I listened and corrected the transcript, listening to the recordings at least twice. I created a summary transcript that I shared with the participants for approval and comments.
Responses and Story writing	Using the transcripts and the responses (which were disappointingly few or brief) I wrote short stories and created imaginary connections between the short stories for the vivencias.
Share Stories	I shared the stories with each person, when it was possible, two of the participants were no longer contactable which is a very common occurrence with Venezuelan people in fluid migration flows in and through Colombia. Only three participants offered some details in their feedback. One more simply responded agreeing with the content.

The interview method and stance evolved after my first two pilot interviews with two Venezuelan mums during which I became acutely aware of potential barriers and pitfalls in our conversations that I wish to expand on here and how they influenced my ethical approach during the interviews.

1. My privileged position
2. Their previous experiences of interviewings
3. Their present day needs
4. Beyond do no harm

1. My privileged position

My privilege took on many forms: as a member of the RLO foundation they were requesting help from, as a researcher dictating the conversation and as a privileged Venezuelan professional with dual nationality. My original intention of giving voice and flattening my positionality by ignoring the hierarchy was challenged by the deference of people talking to me. At this point I had not yet come to autoethnography as the methodology. Rather than presume to eliminate the hierarchy I had to accept it, while questioning how it impacted the conversations. All forms of knowledge and information in research are embedded in forms of power and as a researcher I often felt quite powerless and frustrated with how little I'm able to do to change the perception of hierarchies. This is where the activism felt useful as at least I could point people towards solutions. In regards to presuming to represent the 'Other' as Spivak (2010) questions I remained uncomfortable. The Charter of Decolonial Research Ethics from the website Decolonialidad Europa postulates: "The logic that the researcher collects information to take to the university to analyse remains untouched, the privilege of the last word is successfully protected, and so is white imperial identity behind it" (*Charter of Decolonial Research Ethics*, 2013.) Remaining uncomfortable was an ethical necessity and when I came to listen to the interviews this tension moved me to autoethnography to displace representation of 'Other' with critical reflexivity on my positionality.

2. Women's previous experiences of interviewings

I became aware that the people I interviewed have sat through institutional interviews as we all

do throughout our lives, but in particular in their recent history they would have undergone borders interviews with police and or migration officials, health service interviews, local government registration interviews; or they might have found ways to avoid all of these interviews as they crossed borders and were highly suspicious of any authoritative interviews. They have particular unique complex experiences of institutional interviewing and intimate knowledge of these experiences. Each potential interview was an opportunity for access, or a barrier or worse an official condemnation of their presence in Colombia with very real repercussions of deportation. I was very clear from the start that the interview would not impact the support they were receiving from the RLO or their role as a professional and that they could stop at any time. I opened interviews with the ethics questions and consent, and I tried to co-construct whether this was of interest to them, what were their priorities, and we could come back to this during the interview if they felt uncomfortable. Listening to the directions the conversations travelled to in people's memories, wishes, and nostalgias, I used the list of potential questions to dip in and out of the themes that arose in the conversations.

3. Present day needs

The pilot interviews gave me the acute awareness that people's present day needs took precedence over any conversation about life histories and their lived experiences. I was aware that while people were open to talk, the motivation could very well be what they could gain. The reality of their need to be out earning a living, the urgency of unfulfilled basic needs, the future of families was at stake and took priority. As I had set out from the very start of this research, I intended and hoped to stay open to hear the stories in the smallest moment of the conversations, to listen to the Nos hidden in the need to be complacent, the politeness and the need for connections.

4. Beyond Do no harm

I was also very acutely aware of how I could elicit harm in the conversations by bringing up difficult memories of forced migration travels, talking about diagnosis, and talking about leaving home or indeed of inadvertently giving false hopes. I don't think we can ever guarantee no harm, every action can have unknown triggers or consequences, but I could support trauma recall empathetically if the person so desired to share and I knew I counted on the ground with a team

of social workers, community leaders and psychologists to whom I could also refer a person for more support if they wished. Considering the precariousness of Venezuelan forced migrants lives the answer for me to 'do no harm' is rather to have an ethics of 'do good' within my possibilities (Mackenzie et al, 2007).

A way to enact an ethics of 'do good' was to be with the women in dialogue spaces, not as neutral one sided interviewing but as a conversation. It was important to acknowledge their strength, listen to their requests, let them lead the relational emotional dialogue and be aware of the responses they evoked in me. When I felt it was appropriate to give space for solidarity and empathy, I shared my responses. I would like to give a brief example. One mother was telling me of her daughter's diagnostic process in Colombia, and one element of her story in particular resonated with my own experience as a mum, when she finished telling me about the diagnosis I shared that I had had a similar experience with my daughter, without going into detail. This sharing made her very emotional and she proceeded to share a lot more about her opinion on the differences of the process of diagnosis between Venezuela and Colombia. Being open to share on my part is a delicate balance. However I have extensive experience as a psychologist and counsellor in talking, interviewing and listening to people, this is my daily job. In my professional experience over time I have had the realisation that leaving my personal self totally out of interviews and conversations (as I was trained in my psychology degree) creates an illusion of the expert professional that I endeavour to shed to make less distance, more connection and honour people's expertise of their lives. In my daily practice as appropriate and centred on the person in front of me, I do share my life experiences and what I have learned and researched in a very explicit manner. I find this way of working more authentic and human. As an activist researcher these interviews were different to my work roles in the objective but my experience of talking to people helped me to build empathy and reciprocity in the conversation.

2.4 Vivencias Writing Process

In this section I outline the trial process for writing up the interviews and my own experiences writing in a narrative storytelling format. I have written with an autoethnographic eye and created stories based on the interviews. These stories are presented from an autoethnographic

stance, that is I am placing myself as the writer. I am accepting I have had time and geographical limitations to create the methodology of participation led within a collective that I had hoped for. I have endeavoured to relay the summaries of transcripts and drafts of the stories to the people interviewed. The response was disappointing and limited to four people, all of whom were the professionals I engaged with. This was one of the many reasons why I have set out to not say I am representing the voices of participants but telling stories 'from my eyes' as I received them. The stories are written surfacing autoethnographic reflections weaving the interviews, my positionality and other information sources. I made the choice to not attempt to analyse the interviews with linguistic analysis, discourse analysis or finding thematic concepts or coding for content analysis (Cohen et al, 2011) but to write stories where of course I am editing and picking the narratives with the themes that resonated with my explorations and responses to their words (Diversi et al, 2021; MacLure, 2013; Schewe & Vain, 2021).

The vivencias I put forward are what I have heard, learned and gave me pause to reflect how we gather stories in the RLO. The listening, feeling and retelling with the mediation of my own identities, was and continues to be my explorative descolonial responsibility.

The 'Vivencias' in Spanish use Venezuelan slang, idioms, dialogue from the conversation and are a fusion of various interviews. This is important because I know that speaking with Venezuelan idioms and accent was an important rapport with the women. The storytelling artefact I have written the stories with has been to put people's ideas and words within an imagined narrative of having met Esperanza, and to fuse moments from different interviews. Both volunteer professional RLO workers and the women interviewed have been fused into characters that hide their identities but use their words to tell stories as I heard them. This fictionalisation artefact of fusion is an autoethnographic revelation of my descolonial imaginary, of my privileges in the research space and hopefully also of my unlearnings. I have avoided all encompassing life stories and preferred to focus on moments I was told about that impacted me, like getting a lift from someone, or the effect of meeting one person, or having to get on a bus to beg. I hope that by focusing on located and specific scenes I have avoided portraying essentialized identities. Each of the women who spoke with me have their own stories that are not generalisable to a whole community, they are sometimes micro moments that the person

talking felt was an important moment for them or arcs of their migratory story. The use of some fictional elements such as creativity, analogy, fusion in social science methods has been proposed as divergent modes of constructing knowledge from a critical and troubling stance (Dutta, 2018). The gestures translated into fiction - such as giving a late night lift to Venezuelan caminantes- allowed me to return to some stories of arrivals and walkers. By merging different interview experiences with the news and professional experiences, including my own, by telling them in this different fictionalised form I felt I could expand our imaginations- the writer and the reader- to put ourselves in the car. In a way I am searching for devices that limit the readers tolerance of emergencies as we are inundated by tragedy every day in the news and to expand to epistemologies that inhabit the urgency of up until now unimagined lives. One of the professional interviewees in a review of the story, suggested the inclusion of hearing the drivers inner thoughts which implicated a critical thinking that I hope enhanced the possibility of the reader putting themselves in the shoes of the driver. It is not a heroic saviour story but the solidarity of giving a lift represents the solidarity I see daily in the work the Venezuelan and Colombian professionals do everyday at the RLO.

The stories are about my entanglement with the research activist process and with the discourses of the Venezuelan forced migrants I have talked to and within the workings of the RLO within the global aid system. The stories are contingent and reconstructive of activist relationalities within colonial hierarchical governmental, medical and humanitarian structures (Dutta, 2018) that we are growing in awareness of and endeavouring to shed in the way we do our work in the RLO.

Outline of the story writing process:
- Summary transcript of each interview
- Summary transcript sent to each participant
- Feedback received
- Story writing with verbatim narratives
- Request for story feedback
- Rewriting of the story

The stories are written based on the summary transcript of each interview. The transcripts were sent to each participant as part of the relational ethics I wanted to adhere to and so they could

talk back to the written words I had recorded and amend, add or respond in any way they wished. The stories were then written based on those transcripts. I used snippets from the transcripts, the ones that represented the themes I am exploring of othering such as : diagnosis, forced migration, school placement and inclusion. The hardest choice I made in writing these stories was the contradiction of upholding the principle of not speaking for 'others', of making people's voices count whilst I openly focused on the personal connection and response I have had to their stories. This manner of reproducing the narratives is the most authentic way I felt to be transparent about this being my interpretation. The names and any distinguishing features of a person's identity within the stories were altered and identities fused fictionally to protect confidentiality and anonymity without altering the essence of our conversations (Sparkes, 2024; Tullis Owen et al., 2009).

I then sent the stories to the participants for feedback. This is probably the most disappointing aspect of the research that personally I had to come to terms with. Most people were not contactable any longer or did not want to respond. This was where I had felt the participation could have been fruitful and collaborative. I am aware of the difficulty of maintaining contact with people who are on the move migrationally or professionally, and this included the three women with whom the RLO lost contact and one professional that lived in another city. This is one of the learning spaces to be developed within the RLO for more collaborative research in the future.

According to Ellis (2007), relational concerns are an important dimension of reflection in autoethnography that need to be continuously present during the research and writing process. This also requires autoethnographers to share the writings to people who have been interviewed, acknowledge and include their responses. I was disappointed I didn't get as many responses as I had hoped for, even acknowledging the financial and communication barriers the response was low. I have had to accept this as a reflection of my expectations of others when they do not truly feel participative in the research. I got detailed responses from professionals with whom I had had a relationship prior to the research interviews. I only received feedback from one mother and it was one of approval with no comments and we were not able to find a moment to talk.

2.5 Quality in Qualitative descolonial Research

> A critical social science literally requires that the researcher reconstruct the purposes of inquiry to engage with the struggle for equity and justice, while at the same time examining (and countering) individual power created for the researcher within the context of inquiry. (Cannella and Lincoln, 2018, pg. 173)

Questions of validity, reliability and the criterias to assess them are highly contested and disputed in qualitative research (Lincoln, Lynham and Guba, 2018). The fundamental strategy and notion that has guided me in regards to the quality of the research is subjective reflexivity.

Writing auto-ethnographically with subjective reflexivity is not simply talking about myself but about planting myself in the dialogue (Harari, & Pozzebon, 2024; Lincoln et al, 2018; Maldonado-Torres, 2016), and with 'sentipensar' using narrative to describe the ethical contradictions of my privileges, the tensions of activist scholarship, the complexity of the cultural environment, the relationality in the interviews, the risks of reenacting of discriminatory cultural and political practices in the aid system. As I was listening to the women I talked with and reflecting on my responses to the culture of displacement, I often felt overwhelmed.

Why does my response matter in the light of what Venezuelan forced migrants are going through? Canella and Lincoln (2018) propose an ethical reflective perspective based on relationships rather than subjects. Walsh (2018) focuses on dialogue not being sufficient if the hierarchy in power relationships is not acknowledged, she uses the term interculturality to move away from attempting to represent the 'Other' and rather be proactive in recognising and naming the differences to build relationships that open intercultural dialogue.

I have come to review self-reflexivity not as a navel gazing exercise but rather as essential unlearning needed to enact methodologies within a descolonial turn. Following McCabe and Holmes (2009) I am not engaging in an understanding of my subjectivities as an exploration of my biases. I am examining reflexivity as a tool on how my contradictory identities, my privileges and my history impact the research process and my relationality with participants, as well as how these relationalities are a reflection of the coloniality of power within which we inhabit. Hence, subjective reflexivity is not an admission of bias to ensure validity in the

research, but rather I am questioning the modern psyche knowledge I was trained in and my hierarchical position due to the geo-political history I was born into.

In regards to reliability within autoethnography, Ellis, Adams & Bochner (2011) frame it as related to the narrator's trustworthiness. They ask:

> Could the narrator have had the experiences described, given available "factual evidence"? Does the narrator believe that this is actually what happened to her or him (Bochner, 2002, p. 86)? Has the narrator taken "literary license" to the point that the story is better viewed as fiction than a truthful account? (Ellis, Adams & Bochner, 2011, p. 282)

Lincoln, Lynham and Guba (2018) state that validity concerns in qualitative research are about legitimacy and authenticity, they ask if findings can generate actions for participants that can benefit them? In autoethnography, Bochner and Ellis (2016) focus on authenticity when they ask: is the writing describing events that are realistic, plausible, makes sense? I hope by describing my writing process where I am producing knowledge about my vivencias of the conversation with the participants I have managed to convey the social realities of our conversations and that in some manner allow the reader to enter into the subjective world of the relationships between myself, the professionals and the people experiencing forced migration in Colombia. I find Bell's (2018) reflections on descolonial atmospheres relevant here, she states how rising subjectivity within psychology and pedagogy relate to reflexivity in the quest to reconstituting ourselves and the groups within which we operate, outside of coloniality.

My subjectivity in this search for alternative methodologies is also imbued with other elements that are traditionally kept outside of the rationalists western episteme toolbox: feelings, senses, connections, relationships. Harari and Pozzebon (2024) describe radical principles that unlimit methodology to stay within solely conceptual/rational/critical explorations and move towards unlearning and interculturality (Walsh, 2012). Two of the principles they have reassembled from their Latin American literature review are "escrevivencia' (writing living) coined by Evaristo and 'sentipensar' (feelthinking) of Fals Borda (2009). These are tools that have connected me to writing narratives based on my dialogues with forced migrant Venezuelan women and

professionals that are imbued in my personal subjectivity and my experience of them. I have written about my understandings, my connections and responses in the conversations as an analysis of the geopolitical reality that we are immersed in, and how this process constructs relationships between us but how we do collaborative work with them in the RLO now and in the future.

Methodological Implications꞉ Explore Altern Methodologies for representation

In the last two chapters I have been exploring ethical methodological choices given the context of the research, the 'vulnerabilsed' community I am working within and my own critical reflexivities with the complexities of self-descolonising, representation and voice. The methodological implications arising have been about embracing 'other' ways of knowing (Thambinathan and Kinsella, 2021). I had not imagined autoethnography as a possibility at the start of this research but reviewing Spivak's (1988) critical reflexivity on representation and the clear necessity of self-criticality in the face of my internalised imbricated mestiza heterogeneities, autoethnography became my choice of 'metodologias otras'. It is a continuation of my answering the questions on how to descolonise this research and myself. Representation has implied multiple ethical conundrums of not purporting to represent others' voices and at the same time finding ways to tell stories because of the moral imperative of social justice for those who do not have a voice are marginalised and invisible. My experimental hope is that by taking back the storytelling vivencias experience to the RLO we can engage in storytelling by the community.

> … the autoethnographer not only tries to make personal experience
> meaningful and cultural experience engaging, but also, by
> producing accessible texts, she or he may be able to reach wider
> and more diverse mass audiences that traditional research usually
> disregards, a move that can make personal and social change
> possible for more people (Ellis et al, 2011, pg 277)

In embracing autoethnography I am experimenting and embracing 'othered' ways of knowing--through narrating my vivencias whether they be personal autobiographical reflections as in chapters one and two or narrating my reflections following my conversations with participants. The story of Vulnerability is an experimental writing of my reflections from conversations with professionals working in the humanitarian migration sector and women arriving in Bogota. My reflections here are personal and relevant as a researcher in that they exemplify the social systemic structures we are operating within. The story reflects how I relate to the professionals' tension by contesting the discourse and vocabulary of colonial structures in the humanitarian aid system such as 'vulnerable people' while working within the very structures we are seeking to contest.

The frequent suspension moments during this research and the immersion into the descolonial turn of learning and action have led me to attempt a rupture in the dominant academic forms that I was trained in for writing, researching and producing knowledge. How to explore knowledge in a way that is respectful and includes the relationships I have formed in the research? For me this implied a rupture of the dominant forms of writing and producing knowledge of an academic thesis. Ethically and politically it is imperative to remain aware of pitfalls of designing methodologies from the lens of an individual or Global North researcher, I am not proposing autoethnography as a methodology that resolves ethical issues of representation, rather it has been my solution in this individual dissertation. To engage in methodologies for descolonial activist knowledge production necessitates altern methodologies that must be designed within the research community.

Research Question Review

In the previous chapter I questioned what methodology I could engage with ethically to investigate the original conceptual research questions around (dis)ability from a descolonial lens. In this chapter I have explored autoethnography as an "othered' way of enacting ethical research. I now turn back to the conceptual research questions focused on what it is that I am researching about (dis)ability in the context of forced migration through a descolonial lens. Given my background and what brought me to the research, and the context of working with mothers at the RLO I have changed Venezuelan families to Venezuelan mothers in the question.

If I include the notion of (dis)ability in my line of questioning, am I staying within the very same western hegemonic knowledge on (dis)ability that I set out to question? In the next chapter I turn back to conceptual questions on disability in the context of how it could be formulated in research questions while the focus of the research is contesting the very conceptualisation of (dis)ability. The question I turn to address in the next chapter is:

- What can the term (dis)ability mean in a descolonising research question in the context of Venezuelan mother's vivencias of forced migration?

Chapter Three Summary

In this chapter I have reviewed autoethnographic storytelling methodology and how 'sentipensar' defines my presence in the research. I have described the ethical conundrum of interviewing and conversing online with people for my research in hard moments of their lives, and how I could only reconcile by ensuring the people I was talking with were receiving support from the RLO or another organisation, and by having the goal of creating some draft principles for the RLO that we can develop in the community for co-crafting storytelling. In each chapter I am formulating what these research and storytelling principles could be. That will be the focus of the last chapter.

I have described the steps of the research, the ethical considerations both during the interviews and in the writing process, within the ethical guidance of the University of Sheffield as well as the relational ethical considerations of the context. The ethical concerns are also described as leading to autoethnography. The following chapter starts with mothers narrating diagnostic processes of their children. The *vivencia* we are warrior mothers sets the scene to explore (dis)ability from a descolonial lens as an epistemological stance to ponder 'othering' and how this can inform research question formulations.

Chapter Four Warrior Mothers and (Dis)ability: The descolonial hope of being

> Superiority? Inferiority?
>
> Why not the quite simple attempt to touch the other,
>
> to feel the other, to explain the other to myself?
>
> Black Skin, White Masks
>
> Frantz Fanon (2008, pg 181)

Prelude

In this chapter's story: Madres Guerreras (Warrior Mothers) I write about my vivencias of the conversations with Venezuelan women in Colombia and their migration experiences with diagnosis and finding school places for their children, some of them with a labelled (dis)ability. The stories are my *vivencias* as I heard the conversations and later reflected upon. Listening to the women's *vivencias* also changed me, our conversations impacted my views. Listening to other mothers' *vivencias* made me relive my own family's diagnostic story, reweaving my understandings on colonial history of othering regarding dis/ability, gender, motherhood and other imbricated, naturalised or legalised identities. As in other chapters the fictionalised narrative is based on my interpretation of the *vivencias* shared as well as an auto-ethnographic reflection of my *vivencias* as a mother of my child's diagnosis.The relational materiality of these '*vivencias*' are the meanings I make, with 'sentipensar' and 'escrivivencia'. I stand in this research not because I am a mother of a child with a label but because I know what it feels like to be a mother of a child with a label.

I heard in our conversations how we have internalised the notions of hegemonic western psyche apparatus epistemology within our Venezuelan and Colombian cultures. By reflecting on my story next to the Xiomara and Esperanzita's stories I wish to question and disobey the assumed neutrality of standard western social science researcher positionalities that has universalised 'objectivity' as a form of producing knowledge. These vivencias are part of this thesis' methodological trial on exploring how to formulate 'sentipensar' research questions with contested constructed notions of (dis)ability, migration, childhood, motherhood and love.

Vivencia: Somos Madres Guerreras

Mamá, tengo miedo, ¿es que no soy normal?
Es Neurodiversidad
Ella no puede hablar
Aquí estoy con un nudo en la garganta
porque lo vuelvo a vivir,
pero lo vuelvo a contar cuando lo tengo que contar,
esas son cosas que nunca se nos van a olvidar a nosotros,
no se nos pueden olvidar.

Xiomara

Bueno mira, realmente yo me fui de Venezuela primero fue por mi hijas, como madre yo quiero lo mejor para mis hijas, por esa crisis que afectó a Vzla, no se conseguía nada, no había medicamentos, no se conseguían alimento, nada y realmente uno solo trabajaba para apenas sobrevivir.

Me traje todos los papeles del diagnóstico de Marisol desde Venezuela. Llegando a Colombia fue cómo construir todo de nuevo. Aquí hay una estructura de salud y educativa muy diferente, nadie te explica cómo funciona y tienes que aprender. Mientras más tu exageres algo, más las autoridades en salud y educación te prestan más atención. Eso me lo decían también los mismos médicos: hay que exagerar. Aquí nos reconocieron el diagnóstico de autismo de mi hija pero quisieron hacer todo el proceso de nuevo y tener la información de primera mano y con todos sus especialistas y verificar si ese diagnóstico coincidia con la realidad.

Esperanzita

Bueno en nuestro caso realmente yo no sé si eso contaría como una discapacidad como tal pero a ella me le cuesta mucho comunicarse así como estamos hablando nosotras. Para comunicarse es súper difícil porque ella tartamudea, casi nunca puede hablar tan fluido. Entonces hay momentos en que le cuesta mucho mucho decir una palabra, a veces para decir una sola palabra tiene que quedarse callada un rato y entonces uno como que la va ayudando. Cuando estaba muy pequeña en Venezuela, tenía como cuatro añitos más o menos yo la llevé un par de veces a terapias de lenguaje pero después no pude llevarla más por la misma situación económica. Siempre he sido sola porque su papá falleció cuando ella apenas tenía tres añitos.

Eliza

El proceso de diagnóstico de mi hija fue un acto de equilibrio para protegerla. Mi hija siempre ha sido divertidísima en casa y dolorosamente tímida, casi muda más allá de los límites de la casa. Yo sabía que mi chiquita tenía características que podrían calificarse de autistas (extremadamente tímida y callada) y también sabia que no se reconocerían como las características autistas "típicas" (masculinas). Fue el día a los 9 años cuando compartió con una psicóloga sus experiencias de alucinaciones y visiones que disparo la alarma. La psicóloga insinuó preocupaciones alarmadas de psicosis. Fue entonces cuando busqué activamente especialistas que descartaran esa idea. Sabía que un diagnóstico de psicosis no era para mi hija, y además que ese diagnóstico sería condenatorio, psicoactiva mente peligroso por los medicamentos que podrían indicar y muchísimo más discriminatorio que un diagnóstico de autismo para su contexto escolar. Fue una batalla emocional, una montaña rusa de aprendizaje en la que tuve que ser un motor sin parar para proteger a mis dos hijas. (Escuchar a Esperanzita y a Xiomara me recuerda mi privilegio de saber navegar el sistema por ser profesional del mismo sistema y por no ser pobre, ni migrante, los profesionales me escuchan y tengo los medios para acceder al sistema.)

Xiomara: Es Neurodiversidad

Pues les cuento que Marisol fue objeto de estudio (por decirlo de una manera) porque recibimos apoyo de una universidad aquí y se ofrecieron a darnos también un psicólogo, es decir que teníamos un psicólogo por el SISBEN (seguro social) y otro por la universidad. Y como Marisol en ese momento era no-verbal a los tres años en todas las pruebas psicológicas daban para un diagnóstico autista pero lo que pasa es que tenía muchas habilidades que otros niños autistas no tienen y otros criterios que ella no cumplía. Por ejemplo ella no tenía conductas repetitivas, socializaba super bien, no tenía esas sensibilidades como otros de taparse los oídos, de pronto el tema del tacto, eran todas esas características que no reunía. Entonces allí es cuando los especialistas me dijeron que estamos hablando de un espectro que es muy grande y que realmente no podemos etiquetar a la niña como autista porque realmente no reúne todas las condiciones para hacerlo, es neurodiversidad. Sin embargo decían que desde el punto de vista del sistema de salud acá lo vamos a tener que hacer para que le presten más atención a la niña y también para que respeten eso dentro del sistema educativo.

La psicóloga me dijo: Si yo no le doy este diagnóstico cuando la niña se enfrente al colegio no van a tener esas adecuaciones académicas que ella necesita, sino que le van a exigir como a todos los niños neurotípicos, van a tener muchas frustraciones y la niña no va a avanzar. En cambio con un diagnóstico es distinto, le van a dar mas apoyo. La psicóloga me preguntó si yo estaba de acuerdo en darle el diagnóstico. Es decir, me consultó en aprobar el diagnóstico aunque no era claro. Yo le decía que todo lo que fuera para beneficios de la niña yo lo aceptaba, sobre todo para que le dieran las terapias de lenguaje. La consideraron un caso atípico y la decisión fue darle un diagnóstico de autismo leve.

El apoyo en la escuela es bueno, pero no es suficiente. Muchas veces me llaman para que la recoja antes de que acabe la jornada escolar porque ella ha recogido todo en su morral, sale de clase y se va para afuera sola al patio a esperarme. Dicen que no tienen suficiente apoyo para ayudarla.

Esperanzita

Yo no pude como quien dice continuar con las terapias de lenguaje en Maracay pero lo que me decía la terapista era que la tartamudez es algo que no tiene cura, solo que a medida que van creciendo ellos lo van aprendiendo a controlar pero yo he notado que ella no está okay y le cuesta mucho en público. La intente matricular en el colegio aquí pero cuando la escuchaban me decían que no había cupo. Así que no fue tan inmediato lo del cupó. Lo logre cuando hice todo el proceso que se hace por la página web y le había salido colegio por allá lejísimo de la habitación, y a mí me daba miedo porque le pasara algo porque salía en la tarde. Le tocaba el turno de las 3:00 a las 6:45, casi que salía de noche. Imaginate si yo no conocía nadie hacia allá. Pero ella tenía que seguir su educación aquí en colegio colombiano. Entonces por suerte aquí una señora que conocí me hizo el favor, me dijo no te preocupes vamos aquí al colegio cercano yo hablo con no sé quién, hacemos no sé qué y así fue lo hablamos y me pidieron los papeles yo los tenía la mano y me lo hicieron las matrícula del mismo colegio aquí cerquita. Pero nunca me han dicho nada de psicologo o terapia de lenguaje.

Eliza

A mi familia al final nos dieron el diagnóstico de Trastorno Generalizado del Desarrollo No Especificado (TGD-NOS). ¿Imagínense cómo explicar ese nombre a mi niña? Un dia me pregunto "Mamá, tengo miedo, ¿no soy normal? En su colegio compartimos el diagnóstico como espectro autista, yo siempre me negué a la palabra trastorno. ¿Cómo explica una madre, un padre estos términos a nuestras hijas sin marchitarlas? ¿Cómo no hacerles sentirse invisibles y/o inseguras ante sus adultos más queridos y que les dan seguridad?

Xiomara

En el colegio la aceptaron porque aquí es diferente que en Venezuela, aquí tienen que aceptar a todos los niños por la inclusión. Fue duro cuando inició primaria, el apoyo es una o dos veces a la semana y para Marisol llegaba el momento que no podía más. Iba todos los días feliz pero a media mañana recogía sus cosas y se iba afuera a la zona de recreo a esperarme. Me llamaron que no tenían personal para estar con ella. Y allí me la encontraba parada sola afuera con su morral esperándome.

Esperanzita

Si le gusta aquí o no el colegio no lo sé, creo que si le gusto, no se si se burlan o no se burlan de ella o si le hicieron bullin. ella no me lo dice no se si le dará pena para no preocuparme, no me dice nunca por ejemplo que pasó una mal momento, no nunca jamás me lo me lo llegó a contar, no lo se. Yo tengo que resolver, yo he llorado mucho pero yo soy polifacética, yo sé hacer muchas cosas pero me ha tocado vender bolsas de basura en el transmilenio. A nosotras que nos ha tocado trabajar informal. Ahora que esta más grande a veces ella quiere ayudarme a salir a vender bolsas o dulcitos, imagínate montarte en un bus por horas a ofrecer vender conmigo y no puede hablar, eso es fuerte. Aquí estoy con el nudo en la garganta- lo vuelvo a vivir.

Eliza
Escuchar las historias de tantas mujeres ha sido doloroso, incómodo, tierno, a veces nos reímos, a veces hay silencios, a veces les digo que son fuertes, a veces me cuentan cosas que me dan tanta tristeza, oigo el duelo en sus voces y tambien veo la esperanza. También me recuerdan momentos de mi vida, y he revivido la etapa de diagnóstico de mi niña. Me di cuenta de que había un segmento de esta historia de diagnóstico-el segmento psicótico- que nunca había conversado con mis hijas. Necesitaba hablar con las dos antes de compartir por escrito aquí este momento en nuestra historia familiar. Si estás leyendo esto ahora, sabes que lo hemos hablado mis hijas y yo, que ellas leen y son parte de tu lectura y mirada. El recuerdo es asi:

Un día llegamos a casa del colegio y estábamos haciendo nuestra rutina de presión profunda para mi hija que le alivia las tensiones del día, (aun hoy en día le encanta) y fue entonces cuando me preguntó en voz baja: "Mamá, tengo miedo, ¿no soy normal?". Sentí tristeza, indignación, dolor.... No sé si tengo palabras para describir el torrente de emociones. ¿Qué significan para ti los términos PDD-NOS y 'trastorno'? Para mi 'trastorno' es la frontera entre los que no tienen diagnóstico por un lado, y todos los demás, los problemáticos y los condenados, del otro lado. Este término desconcertante no existía cuando me licencié en la universidad y tampoco existe ahora, ya ha sido eliminado del último DSM. ¿Cuánto tiempo duró esa categoría? Y pensar que formo parte de sistemas profesionales que hicieron que mi hija -o cualquier niño- se sintiera así. En ese momento lo mejor que pude hacer fue explicarle a mi hija que lo "normal" era un invento, que nadie es normal. Tomé prestado a medias el lenguaje de la neurodiversidad -no la parte de que sólo algunos son neurodiversos-, que todos somos diversos como las flores. Fue la mejor metáfora que pude encontrar en aquel momento para que mis dos hijas de 9 y 11 años procesaran el diagnóstico.

Conversando con mamás venezolanas migrantes en Colombia, sentí que sus historias y las mías compartían vivencias de madres protegiendo a sus hijas y sobreviviendo. Pero nuestras supervivencias son muy diferentes, la mía está llena de privilegio de mujer profesional mestiza blanqueada en Europa. Como psicóloga profesional yo pude buscar un equipo que le diera a mi

hija un diagnóstico que dentro de nuestro contexto protegeria su derecho a la educación. La historia de Esperanzita es de determinación, pobreza, abandono institucional, solidaridad, y amistad. Xiomara, en su migración tuvo que moverse mucho, y como profesional tiene las herramientas para navegar el sistema. Quizás lo que compartimos desde espacios muy distintos es ser madres batallando contra el sistema.

Yo quería que mis dos hijas se sintieran personas completas tal y como son y que se sientan ante la vida como se han sentido en familia; abrazadas ferozmente tal y como lo han hecho generacionalmente nuestras madres venezolanas, colombianas y galesas. Quiero que sientan que su madre, la madre de ella y su abuela, todas nuestras madres ancestrales nos mantienen unidas atravesando continentes habiendo pasado por quién sabe qué historias indocumentadas de pobreza extrema, xenofobia, prejuicios, violencias, abandono, hambre, migración, adopción, denigración, otredad, asfixia. Una etiqueta diagnóstica no iba a quebrar la fortaleza que nos viene de nuestras madres ancestrales a ambos lados del Atlántico, que inspirada por las representaciones en teatro de mi hija, aquí nombro: Margaret Elizabeth, Patricia, Sonia, Elisa, Margot, Fidelia, Sarah Ann, Natividad, Jane, Nena, Antonia, Mary, Nieves, Catherine, Anne, Olga, Lida, Ana...

We are Warrior Mothers in Translation

Mama, I'm scared, am I not normal?
It's Neurodiversity
Can't speak
Here I am with a lump in my throat
because I'm reliving it,
but I tell it again when I have to tell it,
these are things that we will never forget,
we cannot forget them

Xiomara

Well look, I left Venezuela really first of all for my daughters, as a mother I want the best for my daughters. Because of the crisis that affected Venezuela, you couldn't find anything, there was no medicine, you couldn't find food, nothing and really you just had to work to barely survive. Having a child with autism wasn't the problem, feeding them to stay alive, that is the problem and the reason to leave.

I brought all of Marisol's diagnosis papers with me from Venezuela. Arriving in Colombia it was like building everything all over again. Here there is a very different health and educational system. We had to learn how the system works here, nobody explains it to you and you just have

to learn. One thing I know is that the more you exaggerate something, the more the health and education authorities pay more attention to you. This is what the doctors themselves told me: you have to exaggerate. Here they accepted my daughter's autism diagnosis but they wanted to do the whole process again and have the information first hand and with all their specialists and verify if the diagnosis coincided with reality.

Esperanzita

Well in our case I don't really know if that would count as a (dis)ability as such but she finds it very difficult to communicate like this the same way we are talking. It's very difficult for her to communicate because she stutters, she can hardly ever speak very fluently. So there are times when it's very difficult for her to say a word, sometimes to say a single word she has to keep quiet for a while and then you kind of help her along. When she was very young in Venezuela, when she was about four years old, I took her to speech therapy a couple of times but then I couldn't take her anymore because of the same economic situation. I have always been alone because her father died when she was only three years old.

Eliza

The process of diagnosing my daughter was a balancing act to protect her. My daughter has always been fun-loving at home and painfully shy, almost mute beyond the confines of the house. I knew that my little girl had qualities that would qualify as autistic (extremely shy and quiet) and I also knew that her qualities might not be recognised as "typical" (male) autistic characteristics. It was on the day at the age of 9 that she shared her experiences of hallucinations and visions with a psychologist that the alarm was raised. The psychologist hinted at alarming concerns of psychosis. It was then that I actively sought out specialists to rule out the idea. I knew that a diagnosis of psychosis was not for my daughter, but also that it would be damning, chemically dangerous and far more discriminatory than a diagnosis of autism in our context. It was an emotional roller coaster of a learning battle in which I had to be an engine that kept moving to protect my two daughters. Listening to Esperanzita and Xiomara reminds me of my privilege of knowing how to navigate the system because I am a professional in the same system and because I am not poor, nor a migrant, professionals listen to me and I have the means to navigate the system.

Xiomara

Well, let me tell you that Marisol was an object of study (so to speak) because we received support from a university here and they also offered to give us a psychologist, that is to say that we had a psychologist from SISBEN (social security) and another from the university. And as Marisol at that time was non-verbal at the age of three, all the psychological tests indicated an autistic diagnosis, but what happened was that she had many abilities that other autistic children don't have and there were other criteria that she didn't meet. For example, she didn't have

repetitive behaviours, she socialised very well, she didn't have those sensitivities like others, she didn't cover her ears, perhaps the issue of touch, all those characteristics that she didn't meet. So that is when the specialists told me that we are talking about a spectrum that is very broad and that we cannot really label the child as autistic because she does not really meet all the conditions to do so, it is neurodiversity they said. However, they said that from the point of view of the health system here we are going to have to do it so that they pay more attention to the child and also so that they respect this within the educational system.

The psychologist told me: If I don't give her this diagnosis, when the child goes to school she won't have the academic adaptations she needs, but they will demand more from her like all neurotypical children, they will have many frustrations and the child will not make progress. On the other hand, with a diagnosis it is different, they are going to give her more support. The psychologist asked me if I agreed to give her the diagnosis. That is to say, she asked me to approve the diagnosis even though it was not clear. I told her that I would accept anything that would benefit my child, especially to give her speech therapies. She was considered an atypical case and the decision was to give her a diagnosis of mild autism. It has helped with the support she gets in school now, but it is not enough.

Esperanzita
I couldn't continue with the speech therapy in Maracay but what the therapist told me was that stuttering is something that can't be cured, only that as they get older they learn to control it but I have noticed that she is not okay and it's very difficult for her in public. I tried to enrol her in school here but when they listened to her they told me there was no space. So the school placement wasn't so immediate. I managed to do it, I went through the whole process through the website and she got a school placement far away from our rooms, and I was afraid that something would happen to her because she had to go in the afternoons. Her schedule was from 3:00 to 6:45, so it was almost like she was leaving school at night. Imagine, I didn't know anyone there. But she had to continue her education here in a Colombian school. So luckily a lady I met here did me a favour, she told me not to worry, let's go to the nearby school, I will talk to I don't know who, we will do I don't know what, and so we talked and they asked me for my papers, I had them handy and they did the enrolment right there at the school here nearby our rooms. But they have never said anything about a psychologist or speech therapy.

Eliza
In the end my family was given the diagnosis of Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). Imagine how to explain that name to my little girl? One day she asked me "Mummy, I'm scared, am I not normal?" At her school we shared the diagnosis as autistic spectrum, I always refused the word disorder. How does a mother explain these terms to our daughters without making them feel invisible and/or insecure, us being their most loved adults who give them security?

Xiomara

At school they accepted her because it is different here than in Venezuela, here they have to accept all children because of inclusion. It was hard when she started primary school, the support is once or twice a week and for Marisol the moment came when she couldn't take it anymore. She would go every day happy but in the middle of the morning she would pick up her things and go outside to the playground to wait for me. They called me that they have no staff to be with her. And there she was standing alone outside with her backpack waiting for me.

Esperanzita

I don't know if she likes the school here or not, I think she does, I don't know if they make fun of her or not or if they bully her. She doesn't tell me, I don't know if she feels badly about telling me so that I don't worry, she never tells me for example that she had a bad time, she never ever told me, I don't know. I have to work it out. I have cried a lot but I can turn my hand to many things, 'soy polifacetica'. I know how to do many things but I have had to sell rubbish sacks on the bus. We have to work informally. Now that she is older, sometimes she wants to help me go out to sell bags or sweets, imagine getting on a bus for hours to offer to sell with me and she can't talk, that's tough. Here I am with a lump in my throat - I relive it all over again.

Eliza

Listening to the stories of so many women has been painful, uncomfortable, tender, sometimes we laugh, sometimes there are silences, sometimes I tell them that they are strong, sometimes they tell me things that make me so sad, I hear the grief in their voices and I also see the hope. They also remind me of moments in my life, and I have relived the stage of my child's diagnosis. I realised that there was a segment of this diagnosis story - the psychotic segment - that I had never revisited with my daughters. I needed to talk to both of them before sharing this moment of our family history in writing here. If you are reading this now, you know that my daughters and I have talked about it, that they read and are part of your reading and viewing. The memory goes like this:

One day we came home from school and were doing our deep pressure routine for my daughter that relieves her of the tensions of the day, (she still loves it) and that's when she asked me quietly, "Mom, I'm scared, am I not normal?". I felt sadness, indignation, pain ..... I don't know if I have the words to describe the flood of emotions. What do the terms PDD-NOS and 'disorder' mean to you? For me 'disorder' is the borderline between the undiagnosed on one side, and all the others, the troubled and the damned, on the other side. This baffling term didn't exist when I graduated from university and it doesn't exist now either, having been removed from the latest DSM. How long did that category last? And to think that I am part of professional systems that made my daughter - or any child - feel that way. At the time, the best I could do was to explain

to my daughter that "normal" was an invention, that no one is normal. I half-borrowed the language of neurodiversity - not the part about how only some people are neurodiverse - that everyone is as diverse as flowers. It was the best metaphor I could find at the time for my two daughters aged 9 and 11 to process the diagnosis.

Talking to Venezuelan migrant mothers in Colombia, I felt that their stories and mine shared experiences of mothers protecting their daughters and surviving. But our survivals are very different, mine is full of privilege as a white-washed mestiza professional woman in Europe. As a professional psychologist I was able to find a team that would give my daughter a diagnosis that within our context would protect her right to education. Esperanzita's story is one of determination, poverty, institutional neglect, solidarity and friendship. Xiomara, in her migration, had to overcome a lot, and as a professional she has the tools to navigate the system. Perhaps what we share from very different spaces is that we are mothers battling against the system.

I wanted my two daughters to feel that they are complete people as they are and that they feel when facing life as they have felt within our family; fiercely embraced as our Venezuelan, Colombian and Welsh mothers have done generationally. I want them to feel that their mother, and her mother and grandmother, all our ancestral mothers hold us together across continents having gone through who knows what undocumented histories of extreme poverty, xenophobia, prejudice, violence, abandonment, hunger, adoption, suffocation, migration, denigration, otherness. A diagnostic label was not going to break the strength that comes from our ancestral mothers on both sides of the Atlantic that, inspired in my daughter's theatre performances, I name here: Margaret Elizabeth, Patricia, Sonia, Elisa, Margot, Fidelia, Sarah Ann, Natividad, Jane, Nena, Antonia, Mary, Nieves, Catherine, Nilda, Anne, Olga, Lida, Ana…

Chapter overview The descolonial hope of being

This thesis is fundamentally concerned with how I am learning to do descolonial research and what does it mean to do descolonial research? I keep reminding myself of this, because I have been trained to focus on initial research questions and I have not yet explored (dis)ability and we are in the penultimate chapter of this thesis.

I wish to ground this section of my writing by reminding myself that this descolonial exploration of the conceptualisation of (dis)ability, within the intersectional experiences of motherhood and forced migration of Venezuelans to Colombia, is a methodological exploration to continuing reframing the research questions. Mohanty (2003) asked in her groundbreaking article what are our starting points and with whose eyes are we researching. I have become more aware of my starting point being a place of hybrid externalised privilege and internalised colonial mestizaje. My initial questions stayed within the framework of the psyche apparatus by asking what were the conceptions of (dis)ability in various Latin American contexts and assumed this to be descolonising.

How to reframe my questions is my learning in this research process and that can contribute to how we formulate collaborative research questions in the RLO I work with in Bogota, with the communities and our team. The question that frames this chapter is:

- What can the term (dis)ability mean in a descolonising research question in the context of Venezuelan mother's vivencias of forced migration?

A missing element in previous question formulations was who I was speaking to in the families, all the participants are mothers or women working at the RLO. It is mothers who come to the RLO, it is mothers who are seeking support, reporting the barriers in the system and working to give their children a chance of a decent life. The experience of motherhood is intrinsically connected to the vivencias of (dis)ability in this context of forced migration. It is also women who founded the RLO. It is from this localised reality that I proceed in this chapter, following the themes in the stories I explore two conceptual threads. First, I explore what it means to be

othered through a feminist descolonial perspective of motherhood and secondly, I draw from descolonial feminism and critical (dis)ability studies to think through how to formulate (dis)ability in 'sentipensar' research questions. This is the structure of this chapter:

1. Othering- a very western logic

    1.1. (M)othering
    1.2. Constructions of motherhood and mothering
    1.3. Mothering Otherings
    1.4. Catastrophic Othering

2. (Dis)ability- a very western object of study

    2.1 What notions of (dis)ability are exported globalised?

    2.2 Who decides what is (dis)ability on the global stage?

    2.3 What is the genealogy of the globally exported conceptualisation of (dis)ability ?

    2.4 Who is Troubling (dis)ability? Dialogue between CDS and DF

    2.5 Who is the subject of (dis)ability?

1. **Othering- a very western logic**

In this section I explore the notion of 'othering' in connection to motherhood and mothering children with a label of (dis)ability. Mothers were absent in my original research intentionality and questions. What became obvious in the conversations with women in conjunction is the reality that more than 90% of the people who apply for help at the RLO are mothers, this made me reflect on my question formulation initially focused on families. In the context of forced migration it is the Venezuelan mothers who are the carers, who seek support and advocate for their children in their migration to Colombia. How does this impact my research question formulations? What questions arise around motherhood? Who frames what is motherhood? What can it mean to mother a child that is 'othered' by a physical or cognitive or psico-social developmental (dis)ability label? What can it mean to mother a disabled child in the lives of

forced migrant Venezuelan mothers inhabiting new geographies? Where can we place the epistemic origins of (m)othering in this context?

1.1 (M)Othering

Warrior Mothers reflects my 'vivencias' and how I have personally and professionally perceived and constructed narratives about mothers' struggles to protect our children from being pointed at figuratively, literally, metaphorically and concretely when being categorised as 'different'. These stories are mine and I do not purport to talk for others. These particular stories are not intended to make generalisations or universalisations about mothers' experiences, or to uncover the silences or oppressions that are implicated in the othering of families who live at the intersections of (dis)ability, migration, gender, motherhood, poverty, and childhood. I set out from the start of this research, through my 'vivencias' and stories to reflect and question the dominating oppressive exclusionary dehumanising systems which 'other' our children.

From this starting point of mothers being the people actively looking for support, I am interested in how mothers may be characterised in our context of the RLO and beyond. The mothers I have met arrive in the space of the RLO not as vulnerable, passive, quiet or paralysed by their situations. They are active and experienced in seeking recognition for their rights, they could be characterised as exhausted but overall I perceive them as fighters, survivors, capable and alert. My story and how I hear the stories of other mothers is my space to anchor the strength and resistance by 'madres guerreras' to protect our children to survive within dominating oppressive exclusionary dehumanising systems of othering. Xiomara learns to navigate two different educational-health systems in Venezuela and Colombia seeking to access all possibilities that will gain her child a place in the school system and support. The women I spoke to came across as powerful, full of defiance and determination to make a life for themselves and their children.

I stand in this research not only because I am a mother of a child with a label but mostly because I know what it feels like to hear my child articulate feeling scared about not being 'normal'. I know what it feels like to be a mum of a child that needs a Psyche label to survive the educational and mental health system. Professionally I have sat next to many parents going

through diagnostic processes. I know what it feels like to be worried my child might be excluded. I agonised over how to explain the label to my child. I created a pathway that worked for us as a family, that did not objectify or reduce or victimise her. It was a pathway that worked for my child in our particular setting with allies and non allies. Sections of that advocating path I had to invent by myself. My experience is what brought me first to do the research, this was my starting point.

Mohanty's (2003) postcolonial feminist commentary on western vs marginalised feminism reminds me about the centrality and specificity of our starting positions. We construct ourselves and our arguments from our starting positions. My starting points include being a professional psychologist from Venezuela trained in the western canon of the Psyche-apparatus-disciplines and being the mother and aunt of labelled children. By the Psyche-apparatus and disciplines I refer to the bodies of knowledge from the disciplines of psychology and psychiatry that have historically shaped educational practices (Allen, 2014; Barker & Mills, 2018). Activists and researchers come to (dis)ability studies for many reasons (Goodley, 2014), in many cases the starting point is love, family, relationships we care about deeply (Smith, 2021; Runswick-Cole et al, 2016; Douglas et al, 2021). My role as a mestiza mother of a child with an autistic label is central to this research and I have written extensively in the previous chapters about my positionality and the imbricated insider, outsider, privileged, and othering of my mestiza identity. When engaging with mothers at the RLO I became concerned with the ethics of how to engage, and how to avoid the 'othering' of those I conversed with.

In thinking about the Other through Levinas and Spivak, Drabinski (2011) underlines the importance for postcolonial and descolonial thinking of Levinas' insight around morality and responsibility. For Levinas (Wright et al, 1988) looking to understand the Other is not about representation but about ethics, it is about one person's reaction to other's lives. Spivak (1988) is considered (Jensen, 2011; Drabinski, 2011) the first thinker to theorise othering systematically and she sees 'othering' within three fundamental dimensions: power, knowledge and identity. She coins the term Othering as the process of objectification of people from the colonial gaze to turn them into colonial objects, she explores the discourse and politics of hierarchy and subordination within which the other is assigned inferior qualities, is lacking and deficient. This is mirrored in LatAm descolonial thinking where colonial discourse is seen as defining both the

superior master and the inferior groups into existence by naturalising hierarchical relationships. (Wynters, 2003; Maldonado Torres, 2016, Quijano, 2000). Through studying Spivak, Drabinski (2011) exposes Levinas' failure to think about the Other in terms of context while also acknowledging Levianas' formulation of the ethical as pivotal to Spivak's formulation of the subaltern. To turn the tables on the injustices of coloniality Spivak (1988, 2010) repositions the ethics of Othering towards relationality, and through the problems of difference under and after colonialism. It is in this sense I write the vivencias, again not as representation, but as relationality between us as mothers or professionals or Venezuelans or all of these. The vivencias ask the reader to reflect on the ethical demands of (m)othering from our diverse, contradictory, heterogenous, mestiza and overlapping dialogic vivencias.

The exploration of the experiences of mothering a child with a labelled (dis)ability and of how motherhood is constructed in the colonial/modern globalised paradigm is sparse in the academic Latin American descolonial literature (Angelino, 2014). Searches mostly yield research into women with (dis)abilities being mothers in the Latin American context (Ferrari, 2020). Motherhood and (dis)ability in the context of forced migration appears to be absent in my search through the literature. To explore the intersections of motherhood, (dis)ability and descolonial feminisms I start with exploring constructions of motherhood and mothering. Although I am not centering on the conceptualisation of migration, this *vivencia* runs through this whole thesis as a wound within which mothers and children inhabit.

1.2 Constructions of motherhood and mothering

Motherhood as a construction for study has been fundamentally ignored by mainstream feminist academia (O'Reilly, 2016) with notable exceptions (O'Reilly, 2016; Rich, 2021) and by omission it remains portrayed as monolithic conceptualisation within the western bio-natural logic of the cis-hetero-patriarchal paradigm where women are nature, men are culture (Cañero Ruiz, 2022). Hence only women can be mothers, all mothers are women, all women are motherly. The core arguments of the construction of gender and gender politics around motherhood inhabit a complex space with imbricated oppressions within the patriarchal normative dualist paradigm while it is also an intimate collective location of complicity, joy and imagination (Rich, 2021;

O'Reilly, 2004; Escaja, 2022). Adrienne Rich (2021) made this fundamental and long lasting theoretical distinction between the institutional socially constructed notion of motherhood within the patriarchal paradigm and the experience of mothering as a space of joy and political activism. However white feminist contestations of the monolithic notions of womanhood and motherhood have been critiqued (McClain, 2021) as they don't often include nor represent the experiences or contestations from women of colour, black feminists, or women from multiple locations of the Global South: Caribbean, Africa, Asia, Latin America. Universal constructions of motherhood are tied into the specific experiences of white western feminism that silence non-white women's motherhood experiences. These representations are ever smaller as I zero into research in the intersectionalities of motherhood, (dis)ability, forced migrations in the Global South, in LatAm , in Colombia and Vzla.

I approach the relationship between motherly protective care and (dis)ability from a descolonial feminist perspective, a space in which I position myself as a learner reflecting on my experiences and my internalised notions of motherhood and (dis)ability. Travelling between not wanting to legitimise hegemonic representations of (dis)ability as deficit and the role of mothers as sole carers while at the same time as positioning myself fiercely as a protector and seeing other mothers as protectors, that is the uncomfortable space within which I write and reflect. One mother portrayed this ambiguity for me when she called us warrior mothers.

African feminists (Larrier, 1997; Nnaemeka, 1997), African-American feminists (Lorde, Crenshaw, Davies,) and Latin American/Caribbean feminists (Curiel, 2009; Mohanty, 2003; Lugones, 2011; Ochoa Almanza, 2019) contest the distortions and silences of white feminism in its universalist pretensions around a presumed homogenous category "woman". Women from the Global South and women of colour are not impacted by patriarchy or the heteronormative western paradigm in the same uniform way. Global south feminisms trace multiple categories of woman and of mother as 'other' and radically propose and exemplify how gender is transversal in the weavings of multiple modern/colonial constructions and so women are positioned differently within social justice and ethnic rights struggles (Lugones, 2021).

So for instance on African women's literature, Larrier (1997) narrates the limitations of male African writers' nostalgic perspectives on motherhood in contrast to the rich variety of different

models of motherhood when women rewrite themselves over the 'master texts'. She explores how female African writers rewrite motherhood in a myriad of narratives from stories of children's illnesses as springboards into mothering activisms or women's writings that defy Muslim or Christian restrictions that challenge conventional expectations for women. Fraser Delgado (1997), questions the notions of motherhood as metaphor for motherland in a newborn Kenya, she describes it as a monolithic imaginary that is portrayed as the root of womanhood and yet the unfixable identity of Kenyan women makes for unstable ground for monoliths. Anzaldua's (2015) never ended dissertation on 'La Llorona' (the crying mother) is a prime example of latinx feminists' explorations of othering colonial discourses of womanhoods. Lloronas have historical mythic roots in the Aztec Serpent Woman Cihuacoatl who was a goddess of motherhood and fertility. Yet during colonial times Cihuacoatl was metamorphosed into la Llorona, the ghostly murderous mother that haunts many latino children's nightmares. Anzaldua chose Las Lloronas for her doctoral thesis because of the complex oppressive nuances that she says:

> Lloronas explores transgressive aspects of identity-identity formation and dissolution in the complex crossroads of multiple and seemingly contradictory subject positions: racial, ethnic, cultural, lesbian, feminist, ideological, political, historical, sexual, social, geographic, artistic, intellectual and academic. (Anzaldua, 2015, pg 328-329)

Descolonial feminists in Abya Yala (Quiroz, 2020; Rodriguez Moreno, 2021; Mendoza, 2021; Hernandez Morales, 2021) question the institutionalised feminism pro-women's rights in public sectors in LatAm as based on modern colonial white feminist perspective on gender when implementing public policies on gender equality. Rodriguez Moreno (2021) citing Mohanty and Lugones places the representation of woman in LatAm public policy with the professional white woman as referent. Quiroz (2020) in her studies of motherhood, birthing and public policy in LatAm, focuses on racial differentiations and finds how some women are classified as non-women or not-yet women or in the category female, strong, resilient, more or less savage as in opposition to vulnerable delicate good white mothers (Quiroz, 2020). Non white, 'third world' women (poor, illiterate, family-orientated) are placed in LatAm policies as 'en route' to follow the white women's pathway to emancipation. The developmental discourse in gender equality policies is a continuation of the colonial othering that is the unfinished project to continue to

produce women as subjects whose purpose is to reproduce, be maternal and productive for "capitalist exploitation needs" (Rodriguez Moreno, 2021, pg 120).

The modern/colonial global system categories of identity make for imbricated complex transversal oppressions that configure specific practices and experiences that do not follow clear homogeneous constructions of womanhood, motherhood, class, race, or even manhood as fixed, static or universal categories. Some Abya Yala descolonial feminists like Espinosa (2021) and Curiel (2021), following Lugones (2021), deconstructing and carrying out descolonial genealogies on the idea of patriarchy as a colonial western feminist notion contend gender is not universal, in contradiction to other descolonial feminists such as Segato. For Segato (Segato and Monque, 2021), high-intensity colonial patriarchy transformed the low-intensity communal patriarchy of Abya Yala indigenous groups where women and men had complementary roles equally vital for the community. This is a widely debated contentious issue for feminists in LatAm (Curiel, 2021). I leave this issue here without further analysis at this point to signal the huge diversity and contradictory discourses that descolonial feminisms from the Global South contribute to the explorations of womanhood, motherhood and (m)otherings, as well as the multi-interdisciplinary methodologies employed by descolonial feminists (that is a term that will suffice for now to refer to as a collective).

This brief naming of the tensions within various feminisms is presented to clarify that I do not want to place the mothers I have written about, including myself, as all encompassing universalising mothering caring role figures from the Global South. We are not a representation, nor are my vivencias representative. We are not static monolithic motherhood identities. The autoethnographic stories are my 'sentipensares' of the relationality between us, you the readers, the women I talk with, the women in my family and myself. I am therefore interested not in a synthesis of the diversity of perspectives on motherhood but I am interested in the ways in which the diverse and competing notions of motherhood interpellate us, the storytellers and the readers in our internal shared dialogues.

In the borderland identity spaces, I chose the story title We Are Warrior Mothers, this came from conversations with women who spoke with solidarity, motivating others, themselves, and me. I found great joy in the solidarity sought and given in the conversations, as Fanon beautifully

phrases: "Why not the quite simple attempt to touch the other, to feel the other, to explain the other to myself?" (2008, pg. 181). In the conversations I found moments of differences and commonalities of feeling as well as an acute awareness of my privileges.

To return to epistemological musings and reformulating research questions, motherhood was a notion that was invisible in my original research intentionality and questions. The relationality between mothers- interviewed and interviewee- in the research space, their overwhelming presence at the RLO as the main group searching for support, our conversations of what it means to be mothers of our 'disabled' children, placed motherhood and mothering into the research space, something I had not foreseen. As Spivak has said in interviews and of interviews, listening to our default modes of responding and how we perceive that the Other sees us: " It's a wonderful way of othering oneself" (Spivak, 1988, pg 36). A vital experience to decolonise the researcher.

1.3 Mothering Otherings

In 'We Are Warrior Mothers' I have reflected on moments from our conversations where I heard 'vivencias of otherings' regarding our children with a labelled or a potential diagnosis. I have placed my memories of our conversations into a dialogic narrative where I see our children standing outside of school boundaries, given school placements where they 'stop growing' and/or cannot speak or be heard or be seen.

As a researcher, in my daily profession and in the work of the RLO I see children being othered, I see mothers resist, navigate and oppose whilst inhabiting and surviving the Psyche-apparatus. In my mothering I am navigating Psyche-apparatus and disciplines from a continual place of relationality and love. The Psyche-apparatus includes the instruments used by psychologists, psychiatrists, medical and educational professionals to measure, categorise, pathologize and diagnose children. This is done globally using the criteria of two seminal instruments: the Diagnostic and Statistical Manual of Mental Disorders (DSM) in its 5th edition by the American Psychiatric Association (APA, 2013) and the International Classification of Functioning, (dis)ability and Health (ICF) published by the World Health Organisation (WHO, 2001). The

DSM and ICF are the seminal reference guides for diagnosing (dis)abilities world wide, I use the term seminal in both its meanings to ground the troubling of these texts as belonging to the colonial/modern patriarchal Psyche sciences.

Our experiences of the enacted practices from the Psyche apparatus rendered my family understandings as meaningless, unimportant and the possibility of pathologizing my child in the category of psychosis was very real and scary. In my mind and experience this posed a threat of intrusive and dangerous drug treatment. As a professional working within the psyche apparatus I was able to use my knowledge of the system and the DSM to advocate towards an autism diagnosis. Navigating psyche systems is hard enough with professional knowledge of the system, forced migrant mothers in a new country like Xiomara and Esperanzita have to rely on others, on previous experiences, and learn to lean into systems and follow bureaucratic protocols to navigate support (or not) for their children. And yet these experiences at the intersections of (dis)ability, childhood and forced migration are not visible in the research or governmental programs. There are three million Venezuelans, and the numbers keep growing, in Colombia (UNHCR, 2021) with young children being around 25% of that population (UNICEF, 2023). However statistics on Venezuelan migrant children with (dis)abilities are virtually non-existent on official government or international organisation websites. The silences about (dis)ability in forced migration, is not unique to the Colombian context, policy gaps are a dominant issue globally (Grech and Soldatic, 2016), however the number of children that remain invisible in the Venezuelan diaspora is unique in its proportions (UNICEF, 2023).

The Platform of Interagency Coordination for Refugees and Migrants from Venezuela (R4V, 2022) published a report, financed by the EU, in September 2022 about the situation of Venezuelan migrants with (dis)abilities across LatAm. The report recognises the double invisibilisation of people with (dis)abilities in the migration process. It is a self-described limited report, focusing on physical and sensorial (dis)abilities and very small samples. In the Colombia section they report on 703 registered children with (dis)abilities, the report is limited to establishing that 70% of these children are not in school. The WHO (2023) assumes 16% of global populations have some form of disability, then we can conservatively estimate that within the three million Venezuelans in Colombia approximately 120,000 are children with (dis)abilities.   UNICEF (2023) published a report called: The Changing Face of Child Migration

in Latin America and the Caribbean, children with (dis)abilities are mentioned twice in one paragraph in reference to the fact more research is needed to understand the risks and deprivations for children with (dis)abilities and those identifying as LGBTQI+ (UNICEF, 2023). At state and national level as well as throughout the continent the situation of disabled forced migrant children is totally invisible and hence no provisions are planned. Mothers are the ones leading the care for their children. Xiomara relates how often she has to cut work hours short to pick her daughter up earlier as the school cannot keep her safely in class. Esperanzita's concerns are to keep her children safe and fed, she has received no in school support for her child's stutter, her concern is how her child is going to make a living.

There is an important, albeit small, academic literature on mother-researcher-activists caring for children with (dis)ability labels critiquing the psyche-disciplines and political apparatus entangled with the gendered role of women being the carers from the Global North (Smith, 2021; Runswick-Cole, 2016; Douglas et al, 2021; Douglas, 2016; Ryan and Runswick-Cole, 2008, Traustadottir, 1991.) From LatAm (Acuña et al, 2021; Angelino, 2014) this small area of research has focused on care being critiqued from anti patriarchal and anti colonial perspectives as a specific female labour with little social value and remuneration. The literature suggests that frequently the failures and gaps of educational and health systems are filled by mothers, this care is mostly invisibilized, often the exclusive responsibility of women-mothers (Revuelta Rodriguez, 2019), and this is enmeshed with the notions of (dis)ability as deficiency, tragic and personal. The responsibility of care relies on mothers and is entrenched in a neoliberal individualist approach of self improvement from the psyche apparatus through normalising treatments that are motherly responsibilities. Simultaneously mothers are being judged as failing in these roles as is made explicit in Hernandez Martinez et al, (2020) when seen to not follow treatment protocols.

As a mother I learned about critical perspectives on autism not in academia or in the consultant's office but through self advocacy groups online. The information given to us by the professionals we met was based on the medical-modelled DSM (APA, 2013). In my nephew's case the label Aspergers was given to his parents when he was 2 years old with no explanation. This was in the UK, in the early 2000's and they were sent home to research the term online. Were the

professionals afraid to explain? The initial encounter with a diagnosis was vague, cold and rendered my brother's family feeling scared and lonely in the process. In my daughter's case it was a battle for which diagnosis. I was the campaigner for a diagnosis of autism to protect my daughter from a more stigmatising diagnosis of psychosis with scary medical and drug outcomes. I could not understand how my child was viewed focusing on one instance of behaviour, so impersonally, by some professionals which was in stark contrast to my rich, loving, complex and frankly more knowledgeable vivencias of my daughter. One report of visualisations/ hallucinations was sufficient for a jump to a possible diagnosis ignoring everything else that my daughter is. A second group of professionals were in agreement with me and yet if I had not used my 'professional expertise' to seek out that group, if I had not become a campaigner and let the first professional lead the case I dread to think where that might have placed my daughter. These familial experiences have set me in this direction to review everything I was contesting from my psychological training around the concepts of (dis)ability, autism in particular and normality overall. (Dis)ability, and in my family's case autism, are categories inserted in western scientific paradigms of hierarchical psychological developmentalist categories, that place our children as abnormal, as 'other'. Who decides what is 'normal'?

In practice, in my family, we used the label when it was necessary to navigate the school system and get the support she needed to be able to manage school work and school life. As I see it, the label allowed us to put the 'pathology' onto school systems rather than on her as a person, the school needed to change, not my daughter. I share one small example. My daughter's ILP required teachers to share all assignments in written form. In the past when an assignment was orally announced, sometimes at the end of a lesson, with chairs moving and people talking, my daughter didn't register it, and she missed deadlines. We went from comments like 'should pay more attention in class' and 'does not participate in class' to an ILP that requested teachers to consistently give her advanced warning of participating in class moments so she could prepare and written information about deadlines and assignments. I wonder how many other children benefited from this systematic approach to assignment descriptions and deadlines. So although I theoretically resist using diagnostic labels and prefer to focus on specific access rights, in practicality I have made use of labels to my daughter's advantage, such as requesting changes in school procedures so she could follow the educational program. I am, of course, not alone in this

practice (Lewiecki-Wilson and Celio-Miller, 2011). The critiques of the impact of western psychology have been growing for a few decades (Hook, 2012; Parker, 2007. Williams et al, 2017)

> The impact of developmental psychology on children who are judged as failing to meet developmental stages and goals is that they are considered to be 'other', and as Walkerdine (1993) suggests, otherness within this context can only be understood as something 'at a lower developmental level'. (Mallett and Runswick-Cole, (2014, pg 41).

The psychologisation and pathologisation of childhood, with its universalising concepts of development, milestones, normal and its defining notion abnormal, is being challenged and critiqued within the Global North in many academic disciplines carrying out research such as early childhood education (Mac Naughton, 2005; Dahlberg and Moss, 2005), developmental psychology (Burman, 2024), critical psychology (Parker, 2007) critical educational psychology (Williams et al 2017, Allen, 2014), and critical (dis)ability studies (Douglas & Rice, 2021; Goodley et al 2019;Mallett & Runswick-Cole, 2014;Runswick Cole et al, 2016;Runswick Cole, 2014). Often leading the way of the ableism normalising critique are social movements by self-run advocacy-activist groups such as (dis)ability rights movements like The Disability Rights Education & Defense Fund (DREFD, nd), Disability Rights UK (nd); psychiatric survivors movements such as Mind Freedom, MindFreedom International (MFI, nd), Madness Network (nd) and Mad in America (nd) and specific (dis)ability groups like the Autistic Self Advocacy Network (nd) and the conference for Autistics created by Autistics Autscape (n.d.).

The epistemologies of ableism, of othering and the discrimination of our children and our motherhoods are pervasive in the world I inhabit in Europe as much as they are in Venezuela and Colombia with the Venezuelan migrant women I work with at the RLO. Dear Reader, I have questioned my ethics continuously and felt unease. I can empathise with the mothers who talked of their children and find similar themes in the barriers they have encountered in my experiences. However in my conversational experiences I found that for all my empathy, for all my intentionality of guaranteeing they obtain support from the RLO the women I have talked with inhabit intersectionalities that have made their daily lives so much harder, painful, invisible and unsupported than anything I have experienced, vivencias that I cannot represent. In my daily

professional life in Europe I support families going through diagnosis and battling to understand how to navigate underfunded services often in a country foreign to them. However we do not have to worry about how we will feed our children tonight, will we have enough to pay the rent, or whether we will be deported to the country stamped on our birth passports to unsafe situations. As parents of children with diagnosis in the Global North from middle and professional classes we may recognise parts of our experiences in the experience of Xiomara, we know the inconsistencies of diagnosis processes, we have had to battle with the systems to obtain the support and inclusion that our children are entitled to whether it be at home, in schools or healthcare facilities. There is much we can relate to. However, can we know what it is to stand in their shoes? Can we know what they left behind? or know what capacities they bring but are not given the opportunity to use? We cannot purport to know what solutions best fit their lives and this is why I cannot produce knowledge about them.

The reality of forced migrant lives and the poverty and exploitation they inhabit daily is urgent. The urgency of the work at the RLO suspended this research on many occasions and shifted my understandings as our loved ones, our children, our sisters are systematically ignored, othered and set aside in 'la zona del no ser', the zone of nonbeing human. Maldonado Torres (2016) calls this othering the 'metaphysical catastrophe': the colonial geopolitical and social divisions and structures that produce zones of being human and zones of not-being human or not being human enough. This zone of catastrophic othering is where the practices of the RLO are focused with Venezuelan refugees and forced migrants.

1.4 Catastrophic Othering

Shedding light on how intersectional historical inequities and beliefs about who is human is crucial to acknowledge how these result in discriminatory practices that are harmful to forced migrants living already precarious lives (Savas and Dutt, 2023). Why is it that in Colombian governmental reports (R4V, 2022; Migracion Colombia, 2024) and programs (ICBF, 2019) the lived experiences of forced migration of Venezuelans in Colombia at the intersectionalities of (dis)ability, childhood, migration, poverty, motherhood are not visualised? The categorisation of people into zones (human-nonhuman) is critiqued in descolonial thought and is made visible in

many critical disciplinary studies that contest notions of gender, race, (dis)ability, motherhood, childhood as stated above. As Tuck (2009) asks in her letter to researchers and educators about the impact of the categories we use to help communities: Who is included in what categories? Who is perpetuating these categories? Where is the knowledge about these categories coming from? How are the categories used as individual deficits to be fixed? How can we reformulate questions with communities rather than about them? These types of questions are the drivers in the descolonial turn and descolonial feminisms to uncover the historical roots of catastrophic othering to understand where these categories of the non-human come from.

In the Americas anthropological histories of the conquest of Abya Yala, searching for the origins of the conceptualisation of the 'other' is a fundamental genealogical excavation of the colonial gaze and its conception of the human. The idea that modern European man is a conceptualisation that arises in relation to defining 'others' is at the heart of Quijano's (2000) writings on the coloniality of power. For Quijano (2000) the naturalisation of superior white and inferior coloured races, as objective scientific naturalised bio-knowledge, becomes the means and justification of the power and economic relations of domination by white European men over Indigenous and African people. In other words, the Coloniality of Power is defined by racialisation and racism. The superior Europeans tame and civilise the 'savage' indigenous populations of Abya Yala and the questionably human 'barbaric' African slaves. Maldonado Torres (2016) places this othering racial axis as the pivotal process in space and in time during the invasion and conquest of Abya Yala that constitutes the metaphysical catastrophe we continue to live within our present modern/colonial times where war and violence are naturalised.

> "When it comes to conceptions of humanity and to ideals of inter-human contact modernity/coloniality represents a veritable catastrophe (which means a "down-turn") whereby the world populations started to be divided according to, not merely specific practices or beliefs, but degrees of being human. This catastrophe can be considered metaphysical because it transformed the meaning and relation of basic areas of thinking and being, particularly the self and the other, along with temporality and spatiality, among other key concepts in the basic infrastructure that constitutes our human world. This metaphysical catastrophe is informed by and helped to advance the demographic catastrophes

of indigenous genocide in the Americas and the middle passage, as well as
racial slavery, among other forms of massacre and systematic dehumanization in
the early modern world." (Maldonado Torres, 2016, pg 11).

Questioning the degree or not of humanness of the native Indigenous people of Abya Yala is documented in historic debates in Spain between Bartolome de las Casas and Sepulevda in Valledolid in 1550, 58 years after conquest had begun (Fonseca, n.d.). New laws were being introduced that would change how the Council of the Indias could use slavery and forced servitude for their economic enterprise in the new Americas. Sepulveda, a doctor, argued the case that the Indians were barbaric, inferior, without minds, serfs by nature and who needed a strong hand to civilise them, while de las Casas, a priest, advocated for them as savages to be tamed. These barbaric debates were being carried out while in Abya Yala dissident caciques, tlatoanis, incas, mallkus, tsotsils, lonchos, machis (male/female chieftains) were decapitated and dismembered tying their limbs to horses in public executions. Physical catastrophic genocides and erasures of civilisations were happening on the continent while these barbarian debates were held.

In the Venezuela I grew up in, these histories of the genocide, the Sepulveda-de las Casa debate were not talked about nor taught. The justifying reasoning being that pre-colonial inhabitants had no written form, hence no valid knowledge, this is common educational practice throughout the Caribbean including Venezuela and Colombia (Curiel, 2022). From Bolivia, Rivera Cusicanqui (2010) relates that although these stories were silenced and mostly erased, we do have the perspectives of the Mayas, Incas, Aztecs, Waru, Aymara, in other forms of knowledge. She developed a novel methodology for historical analysis: the sociology of the image. She weaves colonial texts, with memories and indigenous drawings that reveal interpretations and theorisations about the political dismemberment of their colonised societies, rescuing historical memories. The silencing of voices we talk about academically now when referring to oppressed groups, can be historically traced to these learned practices in colony.

The Dominican Bishop de las Casas is historically seen as the figure who defended the 'Indians' as 'human savages' rather than barbarians and was opposed to the forced servitude in favour of their evangelisation (Mora Rodriguez, 2020). The term 'indians' itself erased the hundreds of diverse communities and civilisations that have lived for thousands of years, and some still alive and resisting, in Abya Yala: Mayans, Waru, Nazca, Wari, Inca, Timotocuica, Tolteca, Aymara, Olmeca, Cuicas, Yanomami, Azteca, Carib, Taino, Mapuche, Chibchas, Guaranies, to name a few (Yepes, 2022). De las Casas entered a long complex definition to distinguish the barbarians (non-humans) from the infantile state of development in which he observed the 'Indians' to be. He was also very clear that the people of Africa had no souls, hence as true barbarians, they should be imported to the Americas to substitute the forced labour of the Indians who should be christianized (Fonseca, n.d.). So the codification of people was instituted not only between the zones of being (white male christians) and non being (everyone else), but within the zone of non being there was further hierarchisation that became hegemonic in every sphere and realm of the American colonial era: scientific, beliefs, cognitive, cultural, symbolic, aesthetic that continues to be present today (Maldonado Torres, 2016).

This hierarchisation is what gave the invading Spanish conquistadors and the Spanish crown, in their rational logic, the moral permission for human trafficking, the enslavement and abuse of millions of African black people and the segregation of 'Indians' into servitude and the catastrophic genocide of the populations of Abya Yala (Lugones, 2021, Maldonado Torres, 2016). It is within this catastrophic schism of categorising humans that the formation of the European modern "man" can be placed. As Wynter says: "The rational European man can only be defined in terms of comparison to 'Human Otherness" (2003, pg 301). It is within this schism that we can find many intersectional identities of non-humans tied together with racialised non-whites: women, transsexuals, queer, refugees, varying degrees and types of mestizos and as I explore in the next section people labelled with a (dis)ability. As I explore (dis)ability from this descolonial stance I wonder how far are we truly from the dehumanising Sepulveda and de las Casas debate in 1550 of who qualifies as human?

Illustration .2 Image of the execution de Tupaq Amaru I, the rebel Inka of Willkapampa in Cuzco by Qchichwa cronist Waman Puma. Rivera Cusicanqui creates a Sociology of the Image to retell history from the perspective of 'others'.

(Rivera Cusicanqui, 2010, pg 17)

2. (Dis)ability- a very western object of study exported globally

I embarked on this research as a mother on a quest to explore with hope whether (dis)ability could be understood in ways that are radically different to the dehumanising notions prevailing from the Global North, exported globally and within which I have been trained and am expected to operate within as a professional. The research intention has been to move and disengage from the rhetoric knowledge in modernity to explore 'other ways' of understanding (dis)ability. What I have been exploring in this methodological research is what does it mean to include the notion of

(dis)ability in a research question from a descolonial turn whilst exploring the vivencias of Venezuelan forced migrants. In essaying on (dis)ability in this section I am abstaining from an analysis of what is (dis)ability, and rather looking for the nodules of interrelated oppressions that arise from the systemic othering of disabled people.

In exploring how conceptualisations of (dis)ability as a western object of study, are rooted in the modern/colonial patriarchy, it is radically important to make clear that contesting the conceptualisation of (dis)ability itself from descolonial Abya Yala feminist lenses is not a denial of the experiences and *vivencias* of disabled people, people with (dis)abilities or people who have been labelled as disabled. Disabled people in LatAm are uniquely marginalised populations, often living in imbricated spaces of multiple intersectionalities including racial, gender, poverty, that render them exposed to violence, exploitation, invisibilisation, (Danel et al, 2021) and in the case of many forced migrants pushed out beyond the margins of societal life without access to basic services. Research in the intersectionalities of (dis)ability, forced migration, poverty, motherhood, and education have been scantily addressed from (dis)ability studies in the Global North (Pisani and Grech, 2015), as well as being an overlooked issue in LatAm research both from academic institutions, non-governmental and governmental organisations (Danel et al, 2021; Rojas Campos, 2015, UNICEF, 2023).

As formulated in chapter two in a search for policies or reports from the Colombian government none can be found on the public record that address the forced migrant Venezuelan disabled child population. Migration policies scantily refers to (dis)ability (R4V, 2022), (dis)ability programs do not mention Venezuelan migrant children (ICBF, 2021; ICBF 2024). Educational policies in Colombia guarantee school placements for Venezuelan children no matter their migration status, this guarantee of the right to education is protected under the 1994 General Law of Education that prohibits the discrimination of access to education due to ethnic, migratory or any other circumstances. This is a reflection of Article 67 of the Colombian Constitution of rights to education for all (MEN, 2023). However in practice there is limited guidance at a national level on how to support Venezuelan forced migrant children, no clear guidance on their grade placements nor their migration transition processes nor could I find mention in the public records

any document on the (dis)ability rights of migrant children in the Instituto Colombiano de Bienestar Familiar (ICBF 2019-2024) or Ministry of Education websites (MEN, 2023).

Where are children with a labelled (dis)ability and their families present in the research and policies? How do these vacuums come to be? Who decides what knowledge is important, and how it gets inscribed onto national policies in LatAm? International and national institutions of knowledge and power create social categories such as migration and refugee status (Savas and Dutt, 2023) as well as (dis)ability categories (Ferrari, 2020; Mallett and Runswick Cole,2014) with policies to support these groups such as the CRPD- Convention on the Rights of Persons with (Dis)abilities (UN, 2006) and the 1951 Refugee Convention of the United Nations High Commissioner for Refugees (UNHCR, 1951). Yet simultaneously these groups of people live in vacuums of exclusion, barriers to basic human services, and exploitation. The descolonial turn requires us to ask questions about the rigorous exclusions of groups of people to the zone of non-being, what are the origins of these exclusions? Thinking about how to think about (dis)ability in descolonial research at the intersectionalities of the zones of non-being requires delving into understanding our starting points as researchers and the epistemological origins of the conceptualisations so as to challenge the self-endowed objectivity, dominant colonial logic and universalist monopoly of knowledge from the Global North (Meekosha, 2010; Danel, 2021). Looking at the generative importance of the geo-political-historical genealogy of othering and focusing on (dis)ability I move towards dialogue nodules between Critical (dis)ability studies (here in CDS) and descolonial feminism (here in DF) as methodologies with the following descolonial questions.

2.1 What notions of (dis)ability are exported globalised?

2.2 Who decides what is (dis)ability on the global stage?

2.3 What is the genealogy of the globally exported conceptualisation of (dis)ability ?

2.4 Who is Troubling (dis)ability? Dialogue between CDS and DF

2.5 Who is the subject of (dis)ability?

2.1 What notions of (dis)ability are exported globalised?

(Dis)ability has been defined in a multitude of ways from various perspectives and fields of study. Broadly it has been defined as centred on impairments in a person's body structure or functioning, or mental functioning in interaction with environmental factors (WHO, 2023) or as a cultural historical-contextual social construction (Oliver, 2013). (Dis)ability has in the last decades gone through a revolution in the political, activist, and social arenas that have materialised in many academic fields of study. To put forth what notions of (dis)ability are exported is not straightforward given the complexities and diversity of conceptualisations from the Global North. Rather than approaching this question from an academic conceptualisation I first turn pragmatically to the tools and models of (dis)ability that are used around the world by professionals of the Psyche apparatus. The diagnostic tools for measuring, classifying and diagnosing (dis)ability are the International Classification of Functioning, (Dis)ability and Health (ICF) of the World Health Organisation (WHO, 2001a) and the Diagnostic and Statistical Manual (DSM) of the American Psychiatric Association in its fifth edition published in 2013 (APA, 2013). They are the most broadly used diagnostic tools for physical, mental and psychosocial (dis)abilities, around the world created, researched and exported by organisations from the Global North.

The ICF and DSM define (dis)ability using Global North models of (dis)ability. This endeavour is fraught with ideological complexities as there are many different perspectives from the medical model to social justice stances with a myriad of definitions (Mallett and Runswick Cole, 2014; Gronvik, 2009; WHO, 2023; ICF; Oliver, 2009). All of these originate in western Global North studies of (dis)ability. In a greatly simplified way I summarise, as do others from the Global South (Ferrante, 2021), the two overarching models emanating from the western psych apparatus on (dis)ability: the medical model and the social/construct model.
The medical model is the more traditional and long dating model relying on medical descriptions with diagnostic criteria to define a (dis)ability as human deficiencies within a person's body, that require professional treatments to normalise those bodies (Mallett and Runswick Cole, 2014; Snyder and Mitchell, 2006). The social/constructivist models of (dis)ability place social structures, attitudes and constructs of normality as barriers in people's lives rendering them

disabled and with inequitable access to their rights (Eide & Loeb, 2016; Mallett and Runswick Cole, 2014; Oliver, 2009). The paradigmatic change that the social model of (dis)ability introduced and the political activism it has gone hand in hand with have deconstructed what is understood as (dis)ability (Shakespeare, 2002; Oliver, 2013; Grech and Soldatic, 2016; Mallett and Runswick-Cole, 2014; Barnes and Sheldon, 2010; Goodley et al, 2019). The social model was developed originally in the United Kingdom and is inscribed loosely within a marxist tradition. There are many variation models that can be placed somewhere within the medical or the social models, addressing functionality, rights, impairments and/or therapeutic needs. Overall the social model has critiqued the medical naturalisation of (dis)ability *as an axis of inequality, discrimination and oppression originating in socio-cultural attitudes and barriers.* The social model has offered a critical perspective that has represented an important paradigm change upholding disabled people's rights with global impact. (Mallett and Runswick-Cole, 2014; Oliver, 2013; Danel et al, 2021, Goodley and Swartz, 2016)

The ICF portrays its bio-social-psychological model of (dis)ability as a balanced holistic approach where it has included some notions of the social model into the medical model by including environmental factors as contextual factors that "...make up the physical, social and attitudinal environment in which people live and conduct their lives" (WHO, 2001b, pg 10). Here (dis)ability is seen fundamentally as natural body structures and/or functions that have an anomaly, defect, loss or deviation from generally accepted biomedical standards. (Dis)ability is in the body and/or mind of a person, it is something to be fixed, and what the context does to disable the person is less important than who the person is in that context (Oliver and Barnes, 2012). The ICF's 'holistic' argumentation continues to uphold a deficit understanding of human diversity where (dis)ability is centred in the individual more than the disabling environment, and continues to focus on dualist function/dysfunction and ability/(dis)ability as the standard measurements for diagnosis. Stemming from a Eurocentric ethnic cultural formulation, the bio-social-psychological model of (dis)ability continues to uphold a primarily medical perspective based on dualistic western ideology (Solli and da Silva, 2012) and centred on the neoliberal individuality of the dominant narratives of western modernity, coloniality, capitalism and patriarchy emblematic of the Global North (Rojas Campos, 2015; Danel, 2019; Goodley and Swartz, 2016).

I have set out a very simplistic summary of models and tools, I abstain here from an overview of the important history of these models and the critical epistemological and political views on disabilty of the Social Model. However in regards to the exporting of Global North models of (dis)ability to the Global South having this simple distinction is useful in how the models have been subsumed in LatAm countries politically and socially (Danel et al, 2021; Grech and Soldatic, 2016). As Yarza de los Rios et al (2019) exemplify in the book 'Critical studies on (dis)ability: a Polyphony from Latin America':

El componente ideológico "en clave de derechos" abre la duda sobre cuánto hay de reconocimiento real y reducción de brechas entre dichos y hechos. No deja de hacer ruido la casi anulación en el plano de los discursos y marcos normativos de la Convención de la OEA y la expansión absoluta en América Latina de la CDPD. En este último aspecto, un elemento preocupante y extendido en la región, lo constituye la acrítica asunción de un "cambio de paradigma en la discapacidad" a partir de la CDPD. Esta aceptación parecería asumir que los derechos en el papel por sí mismos transforman automáticamente prácticas estatales que perpetúan injusticias de distribución, cuando, además, se alude a la región que se caracteriza por ser la más desigual del planeta. (Yarza de los Ríos et al, 2019, pág 33)

The ideological component "in terms of rights" raises the question of how much there is of real recognition and reduction of gaps between words and deeds. The near annulment of the OAS Convention in terms of discourse and normative frameworks and the absolute expansion of the CRPD in Latin America is a cause for concern. In this last aspect, a worrying and widespread element in the region is the uncritical assumption of a "paradigm shift in (dis)ability" based on the CRPD. This acceptance would seem to assume that rights on paper by themselves automatically transform state practices that have perpetuated distributional injustices, when, moreover, the region is characterised as the most unequal on the planet. (Yarza de los Ríos et al, 2019, pg 33)

The Convención of the OEA they refer to above was the Inter-American Convention On The Elimination Of All Forms Of Discrimination Against Persons With (Dis)abilities (OEA, 1999) that all Latin American countries subscribed to in 1999 (except for Honduras that signed in 2011). Although still legally binding it was in effect wiped from legal policy guidance when

LatAm countries signed up to the UNCDPR in 2006. Crucially it was underpinned by two principles that go beyond the CDPR (Yarza de los Rios et al, 2019). Firstly, in its definition of (dis)ability in article one it states that the term (dis)ability "can be *caused* or aggravated by the economic and social environment" (OEA, 1999) and secondly also in article one it carefully defines discrimination against people with (dis)abilities:

<table>
<tr><td>El término "discriminación contra las personas con discapacidad" significa toda distinción, exclusión o restricción basada en una discapacidad, antecedente de discapacidad, consecuencia de discapacidad anterior o percepción de una discapacidad presente o pasada, que tenga el efecto o propósito de impedir o anular el reconocimiento, goce o ejercicio por parte de las personas con discapacidad, de sus derechos humanos y libertades fundamentales. (OEA, 1999, Articulo 1)</td><td>The term "discrimination against persons with (dis)abilities" means any distinction, exclusion, or restriction based on a (dis)ability, record of (dis)ability, condition resulting from a previous (dis)ability, or perception of (dis)ability, whether present or past, which has the effect or objective of impairing or nullifying the recognition, enjoyment, or exercise by a person with a (dis)ability of his or her human rights and fundamental freedoms.(OAS, 1999,Article 1)</td></tr>
</table>

The erasure of the Inter-American Convention On The Elimination Of All Forms Of Discrimination Against Persons With (Dis)abilities (OEA, 1999) when the ratification of the UNCPDR was adopted without critical questioning, is an example of Eurocentric modernist perspectives from the west being assumed as universal emancipation routes of equality for all and imposed universally on all countries. Crucially the elimination of causes and discrimination, that were central to the OEA convention, from the legal policy making guidance in LatAm had a huge impact. The implementation of policies now focus on the CPDR more medical provisions silencing social and economic structures that produce (dis)abilities (Oliver, 2008; Grech and Soldatic, 2016; Yarza de los Rios et al, 2019). The conceptualisations and models of (dis)ability constructed in the Global north are exported, imposed, and consumed as universal truths. This global domination of knowledge and power, that Quijano(2000) defined as the coloniality of power, started in 1492 and is embedded in the modern/colonial world system. Erasures such as the one described above are not discussed in the global arena and dualist categorial knowledge is perpetuated. Normal/abnormal, able/disabled, superior/inferior are akin to racial dualisms white/

nonwhite, rational/barbaric, civilised/savage, that are produced in the Enlightenment definition of the human that is rooted in western rational humanism of the Renaissance (Mignolo, 2021).

> "I read the great Enlightenment figures as a psychologist – not as an historian or a philosopher – and I found that the apparently random racist remarks and racist assumptions in intellectuals such as Kant, Hegel, Marx and Engels, David Hume and Jefferson were not as random as they look at first glance. It is my contention that much of the knowledge bank that was developed in the nineteenth century was a victim of colonialism." Ashis Nandy (Nandy & Darby, 2018 pg)

Here Nandy and Darby are questioning who is creating the psyche knowledge we take for granted and also how is it that this knowledge becomes neutral? Questioning (dis)ability as a western notion imported to the Global South becomes central to rethinking my research questions. In descolonial thinking the question of who creates knowledge that is globally exported is fundamental, and it is this that I turn to now.

2.2 Who decides what is (dis)ability on the global stage?

Knowledge on (dis)ability emanates from various fields of study such as psychiatry, psychology, (dis)ability studies, and education based on research that has come principally from the Global North academia (Meekosha, 2011; Yarza de los Ríos et al, 2019) The first global report on (dis)ability, the World Report on (Dis)ability (WRD), was co-published in 2011 by the World Bank (WB) and the World Health Organisation (WHO, 2011). The WHO is the same organisation that publishes the ICF diagnostic manual based on research carried out fundamentally in the Global North and mainly on Global North bodies and lives.

The WHO, the UN, the World Bank (WB), the American Psychiatric Association (APA) are the Global North organisational bodies that define (dis)ability purported to be neutral with universal knowledge based on Global North experiences and issues whilst the experiences of disabled people from the Global South are under problematised in educational, legal, medical and social practices world wide (Grech et al, 2023; Danel et al, 2021; Yarza de los Rios et al, 2019,

Meekosha, 2011). These global organisations have used their political clout for these conventions to be the golden standard for global agendas and policies.

The inaugural World Report on (dis)ability (WRD, 2011), the United Nations Convention on the Rights of Persons with (Dis)abilities (CRPD, 2006), and the Salamanca Framework for Action (1994) are all groundbreaking international publications and policies addressing the importance of disabled people's access to equality and their human rights. These global organisations have set out to combat the marginalisation and discrimination of disabled persons and encourage countries all across the world to advance the equity for people with (dis)abilities. The CPDR was promoted by Latin American governments as an important global document, which it is, but they also put to one side the OEA convention that had been regionally formulated with important focuses on causes of (dis)ability and discrimination. The WRD has become an essential resource for national governments all over the world when creating their own national educational, social and medical policies for disabled people. Importantly the WRD included disabled people in its formulation and advances the ideas of integrating and including persons with (dis)abilities in all spheres of social life. Together with the CDPR, the WRD has represented a breakthrough and has been welcomed on changing paradigm and attitudes towards (dis)ability by disabled people and allies around the world (Oliver and Barnes, 2012). Most critical (dis)ability researchers I think celebrate these important rights-based documents. But framing (dis)ability only from the Global North and projecting it as universal continues to ignore the realities of millions of disabled people in the Global South (Yarza de los Ríos, 2019; Grech and Soldatic, 2016). From many differing fronts there are global calls for social justice efforts from disabled people's movements, activists, and allies.

When organisations and academic institutions in the Global North get to decide what is knowledge, only accept knowledge that is produced in their localisation under their rules of logic and presume it to be universal, we are beholding the political logics of modernity/coloniality (Mignolo, 2021). While rights for people with (dis)abilities are being upheld, these seem to be applicable to some people with (dis)abilities, most disabled people from the south are not situated in the research and the harsh realities of imbricated lives of social and economic oppression are ignored. In universalising Global North knowledge about (dis)ability, the breadth

and depth of multifactorial and localised processes, beliefs, and lives beyond the borders of the Global North are erased (Gilroy et al, 2021; Mills and Fernando, 2014; Grech 2015).

As an example, in LatAm, the medical model of (dis)ability still prevails at professional and diagnostic sites whereas the exported 'partial' paradigm change of the bio-social-psychological model of the ICF and the WHO has dominated governmental policies and social rhetoric producing ambivalent and ineffectual practices (Ferrante, 2021). Xiomara's story has examples of these ambivalent practices with reticence but urgency felt by professionals to diagnose, the concern of possible school exclusions or lack of support that should be in place, the legal inclusive right to school placement whilst simultaneously the school not feeling able to contain her diagnosed child resulting in her child's choice to stand outside. The prevalence of neoliberal individually focused narratives of independence and rights around (dis)ability has limited the boundaries of knowledge production on (dis)ability from within our continent and has invisibilized the localised social experiences of (dis)ability within particular intersectional dimensions (such as poorly funded schools, family poverty, migration, xenophobia) subsuming disabled people's experiences under universalist discriminatory paradigms and failed practices (Ferrante, 2021; Grech et al 2023).

Wherever our starting points may be, wherever we centre our positionality around (dis)ability and impairment, whether from the medical model, the british social model, the ICF bio-psico-social model or from other critical stances questioning the very notion of 'normality'; wherever we start it is clear that much work is needed to be done to challenge the oppression and discrimination of people with (dis)ability labels from many different territories around the world and for their ideas and choices to lead solutions and change globally.

The WHO statistical inferences estimate the prevalence of (dis)ability to be around 16% of the world population in March 2023, that is 1 in 6 of us globally (WHO, 2023). In these statistics there is some mention of the correlation between poverty in the Global South and (dis)ability, however in these numbers people around the world are homogenised and so women, refugees, children, non whites, war displaced people, exploited people, people in poverty who are also disabled rarely get visibilized when Global North based developmental policies are invoked.

Oliver (2009) critiquing the WHO's review of the ICIDH argues that its universal policy based on notions of:

> "empirically grounded human normality is code for biologically and medically based classification systems at just the point when social theory is attempting to come to terms with the universality of difference rather than the universality of expanded categories of normality" (pg 112).

Attending to plurality, localisation, and politics of oppression is not on the agenda of globalised development and very diverse groups of people in a variety of geo-political and social circumstances are homogenised, invisibilized and dehumanised (Grech et al, 2023; Grech, 2015). The agenda of descoloniality is to uncover the specificity of Global North production and to recognise its historical genealogy.

2.3 What is the genealogy of the globally exported conceptualisation of (dis)ability ?

To excavate the western conceptualisations of (dis)ability imported to LatAm and the rest of the world means not only to ask, as postmodernists do: what notions are being exported? who is creating knowledge and policy?' and what is their power base? To also ask from a descolonial lens what are the geo-political historical colonial spaces of the knowledge producers, that is to establish the epistemological and ontological genealogy wherein the knowledge producers work. Genealogy is an essential tool in feminist descolonial methodology to document past and present archives (Espinosa-Minoso, 2021; Mendoza, 2021) with the complex intentionality of not reproducing the very concepts being researched, of not presuming to arrive at universal 'truths' while portraying altern versions of experiences and delinking from dualist universal binaries. This signifies stepping out of the western knowledge systems we have all been trained within (Miñoso-Espinoza, 2021; Mignolo, 2021) to decolonise ourselves and the knowledge we work with.

The history of (dis)ability may be portrayed in the natural sciences and the history of medicine as a story that goes back to the beginning of human life on earth. The current global understanding of (dis)ability as universal and ahistorical is entrenched in the medical model exported globally. Weaving notions of (dis)ability within the decolonial turn is connected to understandings of race

and gender in coloniality The invention of race has been tied down as a colonial conception by Quijano (2000), and the naturalisation of gender is questioned by Lugones as 'one of the marks of the human' as defined by colony (Lugones, 2021, pg3). The notion of normal/abnormal has also been challenged as a construction by (dis)ability rights movements and academically by the social model of (dis)ability and in the field of critical (dis)ability studies (Meekosha & Shuttleworth, 2009). LatAm descolonial thinkers are starting dialogues across the fields of critical (dis)ability studies and descoloniality:

En términos generales se aprecia una subteorización, marginalización y ausencia del abordaje crítico de la discapacidad en esa compilación del pensamiento social latinoamericano y caribeño.
(Yarza de los (Rios, 2019, pág 37)

In general terms, there is an under-theorisation, marginalisation and absence of a critical approach to disability in the compilation of Latin American and Caribbean social thought.
(Yarza de los Ríos, 2019, pg 37)

There is a common recognition in descolonial approaches to (dis)ability and CDS that (dis)ability is a form of classifying and reducing people as inferior in comparison to a norm, a dichotomy of who is human that is constituted in the modern/colonial capitalist ableist globally dominant system of the present age (Danel et al, 2021; Meekosha, 2011; Grech, 2015; Yarza de los Rios, et al, 2019).

The genealogy of (dis)ability entails a vast archaeological account that is slowly being constructed over time and through many voices outside of the colonial seats of knowledge from altern pluriverse perspectives (Bregain, 2021; Danel, 2021; Yarza de los Ríos & Romualdo, 2021; Yarza de los Rios et al, 2019) This historical excavation can uncover a multitude and pluriverse of stories from different locations, eras and through different paradigms. This is a huge undertaking, which can uncover important imaginaries of altern possibilities that help us look to the future.

Why is the geo-politics history of (dis)ability important? There is a vast literature on the history of (dis)ability produced in the North (Bernstein et al, 2014) from both traditional medical

(Bregain, 2021) and critical philosophical and critical disability perspectives (Goodley,2014; Tremain, 2017). There is no systematic history of (dis)ability from Global South eyes, from indigenous, mestizo, and slave descendant perspectives. There is already important documentation and history of stories of how (dis)ability has been enacted in many cultures across history, although often these histories are entangled with the history of western medicine and its own paradigm of thought (Bregain, 2021). The rational western dualist sciences that rely on their own created principles of universalism and neutrality in the production of knowledge (Mignolo, 2021) swallows up the historicity of its own thought, rendering it naturalised, objective and erases all other stories. Historical research on (dis)ability could be broader to focus on pluriversal possibilities of understanding (dis)ability, researching intersectionalities, geo-social-political spaces, religious beliefs, institutionalisation or not, the agents of care and of self-agency in various contexts, and so much more.

To speak of impairment and (dis)ability as universal and transversal throughout history and cultures assumes they stretch throughout time as stable ideas and experiences. To trace histories of altern modes of understanding and living beyond our modern categorical understanding of what we call '(dis)ability' can be a useful genealogy of altern universes, not to romanticise or essentialise forms of 'alterity' but to critically hear a pluriverse of stories. How can we move outside the categorical, hierarchical discriminatory lines of thinking from western rationality if we don't explore ambiguous, contradictory, complex, non linear localised altern stories? Listening to stories of altern views and ways of living are important to illuminate the possible futures and maybe invoke borders of 'sentipensar' reflective care. I offer a couple of research narratives that I believe highlight the importance of altern stories.

When researching what (dis)ability meant in Mapuche cultures in Chile I found an anthropological dissertation: 'Una aproximación a la identidad en los discapacitados Mapuche de la comunidad Kallfulikan', (An approximation to the identity of Mapuche disabled people in the community of Kallfulika) by Gregorio Pérez-Serrano (2008). He set out to explore the view of (dis)ability in Mapuche culture, through ethnographic research in various communities. He reports the absence of terms in Mapuche language for (dis)ability, and the differences between Mapuche communities as to how they enacted practices towards people with (dis)abilities. He

observes that those communities that remain resistant to Chilean governmental influence who have totally different attitudes towards (dis)ability than those that are living within Chilean culture. He quotes a Lonco and a Machi (authorities in Mapuche communities) saying:

"De acuerdo a mi cultura el discapacitado no es culpable de lo que le sucede, si no la persona es así es por los errores de nuestros ancestros, de nuestros padres, desde ese punto es mirada la discapacidad". (Perez-Serrano, 2008, pág 131)

"According to my culture, the disabled person is not to blame for what happens to him/her, no, if the person is like that, it is because of the mistakes of our ancestors, of our parents, that is how (dis)ability is seen". (Perez-Serrano, 2008, pg 131)

"La discapacidad dentro de la cultura Mapuche, se ve como bueno. Dentro de la cultura Mapuche uno es como es, cada uno es no más. No es diferenciado, discriminado: Juanito, Pedrito. Cada uno es diferente, todos son personas distintas unos tienen una cualidad, otra cualidad, algunos tienen un defecto, otro defecto pero son todos seres humanos." (Perez-Serrano, 2008, pág 133)

"(Dis)ability in Mapuche culture is seen as a good thing. Within the Mapuche culture, one is as one is, each person is and that's it. People are not differentiated, discriminated against: Juanito, Pedrito. Everyone is different, everyone is a different person some have one quality, some have another quality, some have a defect, some have another defect, but all are human beings.". (Perez-Serrano, 2008, pg 133)

In one example he relates his observation of a Down syndrome adult man who is non-verbal participating in a community seminar about intercultural medicine:

En el turno de las preguntas, este emitía sonidos, aplausos y gritos, los miembros de la comunidad que lo acompañaban lejos de hacerlo callar, lo escuchaban atentamente en silencio y con respeto. En los eventos importantes de la Ruka siempre está presente …. interactúa en este espacio como cualquiera siguiendo la dinámica de los mapuche una en que el

diálogo y el humor es la base de las relaciones personales, él lonco le hace bromas…(Perez-Serrano, 2008, pág 141)

When it was his turn to ask questions, he emitted sounds, clapping and shouting, the members of the community who accompanied him, far from silencing him,

listened to him attentively, silently and respectfully. In the important events of the Ruka he is always present … he interacts in this space like anyone else, following the dynamics of the Mapuche, one in which dialogue and humour is the basis of personal relationships, the lonco makes jokes with him...(Perez-Serrano, 2008, pg 141)

The Lonco is the chieftain of a Mapuche community or group of communities.

In contrast when Perez-Serrano visits Mapuche populations that have been evangelised protestant or catholic and that operate within Chilean society, he finds in his conversations with disabled people and their families multiple examples of guarded admissions of (dis)ability, discrimination within the community, exclusion, narratives of charity and keeping disabled persons hidden from the community. One mother tells him:

Entonces, no me lo admitieron en un colegio normal tuve que ponerlo en un colegio especial, ahí estuvo hasta los veintitantos años. Después le enseñaron amasandería, aprendió, él hizo su práctica en un supermercado que se llama Ekono Max que es el único que acepta personas con discapacidad. Usted ve que en ninguna parte aceptan, y son siempre rechazado que por esto por esto otro (Perez-Serrano, 2008, pág 174)

So, they wouldn't admit him to a normal school, so I had to put him in a special school, where he stayed until he was in his early twenties. Then they taught him how to make bread, he did his apprenticeship in a supermarket called Ekono Max, which is the only one that accepts people with (dis)abilities.You see, nowhere else do they accept them and they are always rejected because of this, because of that. (Perez-Serrano, 2008, pg 174)

Perez Serrano argues that present day Mapuche communities are marked by socio-political processes of deepening neoliberal attitudes; those communities that continue to resist inclusion to the mainstream Chilean society have strong criticisms of the impositions of discriminatory public education and public health that are antagonistic to their beliefs whereas they have multiple explanations that are centred on relationships for what we call (dis)ability.

Another example is from research by Yarza de los Rios (2021) in Colombia and Romualdo Pérez (2021) in Mexico who explore the languages and meanings around people we would label as disabled from two indigenous cultures: the Ebêra Eyábida and the Ayuuk. They conclude that further extensive dialogic research is needed to understand the complexities of indigenous

thought and the translations. They affirm there is an abysm to explore between diverse ancestral knowledges and western discourse that can complement critical (dis)ability thinking. One example of linguistic representation of ideas is finding terms in indigenous cultures akin to our conception of (dis)ability. 'Jaay Maat' a term from the Ayuuk language which caught my mothering eye:

Jääy Määt no quiere decir que se trate de una "persona descompuesta" o "que no tenga arreglo", sino todo lo contrario: para las cuidadoras y los adivinos son hijos enviados por Dios que son êmanââxy, "frágil como una flor", cuya existencia solo podrá ser posible si se le cuida de una manera amorosa y minuciosa para conservar la vida. (Yarza de los Ríos y Romualdo Pérez , 2021, pg 170)

Jääy Määt does not mean that this is about a "broken person" or "beyond repair", but quite the opposite: for the caregivers and diviners they are children sent by God who are êmanââxy, "fragile like a flower", whose existence is only possible if they are cared for in a loving and meticulous way in order to preserve life. (Yarza de los Rios y Romualdo Pérez , 2021, pg 170)

There is broad acknowledgement by those engaged in praxis and research at the intersectionalities of indigenous beliefs and (dis)ability that there is a need to acknowledge relational epistemological and cosmological accounts of what in the west we call '(dis)ability' rather than only focus on accessibility to services (Grech, 2015; Soldatic and Gilroy, 2018; Yarza de los Rios y Romualdo Perez, 2021). Research focused on access to services and fulfilling CDPR goals from national and international policies alone already starts with an epistemology from a medical paradigm based on needs and western logic of developmentalism, rather than on community priorities of care and 'buen vivir'(good life). Yarza de los Rios and Romualdo Perez (2021) join the call for critical (dis)ability studies and descolonial perspectives to strengthen pluriversal studies in (dis)ability.

In studies with various Indigenous groups in Colombia, Mexico, Chile, New Zealand, Australia, there are frequent reports of indigenous groups not having a term for (dis)ability (Meekosha, 2011; Perez-Serrano, 2008; Rivas Velarde, 2018; Yarza de los Ríos, 2021). To explore the pluriverse of stories from different communities is to acknowledge the complexity, the differences that can no longer homogenise Indigenous, mestiza, rural, urban communities in

Abya Yala as well as other south global territories. Through altern epistemologies we can trouble the paradigms that have constructed it. As Anzaldua says:

> "Each reality is only a description, a system of perception and language. When you learn to access other "realities", you undo one description or plane/level of reality and reconstruct another or others. You learn a new language and a new way of viewing the world, and you bring this "magical knowledge and apply it to the everyday world" (Anzaldua, 2015, pg 38)

Documenting and acknowledging different ways of viewing the world takes us to reviewing epistemologies. While we do so it is vital to place these understandings in the modern reality of global stories of forced migrations, exploitation of territories, wars, mining and hydroelectric projects that disable the land, communities and people. These stories are invisibilized by the health and education policies of governments and global markets (Gargallo Celentani, 2014) intended to amend the very damages they produce but which are ideological and violent invasions encovering exploitation and oppressions that result in (dis)ability.

2.4 Who is Troubling (dis)ability?

I have been exploring in this chapter what it means to place conceptualisations of (dis)ability into descolonial feminist research questions. In other words how to decolonise the research questions when using a complex conceptualisation like (dis)ability born in the Global North. I wish to explore nodes of dialogue between CDS from the north and feminist descolonial studies of (dis)ability from LatAm.

The ontological and epistemological examination of modern/colonial paradigms of (dis)ability from a descolonial lens seeks to uncover the layers of coloniality. It is necessary to step outside of the very system that created the classification labels of (dis)ability as it does not have the tools to dismantle itself as Lorde (2018) makes clear. However this stepping outside still requires us at this time to continue using the category of (dis)ability because to not do so would be a denial of the humanity of people with labelled (or suspected) (dis)abilities and the precarious life conditions they are subjected to. (Grech and Soldatic, 2016; WRD, 2006).

When Xiomara is asked by the professional assessing her child whether she wants the diagnosis, stating it will probably help her child get the services needed even if she doesn't fit the diagnostic category, I hear a troubling by the professional of the diagnostic and educational system. I can relate to this problematising and am aware in my professional life and in the literature of professional psychologists (Parker, 2007; Williams et al, 2017) who navigate a system to get the best for the people they work with even when they have doubts about the classifications they need to diagnose.

Haraway (2015) says the conceptualisations we use to formulate questions and to define further conceptualisations matter deeply and presignify produced knowledge. Following feminist descolonial thought and critical (dis)ability studies I have been concerned with the ethics of who produces the methodology of my research and how to formulate questions that include the conceptualisation of (dis)ability. To continue my methodological explorations I now turn to thinkers in two fields of studies that are troubling (dis)ability. First are the emerging descolonial (dis)ability thinkers who are questioning the naturalisation of (dis)ability as biological fact and coalescing around commitments to critical questioning and critical practices, challenging disablism and the injustices that those with a label living in LatAm (Danel et al, 2021; Munevar et al, 2019; Yarza de los Rios et al, 2019) and beyond. Second are the thinkers in critical (dis)ability studies who align with the social construction of (dis)ability, who are stepping outside of the psyche disciplines and are concerned with social injustices that affect disabled people everywhere and who centre the voices of disabled people in the research (Danel et al, 2021; Ferrari, 2020; Goodley et al, 2019; Gilroy et al, 2021; Grech & Soldatic, 2016; Grech, 2015; Meekosha, 2011; Oliver & Barnes, 2012; Rice et al, 2015; Runswick-Cole et al, 2024; Shakespeare, 2002; Yarza de los Rios et al, 2019).

Critical (dis)ability Studies and Descolonial Feminisms

Descolonisation and anticolonisation, as was described in chapter one, have a continued history of resistance and revolt in Latin America since the moment the invaders set foot on Our America (Marti, 2011) in 1492. The modernity/coloniality group initiated the present descolonial turn in LatAm, formed in 1998 (Lander, 2000). The evolution of the descolonial turn includes many

counter-alternative paradigms to modernity/coloniality not considered within the tradition of Eurocentric modernity (Escobar, 2007) including descolonial feminisms (Espinosa-Miñoso et al, 2021).

In the same decade that the modernity/coloniality group was forming, the ICF model of (dis)ability was being widely taken up by most LatAm national governments as countries signed the 2006 Convention for the Rights of People with (Dis)abilities (CRPD). The CRPD has played a major role in policy writing across the continent (Ferrante, 2021). Simultaneously, the British founding authors of the social model raised concerns on the dogmatising of watered down notions of the social model of (dis)ability (Oliver & Barnes, 2012; Goodley et al, 2021) that were proliferating. Soon after the theorising beyond the social model of (dis)ability in the Global North emerges into the new field of critical (dis)ability studies (Goodley, 2013; Meekosha and Shuttleworth, 2009). The historicity of modernist western hegemonic thought as the global systemic paradigm within which the 'disabled' as alterity is invented, is beginning to be explored within descolonial thinking (Danel, 2021; Ferrari, 2020; Rojas Campos, 2015; Yarza de los Rios et al, 2019).

The convergence and possible dialogue between CDS and descolonial perspectives from LatAm is very recent and with very few productions of discourse in the intersection of these fields of thought being produced globally (Grech and Soldatic,2016; Meekosha, 2011; Meekosha and Shuttleworth, 2009) produced in LatAm (Rojas Campos, 2015; Danel et al, 2021; Yarza de los Rios et al, 2019; Pino Moran and Tiseyra, 2019), produced by descolonial feminists (Villa Rojas, 2020; Ferrari, 2020, Angelino, 2012) and none to date found that explore the intersections of motherhood, (dis)ability, childhood and forced migration through a feminist descolonial lens. The burgeoning dialogue between multiple praxis in LatAm, research in CDC and DF and the gaps in these intersections is the space in which I located my methodological research. Next I explore dialogue nodules and encounters between CDS and DF.

2.4.1 Epistemology and Political Praxis

Black feminists and descolonial feminists place Harding and Haraway's (1988) ideas on positionality and reflexivity firmly within the notions of intersectionality (Crenshaw, 1991) and

imbricated realities of practice (Lugones, 2010). Just as race and gender are constructed inside of the subjectivity of coloniality and its relationships of power, discrimination and subjugation (Lugones, 2010; Schewe and Vain, 2021), so is (dis)ability (Bregain, 2021; Danel, 2019; Rojas Campos, 2015; Moran & Tiseyra, 2015;). However important counter-theoretical thought may be, for DF this can only be of value in the measure that critical thought is created in political praxis and connected to people's lives. The lives of people at the intersections of the imbricated complexities of multiple oppressions in LatAm and across Global Souths (disablism, racism, misogyny, etc) matter but crucially we have to produce knowledge collectively to not step back into privileging paradigms of expertism and externalisation, and hence back to the modern/colonial paradigm. Rivera Cusicanqui says:

<table>
<tr><td>No puede haber un discurso de la descolonización, una teoría de la descolonización, sin una práctica descolonizadora.
(2010, pg 19)</td><td>There cannot be a discourse of descolonisation, a theory of descolonisation, without a descolonising practice.
(2010, pg 19)</td></tr>
</table>

In this respect descolonial feminists like Lugones, Curiel and Espinosa-Miñoso (2021), have been heavily influenced by feminist criticisms formulated by black and indigenous feminists who counter hegemonic feminisms and universalising notions of womanhood, as racist, heterocentric, patriarchal and regional that silence and 'other' already 'othered' women.   Descolonial feminist epistemology formulates and develops the coloniality of gender as the continued patriarchal perpetuation of the distinction between human and non humans; and they are committed to producing knowledge, proposing methodologies and pedagogies from collective community processes to disrupt this coloniality (Curiel, 2021, Espinosa-Minoso, 2021, Lugones, 2021). The political praxis both within modern/colonial society and in the peripheries is thus inherent to the methodology to avoid colluding with neoliberal modes of knowledge production that further reassert Eurocentrism and colonial structures of imbricated oppressions (Espinosa-Minoso et al, 2021)

Across the continent extractivism is understood as a colonial process that includes the appropriation of bodies and territories, and for Rivera Cusicanqui also the appropriation of ideas, marketed in the academias of the north. The pluriversity of descolonial thought is not intended as

a unified articulated theoretical framework to be exported as a decolonial study fields to the Global North. There are many breaking points between the main referents of the Modernity/Coloniality Group, descolonial feminists and indigenous and rural movements. There is criticism that some have de-territorialised ideas, deepening tokenistic descolonial theoretical fetishism (Curiel,2009; Pratt, 2019;Rivera Cusicanqui et al,2016). This constant calling of attention mainly by descolonial feminists and indigenous movements to work in descolonising practices rather than in academic corridors of Global North has become a core argument of political praxis.

This emphasis on knowledge production from the expertise of lived experience by and with people is also central to the field of critical (dis)ability studies (Goodley, 2013; Grech and Soldatic, 2016; Runswisk Cole and Mallet, 2014;) In CDS (dis)ability is seen as a social construction that is shaped by social relations, modes of knowledge production are context specific and not universal. The epistemology of (dis)ability in CDS is vitally connected to praxis. Goodley, Lawthom, Liddiard and Runswick-Cole (2019) in Provocations for Critical (Dis)ability Studies point out the importance of scholarly studies to support social movements as it is here where they see the foundational understanding of (dis)ability from a social model perspective:

> "…maintains a commitment to politically organise and contest disablism and ableism in the everyday lives of disabled people. Social theory should not be distanced from people's everyday realities." (Goodley et al, 2019, pg 977)

The practice of doing this present research from a distance online during the pandemic forced me to listen differently, made more obvious my outsider role while also drawing me as an insider in the community of women with whom we began our collaborative work. Taking a pause on the research and joining a collective advocating for a space at the table of decision making for Venezuelan forced migrants in local and global coalitions drew my focus away from theoretical concerns of (dis)ability, feminism, migration towards very practical work of supporting forced migrants in Bogota. My work shifted towards setting up structures in the RLO that allowed us to enter and navigate the grant and aid system that we needed to have a presence in to to have funds

to carry out the work. Although I was on new terrain and learning so much joining global refugee led coalitions that are demanding changes in the system, something felt familiar. I was reminded of non-academic autistic self-advocate groups that demand changes in the views on autism and (dis)ability in the social, political and educational arenas such as the Autistic Self Advocacy Network (ASAN, n.d.) and Autscape (n.d.). Having entered a new arena of praxis through the RLO I felt a familiarity in the encounter with systemic paradigms of who is included: International NGOs, International global corporations like the UN, governments and who is not: refugee led organisations, forced migration and community based groups. Within the refugee movement the slogan 'Nothing about us, without us' is commonly used, adopted from (dis)ability and autistic movements (Charlton, 1998; Douglas, 2021; Mustafa, 2023; Runswick-Cole, 2014). These group movements had supported my online learning about autism and continuously advocate for the inclusion of their voices in decisions that affect them and for the investment in research to be focused on living rather than curing (Broderick & Ne'Eman, 2008; Runswick-Cole, 2014; Sinclair, 1993). The practice of doing research with critical 'disabled' voices in CDS as well as in anti- and postpsychiatry movement and academic fields is central to changing the research model (ASAN, 2018; Cascio et al, 2021; Grech, 2011; Mills & Fernando, 2014; Timimi, 2014).

This epistemic and political praxis conjunction is a central communality to the intentions and methodologies of CDS and DF in regards to knowledge production and social justice, as well as the refugee-led movement I am now engaged within. This has been and is a growing common ground for dialogue between CDS and DF (Danel et al, 2021).

2.4.2 Coloniality of Gender and Coloniality of Normality

Descolonial feminism starts with Quijano's coloniality of power that places the category of race in a hierarchy that justifies modes of work that privilege a few and oppress 'non beings' in the colonial divide. Lugones (2010) builds on Quijano's (2000) ideas to formulate the coloniality of gender where she affirms that coloniality is not exclusively about race. Gender is an all enveloping axis of power; it permeates all structures of society from governing public spaces, work spaces and private intimate inter-relational spaces. The coloniality of gender has become a

grounding concept not only for descolonial feminists, there are those who think the conceptualisation has moved descoloniality away from solely academic endeavours towards praxis (Curiel, 2022). The coloniality of gender has reoriented subaltern coalitions of resistance to the reproduction of the categorial logic of modernity and coalitions of solidarity beyond borders creating dialogue amongst a multitude of perspectives (Asher, 2017; Pratt, 2019).

I wish to explore Lugones' conceptualisation of Coloniality of Gender (2010) and the fertile ground it offers for possible conceptualisations such as the Coloniality of Ability (Ferrari, 2020) or I posit a Coloniality of Normality. In the descolonial turn we know that 'naturalisation' of colonial ideas such as 'black is barbaric' is exactly opposed to problematising history and the power in knowledge production (Quijano, 2020; Lugones, 2021). To problematize implies to denounce and to deconstruct objective universal mainstream accepted 'truths'. It requires stepping out of known categories and methodologies. This is what Lugones does in the Coloniality of Gender.

Lugones' undertaking in formulating the coloniality of gender has had ramifications in academia and praxis within and beyond DF thought with an expansion in LatAm beyond university programs and hallways. She places gender as an oppressive category that refers specifically to women, not to all people even though we all have a gender. Northern gender studies identify with a specific gendered political oppressive patriarchy. Lugones adds to the voices of non white feminists (Anzaldua,1999; Collins,1986; Crenshaw,1991; Mohanty,2003) critiquing white feminism as universalizing and excluding women from the Global South in white feminists' particular description of patriarchy. Crucially she argues that the resistance to the gendered system by white feminism has failed, for all women. However, Lugones (2021)adds another idea that I have not understood in this particular way in any other sources. She says of white feminisms:

It fails to offer another humanity, another sense being a woman, if such a being should continue to exist under that name (2021,Pg 5)	No ofrece otra humanidad, otro sentir de ser mujer, si es que ese ser debe seguir existiendo bajo ese nombre (2021,Pág 5)

When I read this, it was a cataclysmic moment for me. She opened up so many lines of thought and articulated 'sentipensar' possibilities that reside outside of western thought, a bridge over the catastrophic schism of the zones of being. Lugones (2003, 2010, 2011, 2021) takes the question of women outside of the binary as no other author I have read made me conceive. 'If such a being should continue to exist under that name' conjures for me what Ochy Curiel (2009, 2022) describes as the work of descoloniality: placing ourselves outside of the categories. Lugones (2021) points to faults ignored in the feminist universal movement where the concept of woman as a social construction, is but one possible interpretation of sex naturalised by hierarchical patriarchy as inferior. First, she says not all females are considered in the universal feminist movement, (as do other non-white feminisms), so not all females are women and hence their conditions of oppression are ignored. This dehumanisation is within the logic of colonialism, where women are irrational, mad and inferior, but this only applies to white women. Black, indigenous and mestizas are part of nature and not included in the category 'woman' as white women are. Secondly, she calls for the failure of stepping out of the colonial categories, hence other ways of being and knowing are silenced. Modern/colonial categories have no respect, compassion, empathy or capacity for alter-perspectives, ' othered' women are invisibilized and cannot produce knowledge. This praxis focus of descolonial feminism of gathering and understanding altern knowledge production has reopened the debate of patriarchy and gender amplifying epistemic bases to contest the coloniality of power and being. Revealing the complicity of the categories of race and gender in the emergence of western modernity: "Descolonial feminists have become bridges and facilitators in the crossing of specialized critical thought and knowledge otherwise" (Espinosa-Miñoso, 2021, pg xvi) and in doing this open the possibility to invent new concepts of being human.

It is on this bridge where I find descolonial feminism has so much dialogue with CDS for two reasons. First, as already described above, CDS places disabled people at the centre of research and program designs (Runswick-Cole et al, 2023) as well as building dialogue bridges with diverse critical perspectives from trans, crip, black, posthuman and so on (Goodley et al, 2019). Secondly, CDS recognises (dis)ability as a social construction of discrimination where ability and (dis)ability are co-produced in relationship to each other and CDS actively explores what social justice can look like in the lives of people with (dis)abilities (Grech and Soldatic, 2016;

Goodley et al, 2021) CDS looks for altern paradigms of thinking through (dis)ability intersectionalities with other critical fields of study. CDS has questioned the placing of (dis)ability inside the dualist binary of the western normative normal/abnormal, able/disable seeking to extract it and frame humanity outside of the categorical dualist logic of reductionism. This is clearly centred in the critique that Runswisk-Cole makes of the neurodiverse conceptualisation of (dis)ability. She says:

> "...a 'politics of neurodiversity' depends on the binary of 'neurodiverse' and 'neurotypical' populations. There is, then, a danger that a politics of neurodiversity will fail to pay attention to the other forms of marginalisation that underpin exclusionary and oppressive practices, including heterosexism/sexism, racism, poverty and imperialism, as well as the intersections between them." (2014, pg 1126)

Neurodiversity is then another dualist conceptualisation where on one side we have the neurotypical people (normals, abled) and on the other neurodiverse people (abnormal, disabled). Neurodiversity, sitting in a liberal rights perspective, does not escape the hierarchical dualism of colonial/modernity. It is another perspective from the west that has travelled and been inserted in the Global South. This is the term the professional in Colombia uses ambiguously to explain to Xiomara the validity or not of her daughter's diagnosis. The overwhelming capacity of contemporary neoliberal modern/coloniality to adapt and absorb critical perspectives can only be confronted outside of dualist categories. Though from a rights perspective the neurodiversity movement has been important to raise the profile of 'neurodiverse' and disabled people bringing them closer to the zone of being human, neurodiversity does not escape the catastrophic divide.

Adding the terms of neurodiversity to the binary zones of being and non being adds to the imperative of questioning knowledge internalised as unique and "true" by a Global North that continues to ideologically colonise us from different movements (Yarza del los Rios et al, 2019). In the hierarchical dualist rational division of being of the objective western paradigm I wonder what the words below mean in different contexts and what other words we could add to this catastrophic divide?

Zone of being -Zona del Ser	Zone of non-being Zona del no-ser
Superior	Inferior
Civilised	Savage
Rational	Irrational/Emotional/
Culture	Nature
Normal	Abnormal
Health	Sickness
White	Non-white
Benevolent	Barbaric
Male	Female
Individual	Collective
Able bodied	Broken body
Heterosexual	Weye/Alka/Piilitun/Epupillan/Qariwarmi/LGBTQ*
Sane	Mad
Ability	(dis)ability
Neurotypical	Neurodiverse

*Weye/Alka/Piilitun/Epupillan/Qariwarmi/ These are complex terms from Abya Yala indigenous cultures that refer to peoples' vivencias where genders, in the plural, in one body, are woven into sexuality in situations of connection and transit, not as identity or for reproduction only and where binarism are suspended and opposites are not hierarchical. Altern ways of living and identifying in regards to gender that were obliterated in colonial moral christianity (Lugones, 2021).

It is in this critical border zone of who qualifies as human that questions are raised in both CDS and DF that offer ripe dialogue. Both fields, CDS and DF, are set on paths to unsettle and undo the western hegemony of what it means to be human. In CDS this has been explored in conjunction with many different identity based oppressions fields of study such as queer, black feminism, postcolonialism and posthumanism (Goodley, 2013, Goodley et al, 2019). This field of study has also been reflexive and mindful of criticisms from the Global South on the whiteness of (dis)ability models and study. The foundation of a journal of (Dis)ability and the Global South (Grech and Soldatic, 2014) with authors and editors from around the world signals the aperture of CDS to Global South critical perspectives. CDS is highly engaged with a growing diversity of new theoretical understandings of who is human.

Within the descolonial turn fundamental texts published in the last five years in LatAm: Who is the Subject of Disability (Danel et al, 2021) and Critical Studies in Disability: A Polyphony from LatinAmerica (Yarza de los Ríos et al, 2019) are reformulating what it means to be disabled in our continent. I am interested, in particular, in the possibility of weaving conceptual notions from critical (dis)ability studies and the coloniality of gender of Maria Lugones to question the naturalising conceptualisation of normality, impairment and (dis)ability that permeates conceptions of (dis)ability imported from the Global North.

I wish to draw on the ideas of Lugones (2021) and Ferrari (2020) to explore (dis)ability. Lugones' coloniality of gender framed the modern/colonial as an all encompassing system of classification of humans for the purpose of subjugation and the production of knowledge within these relationships of hierarchy. Placing gender in the colonial wound next to race, she underlines the understanding of intersectionality, taken from black feminists in USA (Crenshaw, 1991, 1998; Collins, 1986), as the imbrication of complex overlapping oppressions. So in Lugones coloniality of power, being, gender are all fused in one oppressive, brutal, dehumanising coloniality. With the coloniality of gender, Lugones opens the critical field to consider as central the multiple complex oppressions in specific territories and populations.

Ferrari (2020) has introduced the term the Coloniality of ability, based particularly on the ideas of the coloniality of power and being and their argumentation of work relations as central to the modern/colonial enterprise.

La colonialidad de la capacidad explica cómo se define la capacidad a partir de la individualización de las posibilidades humanas de hacer frente a la vida y la inauguración de la discapacidad a partir de la generación del esquema del racismo. (Ferrari, 2020, last section)	The coloniality of ability explains how capability is defined through the individualisation of human possibilities for coping with life and the inauguration of (dis)ability through the generation of the schema of racism. (Ferrari, 2020, last section)

This notion is just beginning to be formulated and I wonder if other ideas may also flourish such as a coloniality of normality or a coloniality of (dis)ability that could signal a response to the dehumanising danger of dualisms inside the colonial wound. Using the oppressed category in the concept (race, gender, disabled) can be important as it is the margins, the peripheries, the non-human that have been the markers that are used to define the norm, the central, the human. (hooks, 2015). Thinking through Lugones' coloniality of gender, her words 'If such a being should continue to exist under that name' and seeking to step outside colonial binaries perhaps a 'coloniality of normality' may be useful as a tool to deconstruct not only the capabilities assumptions of modernity but to also decolonise the normativity of all aspects of being (physical, cognitive, ethnic, cosmological, gender, spiritual, emotional, social) that are measured or silenced by the psyche apparatus of the Global North.

In either case the notions of a coloniality of ability or normality are at the centre of the growing intersections of descoloniality and (dis)ability, between CDS and DF praxis on how to move (dis)ability outside of the normative logic of the colonial/modern gender system. The complicity of colonialism within the conceptualisation of (dis)ability is clearly accepted in CDS and in beginning to be deeply excavated in LatAm descolonial studies of (dis)ability (Danel et al, 2021; Yarza de los Rios et al, 2019). Both fields of CDS and DF are enacting and seeking altern methodologies and can collaborate with epistemic resources for understanding (dis)ability as of colonial origin, and coloniality itself as a process of disablement.

2.4.3 CDS and DF in Dialogue

The conceptualisation of (dis)ability from descolonial lenses is wide open to dialogues between ecologies of knowledges. Abya Yala Descolonial Feminist thought has continually dialogued with critical stances from the north as well as other Global South locations (Curiel, 2021; Spivak, 2010; 2021, Lugones, 2021; Cusicanqui, 2010; Ferrari, 2020).

No todo lo que se escribe desde el
Norte Global resulta pensamiento
eurocéntrico y colonial; así como
tampoco todo lo que se escribe desde el
Sur Global es sinónimo de
emancipación y descolonialidad. (Díaz
et al, 2021, pág 38)

Not everything written from the Global
North is Eurocentric and colonial
thinking; nor is everything written
from the Global South synonymous
with emancipation and descoloniality.
(Diaz et al, 2021, pg 38)

In this methodological research I am concerned with the formulations of research questions and looking to CDS and DF to think through how to use words in the questions, in particular examining how to use (dis)ability in the questions. Siliva Rivera Cusicanqui says that words as used within coloniality cover, conceal, disguise, blur, mantle reality to protect the status quo. She says:

Hay en el colonialismo una función
muy peculiar para las palabras: las
palabras no designan, sino encubren, y
esto es particularmente evidente en la
fase republicana, cuando se tuvieron
que adoptar ideologías igualitarias y al
mismo tiempo escamotear los derechos
ciudadanos a una mayoría de la
población. De este modo, las palabras
se convirtieron en un registro ficcional,
plagado de eufemismos que velan la
realidad en lugar de designarla. (2010,
pg 19)

There is in colonialism a very
peculiar function for words: words
do not designate, but cover up, and
this is particularly evident in the
republican phase, when egalitarian
ideologies had to be adopted and at
the same time citizenship rights were
withheld from a majority of the
population. In this way, words
became a fictional register, full of
euphemisms that veil reality instead
of designating it (2010, pg 19).

Together with other DF and indigenous and rural movements, Rivera Cusicanqui (2016) points out that this criticism of words is also applicable to descolonial authors from academia- generally male- whose contribution to the critique of modernity and eurocentrism presents itself as a novelty in the region, as if in isolation with critical thought elsewhere spatially and in time. In her 2010 methodological text : Una Reflexión Sobre Prácticas Y Discursos Descoloniazadores (A Reflection on Decolonising Practices and Discourses) she points out the descolonial academics' appropriation and erasing of the theoretical potential of historical anticolonial thought in Abya Yala and beyond which already embodies conceived notions of internal

colonialism (Rivera Cusicanqui, 2010; Pratt, 2019). Her contributions are important because serious linguistic work is an essential tool of decolonisation as it becomes a source of the new social visions and has to continually resist the power of recolonisation so easily flowing in neoliberalisms' adoption of concepts such as neurodiversity and equity in human rights. She warns of this appropriation both from the politics of the Global North as well as from professional world scholars. It is with this warning ringing in my ears that I turn again to how to formulate questions that include the notion of (dis)ability invented within the modernity/coloniality world paradigm and rooting it in my practice at the RLO. Esperanzita had asked me regarding her son's stuttering, is that a (dis)ability? Xiomara wondered if neurodiversity was or not a (dis)ability. What the word (dis)ability means to each of us is widely different. Even more, when creating collaborative research in refugee communities, is (dis)ability a term that people would want to use?

In CDS the word (dis)ability has been written in many forms to represent critical emancipatory ideas: dis/ability (Goodley, 2013), (dis)ability (Schalk, 2017), 'disability' (Danel et al, 2021). Politically we need the term '(dis)ability' to continue to work in coalitions, not only identity coalitions (that can get subsumed into neoliberal inclusive practices) but also in political, social, legal, praxis coalitions. In this sense how we write (dis)ability always matters to signify the questioning of the underlying social constructed meanings in our positionalities and politics that we bring to research and to our praxis.

At the start of the pandemic, when I had to pause my fieldwork CLASCO Consejo Latinoamericano de Ciencias Sociales with the Universidad de La Plata in Argentina published a book entitled 'Who is the subject of (dis)ability?' The editors Danel, Perez Ramirez and Yarza de los Rios (2021) together with a collective of 28 authors from all over LatAm endeavour to answer this question. This was my core textbook reading during confinement as my household became micro confinement spaces to protect my mother. It made for intense reading in learning from disabled population experiences all over LatAm, already living in their own confinements precovid. The varied chapters made visible and have started consolidating a body of knowledge and methodology to reveal the imbricated exteriority and othering in institutional structures, varied lived experiences of (dis)ability valued along the borders of the zones of being and non being. It is a collection that from the approach of decoloniality problematizes the capacity

dualist model of the rational able bodied modern Global North human being as the referent of normativity. The focus is on varied social practices in Abya Yala people collectives in ecologies of knowledge about their localised histories and geographies with many intersectional categories tracing the colonial wound. A decolonial thinking that exercises a "epistemic justice" (Espinosa-Miñoso, 2021) by putting forth a plurality of forms of understandings.

The question they pose: Who is the subject of (dis)ability? can be framed next to Goodley, Lawthorn, Liddiard and Runswick-Cole (2019) question: Is (dis)ability the object or the subject of studies? These are political and epistemological wonderings asking who is creating the knowledge about (dis)ability, where is the knowledge being produced and who benefits. They ask: Is research in the field of CDS about disabled people's lives or about the generative use of the epistemological construction of (dis)ability for intellectual inquiry on other forms of oppression? Minich (2016) and Schalk (2017) place (dis)ability as a methodology that needs to be framed outside the walls of academia and attend to the socio-political determinants of (dis)ability. We are back to the urgency of praxis. Thinking about subverting single, valid logical rationality through the mantra of praxis is where Lugones (2021) focuses her questions. She wonders if gender is a meaningful concept if we want to escape the very structures that created it? Undoing the processes of knowledge of modernity she asks "Why does anyone want to insist on finding gender among all people of our planet? What is good about the concept that we would want to keep it at the centre of our 'liberation'?" (2021, pg 20).

What would this form of questioning do to (dis)ability? This is clearly not an abandonment of the categories that oppress but rather a situating them clearly in a history so we can step aside and look differently. In regards to (dis)ability, isn't this what many in CDS are already doing? Stepping aside from the psyche apparatus and deconstructing the notion of (dis)ability as social criticism. DF can offer a lens outside of modern/colonial humanist logic. Here CDS and DF have a common thread: a desire to not homogenise people, to eliminate the straightjackets of 'normality' and an urgency to disrupt normative mainstream knowledge, particularly to rethink the methodology. Releasing the concept of (dis)ability is clearly not a social justice option, unless we can envisage a utopian space where we can all care for each other. Releasing the concept of (dis)ability is a decolonial hope of being. There is no question that there is a social justice imperative for keeping '(dis)ability ' in our questions, but, and I think this is crucial but,

only as long as it is clear we are continuously questioning what it means to be disabled. As activists, researchers, as disabled people and allies, these questions have to come from our vivencias, from where we work, from our territories, from people we work with, from collectives. Everyone has the right to think about and respond to the question: what does it mean to be human?

Throughout this thesis I question the ethics of how to do this research from a feminist descolonial turn, away from the western hegemonic epistemology I was trained in. I have questioned how could I conceptualise (dis)ability in a research question from CDC and DF perspectives from a starting place of being with the people we work with at the RLO. So I attempt a first approximation to my response to Who is the subject of (dis)ability?

2.5 Who is the subject of (dis)ability?

I have explored some elements of a geo-political-historical genealogy of (m)othering and (dis)ability through an epistemology of coloniality. I have dipped in and out of DF and CDS to formulate questions. Origin roots and modern practices of (dis)ability are beginning to be dismantled in LatAm academia but more importantly they are being questioned in some areas of praxis such as schools (Acuña et al, 2021; Pereyra, 2021; Sosa et al, 2019), indigenous communities (Yarza de los Rios, 2021; Perez-Serrano, 2008), prisons (Perez Ramirez, 2019), university curricula (Camun et al, 2019), social media (Fiorillos & Narbeburu, 2019).

My exploration of who is the subject of (dis)ability throughout this chapter, this thesis and my work at the RLO is also a 'reclamo' (which means a complaint, a grievance, a reclamation all rolled together). A 'reclamo' that is made to those of us in LatAm who have access to rights, based on whitewashed internalised systemic colonialist vision, the consequence of modernity in the name of development and that hushes the historicity that perpetuates systems of privilege and oppression. This is a 'reclamo' I constantly make to myself at the RLO, in my imbricated contradictory mestiza consciousness I have had bountiful privileges and confronting this reality is my constant descolonial undertaking in the work at the RLO. A mother like Esperanzita with a child that may have a (dis)ability is a warrior mother making sure her children have a safe place,

have food to eat and a school to attend to. Traversing the school system and referrals to the Psyche apparatus, that has strict containment categories and controls to not overload the system, is something she has no time to navigate.

Responding to 'who is the subject of (dis)ability?' is also a critical 'reclamo' that I subscribe to as a mother and a carer, answering with another question: are we not all imbricated in the question? As a person connected to communities of care for people labelled as disabled, for people labelled as refugees or as illegal migrants, I ask are we not all responsible? The answers need to happen in the untangling of (dis)ability from deficiency notions, as something to be remedied and towards a sense of decentering our individual notions of being towards notions of living for each other. From a recognition of each other that moves away from the colonial gaze of I think, therefore I am (I am a white man), and towards Global South notions of community 'Buen vivir' (good living). There are so many pluriverse ways of living to explore and learn from. Famously exported from Africa the Ubuntu philosophy : "I am, because we are; and since we are therefore I am". From Kichwa cosmology in Ecuador 'sumak kawsay' which is hard to translate and can be understood as 'buen vivir' (good living) and also vida en armonia (life in harmony). From the Aymara philosophy in Bolivia 'suma qamaña' vivir bien en comunidad (live well in community) (Torres-Solis and Ramírez-Valverde, 2019). These cosmological 'sentipensar' teachings have much to offer about the idea of co-living even with opposing beliefs, contradictory realities, complexity of histories and challenging modernity; encouraging us to find creative ways of coexistence and mutual acceptance. Isn't this what mothers have been doing for centuries?

Descolonial authors often talk about praxis as love, Maldonado Torres (Barroso, 2016) talks of descolonial love as community builder. Maybe these ways of living give us all the opportunities and responsibilities of learning to care for each other. As a mother-activist-researcher it is in this space of care for each other that I find the strongest nodules of cooperation in the fields of CDS and DF in the praxis and a 'sentipensar' answer to who is the subject of (dis)ability from an ethics of care. In her beautiful book about women, care and (dis)ability María Alfonsina Angelino has some words about care, humanity, responsibility and privilege that I would like to share before I close this chapter because for me they resonate with my feelings on the importance

of how we care for each other with community love beyond the boundaries of family and of western modernity.

La idea de incompletud humana y de fragilidad laten en cualquier relación, pero las imágenes de la discapacidad permeadas y construidas al amparo de la ideología de la normalidad llevan esa máxima a los límites de lo imposible (de lo impensablemente humano). Quizá por eso no importa tanto si tenemos suficiente claridad acerca de que es el cuidado o hasta donde se extiende el sentido del cuidado del otro. Lo importante es advertir y pensar acerca de lo que con certeza no es: el descuido del otro. La falta de provisión de alteridad es descuido aunque se justifique en nombre del cuidado. Y por ello la responsabilidad ante las relaciones de alteridad requiere fisurar el tono moralizante, misional o salvador del otro. (Angelino, 2014, pg 213)

The idea of human incompleteness and fragility is latent in any relationship, but the images of (dis)ability permeated and constructed under the ideology of normality take this maxim to the limits of the impossible (of the unthinkably human). Perhaps that is why it does not matter so much whether we are clear enough about what care is or how far the meaning of caring for the other extends. What is important is to notice and think about is what it certainly is not: the neglect of the other. The lack of provision for otherness is neglect even when it is justified in the name of care. And that is why responsibility in the face of relations of otherness requires breaking the moralising, missionary or saviour tone of the other. (Angelino, 2014, pg 213)

Methodological Implications: Whose knowledge and what references

In this chapter I have set out to explore what meanings the term (dis)ability can have in a decolonising research question in the context of Venezuelan mother's vivencias of forced migration. I have used genealogy to look at the conceptualisations (dis)ability, othering and motherhood from feminist descolonial lenses and I have set out as a mother to seek knowledge production about (dis)ability that is not regulatory knowledge but emancipatory knowledge. My intentions have not been to carry out an exhaustive nor definitive genealogy of (dis)ability. From a descolonial feminist pluriverse stance making meaning through genealogy is not seeking one definitive normative universal altern knowledge. What I am seeking are methodological non-prescriptive ethical practices that can be situated in our continent and in localised contexts. Descolonial and feminist thinkers constantly reiterate that to create our own knowledge we need to delink from the western epistem (Mignolo, 2011), to remember that all knowledge is situated (Haraway, 1988), to define new localised modernities (Rivera Cusicanqui, 2018), to seek for pluriversal knowledges (Escobar, 2018). Humberto Maturana and Francisco Varela, complexity thinkers from Chile, in their book The Tree of Knowledge say it simply:

Todo lo dicho es dicho por alguien. Toda reflexión trae un mundo a la mano y , como tal, es un hacer humano por alguien en particular en un lugar particular" (Maturana & Varela, 1984, pg 14)

"Everything said is said by someone. Every reflection brings a world to hand and, as such, it is a human doing by a particular someone in a particular place" (Maturana & Varela, 1984, pg 14)

The knowledge that we are trained in professionally and that we reference is produced by somebody somewhere, somebody with a positionality. Knowing where knowledge is produced and choosing what references we use following our own positionality and context are important to reflect critically on our needs and methods. This may not be a novel idea in regards to the importance of placing research within a field of studies, however to look beyond one paradigm

of knowledge production is not mainstream in the professional medicalised training of psychology and (dis)ability that is maintained in the context of Colombia, Venezuela and LatAm. As Rivera Cusicanqui (2010) reminds us, whilst we dedicate ourselves to anti colonial, descolonial, representation and ideas that flourish from praxis, we must delink from the knowledge produced in the Global North to represent those who are outside of Europe.

The knowledge we choose to review, to reference, who we choose to read will inform our stance on the choices we make methodologically and conceptually. To make these positionality stances explicit is commonplace in academic social studies. However, given that knowledge production is dominated from the north, from northern science perspectives, and that knowledge production from the south is rarely allowed to transcend border police lines of knowledge production (Segato, 2013), I have chosen throughout this thesis to reference mostly Abya Yala authors, particularly descolonial feminists, and secondly critical fields, especially CDS. Perhaps this has problematised my relationship with some readers because Abya Yala academic literature is lesser known outside of the LatAm borders however I hope this has been enticing and enriching. Critical altern perspectives from within the anglo-european centric knowledge production system are vital sources of knowledge and connection with descoloniality and I hope I have widened potential nodes of dialogue between CDS and descolonial feminism critical psychology. I have endeavoured to read and to weave critical stance from the Global North and the Global South with solidarity from the feminist decolonial turn.

Another choice I have made, regarding reference sources is the use of alternative formats of knowledge dissemination that are not exclusively peer reviewed journal articles and not necessarily contemporary. I recall one lecturer at my university who implored us to reference journal articles not more than 5 years old. In fairness, she was impressing on us doctoral students the importance of due diligence in literature reviews that were recent and not outdated. However, I cannot escape the feeling that putting such a weight exclusively on recent writings can perpetuate the loss of context of knowledge production, historically, geographically and epistemologically. The vast majority of journals accessed in the Global North and in the Global South are produced and published in the Global North. Hence my explicit choice has been to use alongside peer reviewed journals from authors in the GS and GN to also use references that are

new, old, recent, as many as possible published in the Global South, particularly Latin America and also in formats such as oral lectures, conversations and storytelling that digress from the traditional academic "rigour" of peer reviewed journals.

Rita Segato in a lecture in Spain last year (Museo Reina Sofía, 2023) says knowledge is also produced in conversation, thinking-talking with others, so collective dialogues are nodes producers of knowledge. In my research and writing I have tapped into various formats that have included listening to online dialogues in webinars, in lectures, in classes, readings of transcripts of indigenous stories whose verifiable traces are lost in violent histories, listening to activist groups and dialogues with mothers. Overall, I have wanted to stay alert of focusing on academic literature produced outside of the borders of coloniality and hopefully avoid the pitfall of staying within internalised coloniality and sanctioned by it.

Research Question Review

In reviewing the terms (dis)ability, motherhood and othering in a genealogical GS process I have been concerned with the meanings of these concepts in the iterative research questions formulated previously: What can the term (dis)ability mean in a decolonising research question in the context of Venezuelan mother's vivencias of forced migration?

My positionality on the use of the terms (dis)ability, motherhood and othering is better defined by having enacted decolonial feminist practices of genealogy of the concept as arising from the modernity/coloniality 'othering' paradigm as I have carried out in this chapter. I join the movement of academics, teachers, activists who are questioning the modernity paradigm of (dis)ability imported from the Global North structures of knowledge production (Danel et al, 2021; Ferrari, 2021; Yarza de los Rios et al, 2019)

The constant reformulation of questions has been my autoethnographic messy process and my commitment to create routes to ethical participatory research praxis post-covid at the RLO. I continue to have many questions and I return to the methodological implication set out above in the previous chapter's ethical considerations. The ethical imperative of not representing others'

whilst compelled to action in solidarity creates tension between academic research and activism. Being consistent with my reflective research, review of methodologies, reformulation of research questions I put forward some last questions:

Who is knowledge about (dis)ability, childhood, motherhood and migration for?

How do we challenge mainstream knowledge about (dis)ability, childhood, motherhood and migration in Colombia and Venezuela?

What is the political project or positionality of the producers of knowledge in our context regarding these concepts?

Which are the institutional and political frameworks with which this knowledge is produced?

Who and where is the subject of (dis)ability in the process of knowledge production in various key institutional knowledge producer organisations?

Who and where is the subject of forced migration in the process of knowledge production in various key institutional knowledge producer organisations?

What I am trying is to imagine possible ways to formulate future questions in collaboration with others. Rivera Cusicanqui (2010) teaches us that in many Abya Yala cultures, we look forward towards what we can see: the past. This is what we know, we look forward to the past that is remembered and the past that was silenced and is awakening, rediscovering and resignifying memories (Cacopardo, 2018). Linearity of time is a western rationalistic notion, it is but one notion of time. We can walk forward into a past that we constantly rediscover and remember so we can look over our shoulder to imagine unknown potential futures unbound by one single paradigm. In my writing I have looked forward into my past to untangle my coloniality. I have looked forward into how I can practise a methodology of genealogy of conceptualisations, to untangle the roots and routes of conceptualisations I am concerned with: mothering and (dis)ability. The iterative nature of the question formulations have taken me to the realisation that I do not want to answer my questions.

So I finalise the research question reformulations with this:

What research questions does the RLO community want to address?

Chapter Four Summary

In this chapter I have grounded the revision of conceptualisations of motherhood, othering and (dis)ability in feminist decolonial genealogical methodology. Understanding (dis)ability as a conceptualisation that arises within the modernity/colonial paradigm, I reviewed what notions of (dis)ability are exported, and who decides what is (dis)ability on the global stage. In this genealogical exploration I have focused on looking for altern stories from CDS and DF as well as listening to critical interruptions and dialogue within diverse perspectives. The chapter does not present a conclusive genealogy but a methodology for generating questions to contest the conceptualisation of (dis)ability. Moving away from universal hegemonic truths of the psyche apparatus it is important to co-create relevant localised discourses where the intersectionalities of vivencias and knowledge in everyday life of forced migrant mothers can offer community led solutions. Localised critiques of imported pathologizing systems can offer 'other' methodologies to produce knowledge and practises. Looking for co-constructed methodology is what I turn to now in the next and last chapter. The chapter starts with a conversation between myself and RLO colleagues.

Chapter Five Vivencias Interseccionales: Knowledge Creators

> Los seres humanos no nacen para siempre el día en que sus madres los alumbran,
> sino que la vida los obliga a parirse a sí mismos una y otra vez
> (Gabriel García Márquez)

> Human beings are not born forever on the day their mothers give birth to them,
> life obliges them to birth to themselves over and over again.
> (Gabriel García Márquez)

Prelude

This chapter's vivencia is a conversation with my Venezuelan colleagues at the RLO about my research and the ethical difficulties I have encountered regarding asking people to tell me their stories and who is really benefiting from this process. Just like most of the people I have encountered and talked with for this research, my colleagues have a strong desire to have their stories heard and for the stories we hear at the RLO to be told and are less concerned with the ethics of confidentiality and anonymity dictated by the university as I described these to them. Often people I have talked with actually want their name included, I have explained that this is also about their children or other family members who cannot consent at this point and this has been accepted. However they keep expressing strong feelings that stories need to be told from the voices of the people with lived experience. Throughout the research this has given me pause for thought about who dictates the ethics decisions: the university, the researchers or the participants? The conversation with my colleagues starts at the beginning of their own forced migration, something we have talked about many times and a conversation ensues about the intersectional themes of concern in our work at the RLO particularly with mothers who are the main group that sign up with us. The conversation moves around the barriers that Venezuelan migrants face. We talk of our vivencias with thousands of Venezuelan refugees, mostly women with children, of the work the RLO does and the stories that need to be told.

Vivencias Interseccionales - conversaciones

Angela

Yo fui producto de la trata de personas, no lo entendi asi en el momento cuando me pasaba, pero me lo dijo un defensor del pueblo cuando le conte las condiciones en yo llegue. Yo he vivido una xenofobia increíble, todavía a estas alturas con cuatro años aquí, ya regularizada, trabajando, con casa, las sigo viviendo hasta en el edificio donde vivo. Mira en el edificio donde vivo la administradora la tiene agarrada con nosotros desde que llegamos. Ella sabe que nosotros somos migrantes venezolanos y que pertenecemos a una fundación. Desde que llegamos ella nos etiquetó como ladrones, no hay otra palabra para lo que nos dijo, tanto así que a las niñas no les da el saludo. Las niñas yo las he educado que siempre hay que dar los buenos días, así no les contesten, así las estamos educando a ellas, con buenos hábitos pero lo que les dice el entorno es durísimo y ya ellas a los 6 y 10 años se dan cuenta de esa complejidad.

Rosemary

Ay querida, que duró. Dios mío cómo han aumentado los niveles de xenofobia. Yo tengo muchos años en Colombia, ya voy a cumplir 9 años y la xenofobia ha ido aumentando día a día desde que yo llegué. Los niveles de xenofobia eran bajos. A nivel de la sociedad había una percepción, que venía mucha población con educación, con posibilidad de inversión, profesionales. Yo viví barreras más en torno a mi regularización y los procesos internos del Estado. La institucionalidad no estaba preparada para recibir al volumen de gente que fue llegando de Venezuela. Entonces como que habían dos vivencias por un lado la institucionalidad que no tenía la infraestructura burocrática y por el otro la sociedad civil que nos acogió. Pero la xenofobia si ha cambiado, lo sentimos a diario.

Angela

Mira nosotras entramos a una tienda y nos oyen el acento y nos quitan la ropa que estamos escogiendo. En las noticias reportan robos y si cinco son perpetrados por colombianos y cinco por venezolanos la noticia que se hace viral es que los venezolanos son ladrones. Todos los venezolanos que vivimos aquí sufrimos las consecuencias. Entonces de verdad tenemos que buscar bajar esa xenofobia. Esto no pasa nada más aquí creo que eso pasa en todos los países donde hay inmigrantes, porque esto está pasando en Chile, y en todo el continente.

Eliza

Estas historias de xenofobia hay que contarlas, es verdad que suceden en todos lados pero tenemos que contar lo pasa en Colombia, las historias diarias para hacer incidencia. Aquí en Holanda hay mucha xenofobia en las narrativas políticas sobre migración, especialmente cuando no son personas blancas. Pero la migración de Ucranianos demuestra que cuando hay voluntad política, pues es un ejemplo de lo que es posible. Europa absorbió seis millones en pocos meses. Bueno, excepto estudiantes negors de otros países residentes en Ucrania, para

ellos ha sido duro aqui en Holanda. He escuchado decir aquí que los Ucranianos tienen derecho a entrar porque se ven como europeos! En ese sentido quizás los latinos somos más abiertos? Bueno ya se que eso ha cambiado.

Rosemary

La muchacha venezolana que me arregla las uñas me dijo es imposible imaginar todo lo que tiene que aguantar todos los días, lloramos juntas contándonos lo que escuchamos. La xenofobia es uno de los procesos más complejos que vivimos. Dentro de Colombia para tener un desarrollo verdadero y hacer vida es difícil; a pesar de que he aprendido a amar a este país, ser refugiada aquí es muy complejo. Para mi la barrera más difícil y compleja fue regularizarme en el país. Poder reconocerme como refugiada me dio temor y no hice la solicitud, el proceso de aplicación puede ser años, eso significaba renunciar durante el proceso al derecho a trabajar, a estudiar-no era una posibilidad para mi...

Eliza

Como abogada que sabes navegar el sistema y aún te costó tanto?

Rosemary

No te imaginas cuanto, pase por varias solicitudes de Visa pero me las negaron, tuve que hacer un proceso ante la Defensoría del Pueblo y gracias a ellos fue que logré que me diera mi regularización si no no hubiese sido posible. Recuerdo cuando me negaron la visa de estudiante y que apele la solicitud en una oficina de Migración Colombia, el director me trató tan mal como si yo fuese una delincuente. 'Por algo a usted se la negaron porque usted debe tener alguna situación de investigación' y me hizo llorar tanto tanto, me habían dado 5 días para salir del país y yo no tenía para dónde irme no podía regresar a Venezuela, ni siquiera tenía familia en otro lado y me entró un estado de pánico. Le tuve que contar mi historia personal aunque el deber ser es que vean los documentos porque allí cumplía con los requisitos.

Le conté que yo trabajaba en la institucionalidad en Venezuela y me estaban persiguiendo, le conté de mi situación de Diabetes tipo 1 sin medicamentos en Venezuela. Le dije yo vengo para estudiar, estoy pidiendo visa de estudiante. Creo que oír mi historia le tocó el alma y al final me escribió una carta y me dirigió hacia alguien que me ayudaría. Al final me acogí al PEP (Permiso especial de permanencia) para poder estar regular 100% en Colombia. Ahí pues empezó mi historia de lucha y desde ahí fue que yo decidí ese día ahí sentada que yo voy a trabajar por mis hermanos y hermanas venezolanos. Son procesos burocráticos de años, pasar por visas, después tener un registro o una identificación y las cambian las regulaciones, que si se renueva, que si no, que si es solo un papelito no lo pierdas, que si no lo han imprimido, en fin. El derecho a la salud también me costó poder tener un registro para recibir tratamiento.

Eliza
Estas historias de líderes refugiados de las vivencias que han tenido son tan importantes. Cuando puedes relatar una historia con situaciones de la vida real, de la deshumanización, de los procesos burocráticos, de las capacidades de los refugiados, estos cuentos de vivencias pueden girar las percepciones. Los relatos de las vivencias son poderosos y nos dan otra perspectiva diferente de las estadísticas.

Angela
Es que mira yo soy contadora y del mundo de las finanzas pero no creo en las estadísticas. Las estadísticas no cuentan la historia de lo que nos pasa.

Eliza
En lo que he leído y en el contacto que hemos tenido con líderes refugiados en varios países estas historias personales de indignación mueven a las personas a ayudar a otros ser líderes. Creo que allí está el corazón del movimiento de OLR, la representación real.

Angela
Mira otro tema urgente que nos sucede a los venezolanos es la explotación. A veces son los mismos venezolanos que explotan a otros por la situación de necesidad tan grande. Un ejemplo es un familiar mío que estuvo trabajando en un restaurante aquí, eran turnos de 11 horas diarias. Tiene que pedir permiso hasta para ir al baño y lo aguanta para que no le pongan mala cara. Imaginate, eso le ha traído secuelas de salud. Es una presión psicológica y social aceptar cualquier condición laboral por la necesidad porque tú dependes de ese sueldo para tu día a día. Imagínate una persona que vive en Paga Diarios y necesita pagar esa noche para tener donde dormir, pues lógicamente vas a aceptar todas las condiciones que te pongan. Primero están las necesidades básicas como comida y techo. Tantas mujeres que atendemos con hijos si le ofrecen ese trabajo van a decir que no? Y tantas mujeres que nos llegan con historias de violencia de pareja, experiencias de violencia y discriminacion por identidades LGBTI+. ¿Cómo hacen? Pues aceptan condiciones denigrantes y violentas. Y esa es una realidad que nosotros vivimos, la conocemos y allí es donde tenemos que desarrollar más herramientas para generar cambio. Ahí es donde la Fundación busca hacer incidencia por todas estas barreras de xenofobia, discriminacion, explotación y regularización. Tenemos que generar cambio con la xenofobia.

Eliza
Y dentro de esas complejidades como ven Uds la situación de los menores de edad, niños, niñas, con o sin discapacidad?

Angela
Bueno la escolaridad es central. Conseguir cupo es un problema para las familias. Las inscripciones para los niños en la escuela son difíciles, ahorita empezó el año escolar y es

increíble en las noticias ver como hay gente que hacen colas de días enteros para lograr un cupo y si lo metes a uno de los niños en una localidad y no hay mas cupo le ponen al otro hermano o hermana en otro lado, a veces muy lejano y es imposible de que tú puedas llevar a los dos a las 6 de la mañana en cada escuela. La institucionalidad dice que para eso existe transporte escolar pero ese transporte es pago. Y por ejemplo si empiezas a medio mes o a finales de mes igual tienes que pagar el mes completo, y si no puedes pagar entonces los tienes que llevar y se pierden horas de trabajo sin las cuales no se come.

Rosemary
Hay bastante cupo para cubrir la plaza pero a veces las mismas escuelas rechazan la inscripción por falta de papeleo si los y las niñes no están regularizados, lo cual va en contra de la legislación Colombiana. La misma Alcaldía aquí en Bogotá ha dicho que hay como 30.000 cupos pero los empleados públicos no tienen la información clara. Hay demasiada desinformación y desconocimiento sobre las políticas públicas por parte de los mismos funcionarios públicos. Existe una legislación Colombiana muy clara que establece que así no tenga identificación el niño en Colombia hay que inscribirlo porque tiene un derecho superior de acceso a la educación. Entonces por el desconocimiento de algunos funcionarios les niegan el cupo por falta de identificación y entonces es ahí cuando nosotros tenemos que hacer derecho de petición o hasta acción de tutela para que le puedan tener acceso efectivo.

Angeles
Y después está el rechazo en la escuela, conozco a muchxs niñes que en la escuela sienten mucho rechazo. Una familia que conozco han pedido psicólogos porque su hija dice 'yo no quiero tener amigas' . Yo creo que no es culpa de los niños, es lo que escuchan de sus padres y a nivel de la escuela no hay trabajo acerca de cómo integrar a los refugiados. He escuchado a maestras que dicen que eso no le corresponde a la escuela.

Rosemary
Y es lo mismo en el sistema de salud, hay casos que nos ha llegado nosotros que por no tener inscripción en el sistema de salud no quieren atender al paciente. Hemos tenido muchos casos de niños con enfermedades complejas. Los atienden solo en atención primaria de emergencia pero no hay seguimiento porque no tienen papeles. Uno de los problemas en este momento es que hay más de un millón de personas que están esperando el PPT todavía y no se lo han impreso. Esos millones de personas, incluyendo niñes no les dan servicio aunque tienen toda su regularización para acceder a esos derechos básicos porque no les ha llegado la identificación.

Hay otro problema en cuanto a los temas de nivelación hay muchas complejidades con los niños y niñas provenientes de Venezuela principalmente porque no hay protocolos y muchos de los padres no traen apostilla ni la certificación del grado previo en Venezuela. Algunos colegios estratégicamente les han hecho pruebas de nivelación pero depende mucho de cada colegio y de

los funcionarios que atienden de querer hacer esa nivelación. A veces a los niños los exponen a una situación de discriminación porque los ponen en niveles no adecuados y genera pues complejidad sobre el niño. Algunos colegios han dado acompañamiento psicológicos o de trabajadores sociales pero la mayoría no lo tiene. La realidad es que no han capacitado a los maestros en cómo tratar estos procesos más integradores para la población extranjera dentro de las comunidades, colegios y ni de evaluar cómo se están integrando los niños.

Eliza
Si me han contado algunas madres que no hay apoyo en las escuelas para niños o niñas en transición migratoria y mucho menos para los que vienen con diagnósticos de discapacidad, hay iniciativas y legislación inclusivas pero la implementación no se ve. Claro, para muchas madres lo que quieren es saber que sus hijos están en la escuela, están recibiendo una educación y que así ellas pueden salir a trabajar sin preocuparse de dejar a los niños solos.

Rosemary
Con respecto a lo que tu hablas de discapacidad y situaciones en que los niños tengan alguna enfermedad o discapacidad crónica o alguna situación especial sí hay complejidad para que tengan un acceso efectivo a un buen servicio. Por ejemplo los colegios no están preparados para recibir personas con ciertas discapacidades o condiciones como por ejemplo las personas que tienen autismo, y si encima es migrante o refugiado pues se le suma una condición mucho más difícil y muchas veces quedan en el limbo. Por ejemplo, tuve un caso de una señora súper humilde con su hija con síndrome de Down con buen desarrollo verbal y ya estaba yendo a un colegio pero le habían dicho que tenía que cambiar a un colegio más apto para ella y le habían dado el cupo. A último momento se cayó ese cupo, no quisieron cambiarla. La niña tenía ya meses sin asistir cuando yo las conocí. La mama me conto que habia tenido muchos problemas de integración cuando llego, mucha discriminación interna en el colegio. Desde los profesores que también discriminan hasta los más altos cargos de los colegios hay mucha xenofobia. Hicimos un proceso legal hasta lograr el cupo en el colegio que le recomendaron.

Eliza
El sistema educativo Colombiano promueve la inclusión de todos los niñes en colegios para todos, pero he escuchado de muchas madres con niñes con diagnósticos que los colegios no les pueden dar el apoyo y los terminan excluyendo de diversas maneras. Les niñes con discapacidad sufren múltiples discriminaciones y están sujetos a aún más exclusión. Y mientras más prolongado su tiempo fuera del colegio más compleja su situación. También veo que las familias con un niño con discapacidad tienen mucho más común con las familias sin discapacidad en el contexto de migración forzada, igual necesitan colegio, trabajo, hogares, alimentación y comunidad. Pero tiene barreras más complejas por la falta de escolaridad que desencadena dificultades para los padres de cuidado y de poder trabajar.

Rosemary
Si, los niños fuera del sistema educacional son particularmente vulnerables. Están más expuestos a la explotación laboral y también a la explotación sexual. Entran en muchos riesgos. Hay niños que están en la calle trabajando, recogiendo basura, muchos recolectores de basura tienen a sus niños al lado, claro no los quieren dejar solos. Es toda una situación bastante compleja lo que hay detrás de esta dificultad de desarrollo de su familia y de sus padres. Por eso lograr medios de vida le cambia todo a una familia.

Por eso la columna vertebral de nuestra labor es el acceso a la regularización y el acceso efectivo a los derechos. Este es el vacío principal que nosotros como OLR estamos llenando: la asistencia jurídica. Hacemos todos los procesos tanto a nivel de derecho de petición y vamos a instancias jurisdiccionales de acciones de tutela y acciones constitucionales. Tenemos especialistas y expertos en la materia. Y en paralelo hacemos un proceso holístico con la población desde medios de vida, programas de nutrición infantil, talleres de integración y de duelo migratorio, apoyo en la comunidad, información y remisión a organizaciones de ayuda. Nosotras estamos generando soluciones desde la comunidad.

Angela
A los niños les pega mucho dejar a su familia en Venezuela para venirse, eso que dicen que los niños se adaptan rápido no es verdad. Aquí estamos hablando de tantas cosas y seguimos trabajando para llenar los vacíos que dejan el estado y la comunidad internacional. Tenemos tantas barreras, tiene que cambiar el sistema humanitario porque hay mucha burocracia para que la ayuda llegue realmente al migrante, especialmente a los niños. Sabemos que hay mucho dinero a nivel internacional, le entra mucho dinero a los estados, pero se va consumiendo mientras va filtrando y bajando y al final no llega lo suficiente para ayudar a quienes realmente lo necesita. Por poner un ejemplo el Banco Mundial es uno de los donantes más importantes en el mundo, pero su estructura financiera es que solo dan donaciones a gobiernos. Entonces el dinero no nos llega a los líderes con experiencia vivida. Y ese es el trabajo nuestro, de nuestros líderes refugiados embajadores demostrar que hay otras formas de trabajar más efectivas.

Las organizaciones internacionales y hasta el mismo estado se han concentrado solamente en ver la migración como una atención de urgencia o de emergencia sin pensar en el desarrollo o en la realidad que existe detrás de la población que tiene el ánimos de permanencia. Ahí es donde venimos las organizaciones de base como nosotros prácticamente a darle todo o tratar de cubrir las necesidades básicas que tiene la población y esa necesidad de desarrollarse y de querer quedarse en el país con trabajo. Entonces sí le damos ayuda jurídicas pero al mismo tiempo entonces apoyo comunitario y psicológica, ayuda de cómo integrarse, oportunidades de empleo, emprendimiento o sea son muchas vías que nosotros tenemos que buscar para apoyarlos. Prácticamente nosotros estamos fungiendo en parte las funciones del Estado para la

gente que viene a nosotros. Estamos aquí llenando el vacío del estado y de la comunidad internacional. Como dije antes, aunque es contradictorio siendo de finanzas pero cuando vamos a ver las estadísticas no cuentan nada. La institucionalidad continua guiándose por números y no por historias, no van a entender cómo se puede impactar. Seguimos en la misma estrategia que se sabe no está funcionando con mucha burocracia. Yo sueño que si logramos cambiar el sistema habría suficiente dinero para hacer muchas cosas buenas. Hacer escuelas. Hace dispensarios. Ya estamos aquí, pertenecemos aquí y todas queremos contribuir. ¿Cómo lograr que una fracción de los fondos internacionales lleguen realmente al pueblo? Yo creo que si los líderes, esas persona que toma decisiones, sean gente que realmente le duela o sea tenga empatía hacia lo que estamos viendo en la realidad…. porque si tú no conoces la realidad y el que toma decisiones la toman desde arriba entonces nada …. Por eso la incidencia es necesaria y fuerte

Eliza
Las dificultades de las OLR se ven reflejadas hasta en los planes de financiación en el continente. Por ejemplo en la plataforma de coordinación interagencial para refugiados y migrantes venezolanos a nivel latinoamericano publicaron estadísticas en septiembre del 2023 de cuánto dinero estiman que se necesita en Latinoamérica para ayudar a los refugiados y cómo ellos estiman que se va a distribuir. La distribución para Colombia tiene 22% destinado a ONGs internacionales, 72% para agencias conectadas con las Naciones Unidas y 3% tres por ciento para organizaciones nacionales, comunitarias de base y eso incluye a las OLR. A nivel latinoamericano es parecido, solo 4% del dinero que se está solicitando está destinado a organizaciones de base comunitarias.
Por eso tenemos que hacer investigación dentro de nuestra esfera de trabajo, de como estamos cambiando metodología de trabajo efectivamente con programas diseñados por refugiados para refugiados.

Rosemary
Es que no nos ven, en el Foro Mundial para Refugiados no nos dan espacio a los refugiados Venezolanos, solo hay una organización que se auto denomina como la representante de todos los venezolanos y es de gente con intereses políticos y de élite que han hecho mucho lobby. No nos incluyen a las organizaciones de base. Por eso somos parte del movimiento de OLR buscando un cambio en el sistema. Los que hacen las políticas nos consultan y oyen las problemáticas pero están menos interesados en nuestras ideas.

Eliza
Son muchos los niveles de barreras que hay que enfrentar. La representación y participación es una batalla constante. La exclusión en las tomas de decisiones es un reto, y por eso veo la

generación de programas dentro de la Fundación como un ejemplo de cómo se articulan soluciones desde la comunidad. Contar estas historias desde la comunidad.

Rosemary
Y hay una necesidad de reconocer lo duro del trabajo que hacemos, hacemos tantas cosas diferentes para que una persona o una familia logre salir adelante que a uno le remueve el alma. Hay tantos casos difíciles, todo el equipo necesita mucho apoyo, por lo que cada uno ha vivido personalmente y por la labor que se hace a diario, uno lleva esto en el corazón, la injusticia que uno ve queda en el corazón.

Intersectional Vivencias- conversations in English

Angela
I was a victim of trafficking, I didn't understand it that way at the time when it happened to me, but an ombudsman (public advocate for migrants) told me so when I told him about the conditions in which I migrated. I have lived through incredible xenophobia, even now, after four years here, now with my papers in order, having work and a home. Look, in the building where I live, the administrator has had it in for us since we arrived. She knows that we are Venezuelan migrants and that we work at a foundation. From the moment we arrived she labelled us as thieves, there is no other word for what she said to us, so much so that she doesn't even say hello to the children. I have educated the girls to always say good morning, even if no one answers, that's how we are bringing them up, with good habits, but what they experience is very hard and at 6 and 10 years they already are aware of how complicated things are.

Rosa
Oh dear, how difficult it is. Dear God, how the levels of xenophobia have increased. I've been in Colombia for many years, close to 9 years now, and the xenophobia has gotten worse day by day since I arrived. Then xenophobia was not so bad. In society in general, there was a perception that a lot of educated people were arriving, professionals, people that had means of investment. Where I experienced more barriers was around getting my residency papers legalised and all the government processes. The institutions were not prepared to deal with the volume of people arriving from Venezuela. So there were two experiences, on the one hand, the institutions that did not have the bureaucratic infrastructure, and on the other, civil society that welcomed us. But xenophobia has changed, we feel it every day.

Angela
Look, we go into a shop and they hear our accent and they take away from us the clothes we are choosing. In the news they report robberies and if five are perpetrated by Colombians and five by

Venezuelans the news that goes viral is that Venezuelans are thieves. All Venezuelans who live here suffer the consequences. So we really have to try to reduce this xenophobia. This doesn't just happen here, I think it happens in all countries where there are immigrants, because this is happening in Chile, and all over the continent.

Eliza

These stories of xenophobia have to be told, it is true that they happen everywhere but we have to tell what is happening in Colombia, the daily life stories need to be heard. Here in the Netherlands there is a lot of xenophobia in the political narratives about migration, especially when they are not white people. But the example of the migration of Ukrainians shows that when there is political will there is a way. Europe absorbed six million in a few months. Well, except for the black students from other countries living in Ukraine, it has been hard for them here in the Netherlands. I have heard it said here that Ukrainians have the right to enter because they look like Europeans! In that sense maybe we Latinos are more open? Well I know that has changed.

Rosa

The Venezuelan girl who does my nails told me it's impossible to imagine what she has to put up with everyday, we cried together telling each other what we have to listen to. Xenophobia is one of the most complex processes we live with. It is difficult to get ahead in life in Colombia; even though I have learned to love this country, being a refugee here is very complicated. For me, the most difficult and complex barrier was to get my legal status in order. I was afraid to apply for refugee status so I didn't apply, the application process can take years, that meant giving up the right to work, to study…it was not a possibility for me...

Eliza

As a lawyer you know how to navigate the system and it still took you so long?

Rosa

You can't imagine how long it took, I went through several visa applications that were denied. I had to go through a process before the Ombudsman's Office and thanks to them I managed to get my temporary residency in order, otherwise it wouldn't have been possible. I remember when they denied my student visa and I appealed the application in a Migracion Colombia office (Ministry of Foreign Affairs migration offices where foreigners register for residency), the director treated me as if I were a criminal. He made me cry so much, they gave me 5 days to leave the country and I had nowhere to go, I couldn't go back to Venezuela, I didn't even have family anywhere and I panicked. I had to tell him my personal story even though the obligation is that they check the documents and I fulfilled all the requirements.

I told him that I had worked in government institutions in Venezuela but I was being persecuted. I told him about my type 1 diabetes and that I had no access to medication in Venezuela. I told him I had come to study, and I was asking for a student visa. I think that hearing my story touched his soul and in the end he wrote me a letter and directed me to someone who would help me. At last I applied for the PEP (Permiso Especial de Permanencia- Special Permanence Permit) to be able to stay 100% in Colombia. That is where my story of struggle began and it was then that I decided that day, sitting there, that I was going to work for my Venezuelan brothers and sisters. There are years of bureaucratic processes, going through visas, then having a registration or an ID card and the regulations change, whether it is renewed, whether it is not, whether it is just a piece of paper, whether you don't lose it, whether they haven't printed it.. The right to health was also difficult for me to get registered to receive treatment.

Eliza
Your stories as refugee leaders and the experiences you have had are so important to tell. When you tell a story about real life situations, about the dehumanisation of the bureaucratic processes, about the capacities of refugees, these stories of lived experiences can change perceptions. Stories of experiences are powerful and give us a different perspective than the statistics.

Angela
Well, I'm an accountant and I'm in finance but I don't believe in statistics. Statistics don't tell the story of what happens to us.

Eliza
In what I have read and in the contact we have had with refugee leaders in various countries these personal stories of outrage move people to help others to be leaders. I think this is at the heart of the Refugee-led movement, real representation.

Angela
Look, another urgent issue that happens to us Venezuelans is exploitation. Sometimes it is the Venezuelans themselves who exploit other Venezuelans because they are in such great need. An example is a relative of mine who was working in a restaurant here, 11-hour shifts every day. She had to ask permission even to go to the bathroom and she put up with it so that they didn't dismiss her. Imagine, this has had health consequences for her. There is psychological and social pressure to accept any working conditions because of need, because you depend on that salary for your daily life. Imagine those who pay daily rent and need to pay for a place to sleep each night, well, logically you are going to accept all the conditions that they put on you. The first things you need to cover here are the basic needs like food and shelter. How many of the women with children we attend to would say no if they are offered such a job? There are so many women who come to us with stories of intimate partner violence, experiences of gender violence and discrimination because of their LGBTI+ identities, how do they manage? They end up

having to accept degrading and violent conditions. And that is the reality that we live, we know it and that is where we have to develop more tools to generate change. That is where the Foundation seeks to advocate against all these barriers of xenophobia, discrimination, exploitation and regularisation. We have to generate change to stop xenophobia.

Eliza
And within these complexities, how do you see the situation of children, boys, girls, with or without disabilities?

Angela
Well, schooling is central. Getting places is a problem for families. Enrolling children in school is difficult, the school year has just started and it is incredible to see on the news how people queue for days to get a place and if you put one of the children in one place and there is no more places there, the other brother or sister is sent somewhere else, sometimes very far away and it is impossible for you to take them both to school at 6 o'clock in the morning. The local councils say that there is school transport for this, but this transport has to be paid. And for example, if you start in the middle of the month or at the end of the month, you still have to pay for the whole month of transport, and if you can't pay, then you have to take them and you lose hours of work and you have no money left for food.

Rosa
There are plenty of places but sometimes the schools themselves refuse enrolment because the children don't have the papers in order, this is against Colombian law. The Mayor's Office here in Bogotá itself has said that there are about 30,000 places but the public employees do not have clear information. There is too much misinformation and lack of knowledge about public policies on the part of the civil servants themselves. There is a very clear Colombian law that establishes that even if a child does not have an ID in Colombia, he or she must be registered because they have an inalienable right to access education. So, due to the ignorance of some officials, they are denied a place because they do not have ID and that is when we have to file a petition or even a guardianship act so they can access education.

Angela
And then there is rejection at school. I know many children who feel a lot of rejection at school. One family I know has asked for psychological help because their daughter says 'I don't want to have friends'. I think it's not the children's fault, it's what they hear from their parents and at the school level there is no training on how to integrate refugees. I've heard teachers saying that it's not the school's job.

Rosa

And it's the same in the health system, there are cases that have come to us that because they are not registered in the health system they don't want to attend to the patient. We have had many cases of children with complex illnesses. They are seen only in primary emergency care but there is no follow-up because they don't have papers. One of the problems at the moment is that there are more than a million people who are still waiting for the PPT and they have not been issued. Millions of people, including children, are not being served even though they have all their regularisation to access those basic rights simply because they have not received the ID.

There is another problem in terms of the grade placement, there are many complexities with children coming from Venezuela mainly because there are no protocols and many of the parents do not bring an apostille or the certification of the previous grade in Venezuela. Some schools have strategically given them placement tests, but it depends a lot on each school and the officials who attend them if they want to do this placement. Sometimes children are exposed to a situation of discrimination because they are placed at levels that are not appropriate, and this generates problems for the child. Some schools have provided psychological support or social workers, but most do not. The reality is that teachers have not been trained in how to deal with these more integrative processes for the foreign population within the communities, schools and how to evaluate how the children are integrating.

Eliza
Some mothers have told me that there is no support in schools for children in migration transition and even less for those with diagnosed disabilities, there are inclusive initiatives and legislation but the implementation is not effective. Of course, for many mothers what they want is to know that their children are in school, that they are receiving an education and that they can go out to work without worrying about leaving their children alone.

Rosa
With regards to what you talk about disability and situations in which children have a chronic illness or a disability or some special situation, yes, there are problems for them to have effective access to a good service. For example, schools are not prepared to receive children with certain disabilities or conditions such as those with autism, and if they are migrants or refugees, it is even more difficult and they are often left in limbo. For example, I had a case of a very humble woman with a daughter with Down's syndrome with good verbal development and she was already going to a school but she had been told that she had to change to a school that was more suitable for her and she had been given a place. At the last minute that place fell through, they didn't want to change her. The girl had been out of school for months when I met them. Her mother told me that she had had a lot of integration problems when she arrived, a lot of internal discrimination in the school. From the teachers who also discriminate up to the highest levels of the school administration, there is a lot of xenophobia. We had to go through a legal process to get the place in the school that was recommended to her.

Eliza

The Colombian education system promotes the inclusion of all children in all schools, but I have heard from many mothers of children with diagnoses that the schools cannot support them and end up excluding them in various ways. Children with disabilities suffer multiple discrimination and are subject to even more exclusion. And the longer they are out of school, the more complex their situation becomes. I also see that families with a child with a disability have a lot in common with non-disabled families in the context of forced migration, they still need school, work, homes, food and community. But they have more complex barriers because of the lack of schooling, which makes it difficult for parents to care for their children and to be able to work.

Rosa

Yes, children outside the education system are particularly vulnerable. They are more exposed to labour exploitation and also sexual exploitation. They are at a lot of risk. There are children who are on the streets working, picking up rubbish, many rubbish collectors have their children next to them, of course they don't want to leave them alone in rented rooms. It is a very difficult situation for the settlement and integration of the family. That's why having work changes everything for a family.

That is why the backbone of our job at the RLO is to support people in the process to get their papers which in turn gives them effective access to their rights. This is the main gap that we as RLO are filling: legal assistance. We do all the processes from rights to petition as well as the jurisdictional instances of guardianship actions and constitutional actions. We have specialists and experts in the field. And at the same time we give wraparound support to the population, livelihoods, child nutrition programmes, integration and migration trauma-informed workshops, community support, information and referral to aid organisations. We are generating solutions with the community.

Angela

It's very hard for children to leave their families in Venezuela to come here, what they say about children adapting quickly is not true. Here we are talking about so many things and we continue to work to fill the gaps left by the state and the international community. We have so many barriers, the humanitarian system has to change because there is a lot of bureaucracy for the aid to really reach the migrant, especially the children. We know that there is a lot of money at the international level, there is a lot of money coming into the state, but it gets used up as it filters down and down and in the end not enough gets there to help those who really need it. For example, the World Bank is one of the most important donors in the world, but its financial structures are such that it only gives funds to governments. So the money doesn't reach us leaders with lived experience. And that is our job, the job of us refugee leaders and our ambassadors to show that there are other, more effective ways of working.

International organisations and even the state itself have concentrated on only seeing migration as an emergency or urgent crisis aid without thinking about development or the reality that exists for the population that has the intention to stay. That is where grassroots organisations like us come in, to try give them everything or try to cover basic needs and their need to progress and to integrate in the country with means of work. So we do give them legal aid, but at the same time we give them community and psychological support, help with integration, employment opportunities, entrepreneurship, in other words, there are many ways that we have to look for to support them. Practically, we are partly fulfilling the functions of the state for those people who come to us.We are here filling the vacuum left by the state and the international community. As I said before, although it is contradictory being from finance but when we go to look at the statistics they don't count for anything. The system continues to be guided by numbers and not by stories, they do not know how to make an impact. The system continues with the same strategy that we know is not working, with a lot of bureaucracy. I dream that if we manage to change the system there would be enough money to do a lot of good things. Build schools. Build hospitals. We are already here, we belong here and we all want to contribute. How do we get a fraction of the international funds to actually reach the people? I think that if the leaders, those people who make decisions, are people who are really concerned or have empathy for what we are experiencing in reality .... because if you don't know the reality, then the decision-makers make decisions from above then nothing changes.... That is why advocacy is necessary and strong.

Eliza
The difficulties of RLOs are even reflected in funding schemes on the continent. For example, the inter-agency coordination platform for Venezuelan refugees and migrants in Latin America published statistics in September 2023 on how much money they estimate is needed in Latin America to help refugees and how they estimate it will be distributed. The distribution for Colombia has 22% going to international NGOs, 72% to UN-connected agencies and 3% three percent to national, community-based organisations and that includes the RLOs. At the Latin American level it is similar, only 4% of the money being requested is earmarked for community-based organisations. That's why we have to do research within our sphere of work, show how we are changing the methodology and working effectively with programmes designed by refugees for refugees.

Rosa
They don't see us, in the World Refugee Forum they donn't give space to Venezuelan refugees, there is only one organisation that calls itself the representative of all Venezuelans and it is made up of people with political and elite interests who have done a lot of lobbying. They don't include us grassroots organisations. That is why we are part of the RLO movement seeking a change in

the system. The policy makers consult us and listen to the issues but they are less interested in our ideas.

Eliza

There are many levels of barriers to be faced. Representation and participation is a constant battle. Exclusion from decision-making is a challenge, and that's why I see the generation of programmes within the Foundation as an example of how to articulate solutions from the community. Telling these stories from the community.

Rosa

And there is a need to recognise the hard work we do, we do so many different things so that a person or a family can get ahead and that moves one's soul. There are so many difficult cases, the whole team needs a lot of support, because of what each one of us has personally experienced and because of the work we do on a daily basis, we carry this in our hearts, the injustice we see remains in our hearts.

Chapter overview: Intersectional Gaps and Knowledge Creators

The intention of this final chapter is to weave together two methodological threads of thought: intersectionality and gaps in knowledge production. The complexities facing Venezuelan forced migrants as described by the RLO workers in the Vivencia throw out many complex areas of concern.

In the context I am immersed in - forced migration and (dis)ability in LatAm- and the context I work within - an RLO in Colombia serving Venezuelan forced migrant families, there are few sources of information where the voices of forced migrant Venezuelan s are documented with the express intention of listening to the community's collective knowledge. As I have referred to in previous chapters when focusing on families with disabled members, particularly children, in the forced migrant Venezuelan diaspora, the research is sparse (UNICEF, 2023; GIFMM, 2022) and mostly calls for the need for research. Research on migration and (dis)ability in Latin America from a descolonial feminist perspective is almost non-existent in the literature I have researched. This chapter delves into troubling knowledge production and exposing the gaps from the lens of intersectionality and proposing action research in the community I work with.

In this chapter I first weave these complex themes of concerns using Collins and Crenshaw's conceptual framework of 'intersectionality'. Intersectionality is a foundational concept in Decolonial Feminism and particularly contested by Lugones' in her discussion on 'fusion' and the origins of categories.I discuss why intersectionality and fusion are central to the

methodological principles and research question writing that I have been concerned with in the context of the imbricated realities of forced migration, poverty, (dis)ability, food insecurity and other marginal vivencias.

Secondly, I describe the gaps in the research literature regarding the Venezuelan diaspora overall, I review concepts from migration studies relevant to these gaps and finally I focus on the gaps in research and policy at the intersectionalities of (dis)ability and the Venezuelan diaspora that have been at the heart of this thesis. I argue that intersectionality can illuminate the vacuum in research and knowledge about the vivencias of refugee Venezuelan mothers and children with (dis)ability in Colombia.

The chapter concludes with the last review of the research questions and the methodological implications I have explored throughout the research. I synthesise the methodological principles concluded in each of the previous chapters to take back to the RLO as a draft for dialogue to co-construct research and storytelling.

1. Intersectionality
    1.1. The Importance of Intersectionality
    1.2. Lugones' Critical Reflections on Intersectionality

2. Gaps in the Research
    2.1. Uniqueness of the Venezuelan Migration
    2.2. Forced Migration
    2.3. Decolonising at the Intersectionality of migration and (dis)ability

3. Research Questions: a final review
4. Methodological Learnings: Limitations and Principles
5. Last Words

1. **Intersectionality**

Ethics has been the driving issue in exploring how to descolonise this research questioning the methodology in the context of the work of the RLO with workers and Venezuelan refugee mothers in Bogota. Activism within this research has brought up many issues on which I have been critically reflecting: ethical, epistemological, methodological and context concerns. Ethical issues concerning representation of 'others' and my privileged positionality. Epistemological issues around what conceptualisations such as (dis)ability can mean in the geo-socio-political context of forced Venezuelan migration in Colombia and how to formulate relevant research questions. Methodological issues exploring altern ways of producing knowledge that reflect the political and epistemic landscapes of Abya Yala.

In previous chapters I have contended that nodules of dialogue between CDS and feminist decolonial thought can contribute to the ever growing critique of the oppressive nature of the conceptualisation of (dis)ability within the global neo-capitalist, normative, patriarchal, heterosexual, gendered and racist modern/colonial canon of knowledge. I have explored how to step outside of dominant narratives on (dis)ability and (m)othering through genealogical methods of DF. In particular, I referred to Maria Lugones' concept of the coloniality of gender as an generative genealogical model to explore delinking the category of (dis)ability from the western canon of knowledge in its universalstic terms. In this sense, I recover previously referenced notions of (dis)ability as a starting point on exploring who is human (Goodley,2014) as a methodology (Minich, 2016; Schalk, 2017), to question who is the subject of (dis)ability (Danel et al, 2021) and to address Sylvia Wynter's (1994, 2003) question: what does it mean to be human?

In searching for 'othered' understandings on (dis)ability my vivencias I have told stories that cannot be disentangled from migration, race, sexuality, motherhood, poverty, gender in the modernity/coloniality dominant knowledge paradigm that creates these categories (Danel et al, 2021; Goodley, 2014; Mallett and Runswick-Cole, 2014; Grech et al, 2023). The genealogies of categories created in this western paradigm may have diverse localised routes and roots (Tate, 2023) that are and must continue to be excavated; but equally they have a common othering systematic justification and origin under the colonial/modern gaze, as Fanon says:

"Because it is a systematic negation of the other person and a furious
determination to deny the other person all attributes of humanity,
colonialism forces the people it dominates to ask themselves the question
constantly: 'In reality who am I?' " (Fanon, 1963, pg 200)

We cannot forget the connections of racism to pathology, the narrative about (dis)ability is imbricated in the narratives of black skins and indians as savage/barbaric/incapable/lacking of skills (Tate, 2023; Quijano, 2020; Fanon, 1963) and of females as mad, witches, non women, incapable (Tate, 2023; Lugones, 2021). Staying within abstract academic accounts disconnected from specific complex contexts is not a viable option for those with lived experiences. In 'Vivencias Interseccionales', based on conversations with colleagues at the RLO, the experiences of xenophobia, discrimination and exploitation permeate the various 'categories' people are placed within: migration status, (dis)ability diagnosis, gendered identities, racialized identities, and poverty with food insecurity and lack of stable income. The specific context of the work of the RLO with Venezuelan forced migrants demands localised research and specific questions within the complex intersectionality that we operate and inhabit. Hence I turn to the conceptualisation of intersectionality that originated in black feminist thought in the USA, as an important epistemological notion.

1.1 The Importance of Intersectionality

Patricia Collins (1986) situated long standing black feminism (even when it wasn't labelled as feminism) at the forefront of attending and theorising on the interlocking nature of oppression, focusing on the interactions between race, gender or class rather than distinguishing them as separate identities as had been represented by white feminism and civil rights focused on black men. The significance of placing these interactions as a path to emancipation is also clear in Crenshaw's thinking.

"The problem with identity politics is not that it fails to transcend
difference, as some critics charge, but rather the opposite-that it frequently
conflates or ignores intragroup differences" (Crenshaw, 1991, pg 1242)

In Crenshaw's 1989 essay on Demarginalizing the Intersection of Race and Sex through analysing legal cases, she puts forth the discrimination of black women who are invisibilized in feminist and antiracist civil rights and in the singular axis scope of anti-discrimination laws. She focuses on how intersectionality as a tool and paradigm can address the experiences of black women that are more than the sum of racist and sexist experiences.

Collins and Bilge's (2020) review of intersectionality states that the narrative has expanded in so many directions, many scholars and practitioners are unaware of the breadth of reach of intersectional scholarship. They propose that using intersectionality as an analytic tool for critical praxis can "shed lights on six core ideas within intersectionality: social inequality, intersecting power relations, social context, relationality, social justice and complexity " (Collins and Bilge, 2020, pg 94). Cho et al (2013) propose how intersectionality has emerged as a field of study that encompasses the use of intersectionality as a framework to explore social dynamics in various fields of study, as a theoretical and methodological paradigm and also as political praxis where scholars and activists work towards community activism and social justice themes.

Crenshaw's (1991) groundbreaking article 'Mapping the Margins: intersectionality, identity politics and violence against women of color' sets out that intersectional inquiry and practice are both needed to address the social problem of violence against women of colour, and solutions cannot be found by imagining women as one homogeneous mass. Cho et al (2013) contend that intersectionality is not one fully fledged homogeneous theory or methodology, and that debates around intersectionality have generative value while they also caution on the adoption of reductionist additive notions of intersectionality into the very same systemic structures where the intersecting power relations being questioned have also been continuously created.

Crenshaw's work (Collins and Bilge, 2020; Cho et al, 2013) on intersectionality has been rooted in praxis within judicial case inquiry reviews where Black women experience multidirectional discriminations. Collins and Bilge (2020) state that because critical practice of intersectionality is aligned with the Universal Declaration of Human Rights then using intersectionality as an analytical tool potentially provides important critical lenses for human rights initiatives.

Drafting initial plans for collaborative knowledge construction within the RLO I wish to place the underlying complexity of reality that makes for silenced groups such as disabled forced migrant Venezuelan families within the conceptualisation that black feminism has raised in the notion of 'intersectionality' (Collins and Bilge, 2020; Crenshaw, 1998). Crenshaw's intersectionality and Hill Collins' matrix of domination have had a monumental impact on feminisms in the Global South.

1.2 Maria Lugones' Critical Reflections on Intersectionality

The development of Lugones' concept: Coloniality of Gender is central to Descolonial feminists' thought in Abya Yala. It is grounded in Quijano's Coloniality of Power and Maldonado Torres' Coloniality of Being as well as in LatAm feminist movements, Chicana thought, indigenous feminisms and black feminisms both in LatAm and in the USA. Intersectionality theorising has come to the fore in developing the coloniality of gender (Lugones, 2010; Velez, 2019), as well as subject-object relations in knowledge production (Curiel, 2021), and critical genealogy as methodology in antiracist decolonial feminism (Espinosa-Miñoso et al, 2021).

This introduction on intersectionality foregrounds Maria Lugones' interpretation and critiques on intersectionality that are of consequence to explain the gaps in research and policy of the experiences of forced migration, (dis)ability, motherhood, of Venezuelans in Colombia. Exploring intersectionality through Lugones' analysis of the notion and responses from other DF such as Velez (2019) and Curiel (2021), is relevant to the narratives I have been exploring in the previous chapter on the mutual constitution of oppressions and their common roots rather than looking at them as disconnected variables or subjects for diverse fields of study (Hernandez Morales, 2021). The lens of intersectionality, I suggest, is particularly important to help make sense of the vivencias and dialogues at the RLO on themes of xenophobia towards Venezuelan migrants, the exploitation they experience based on their migratory status, their poverty, their race, their basic unfulfilled needs, and a host of other conditions they are immersed in including (dis)ability. Central to our daily work at the RLO is to advocate for the conscious awareness that extreme unequal discriminatory power relations are colonially produced categories. The acute hardship and inequality of women caring and responsible for the lives of children with or without

diagnosed (dis)abilities makes it essential to understand and tell the stories of the diversity of women's vivencias and show how there are multiple and particular ways of experiencing being a Venezuelan forced migrant woman.

Lugones' (2010) coloniality of gender becomes so transcendental in descolonial theories because she layers the notions of colonial oppression as solely based on race, and argues that gender is central to colonial categorial logic. Black and indigenous females are not women. Those in the zone of non-being, who lack humanity can therefore not be recognised in the categories of the colonial structures (Lugones, 2021). I have contended in the previous chapter that this stepping out of the western categorial logic can also place the category of (dis)ability as a white colonial categorisation. When Lugones steps outside of the categories she is highlighting the multiple and imbricated intersectional identities that are created and invisibilized in the colonial wound. Here is where Lugones' critique of intersectionality centres on what she describes as its additive nature. She contends intersectionality does not account for the causes of oppression by staying within the same hegemonic categorial logic of naming the identities (Velz, 2019; Curiel, 2021; Lugones, 2014).

> "... we move from the logic of intersectionality to the logic of fusion,
> intermeshing, coalescence. This logic is one of logical inseparability of
> race, class, sexuality, gender. While the logic of interconnection leaves the
> logic of categories intact, the logic of fusion corrupts it." (Lugones, 2014,
> pg 73)

Lugones (2014) views intersectionality as naming oppressions touching each other but, she denounces, overlapping oppression seen only as intersections ignores the concrete realities of the fusion of intermingling oppressions and their fused historicity. Lugones' says intersectionality visibilizes social struggles in overlapping oppressions, whereas fusion places the experiences of oppression in lived relationalities, in historic structures and lays the ground for coalitions. Many DF thinkers affirm this critique of intersectionality saying the danger of the concept as it stands is that it is absorbed into models of diversity and inclusion within the neo-liberal modern/colonial western paradigm (Curiel, 2021).

For Lugones the framework of intersectionality, whilst a crucial contribution, does not address the fact that the categories intersecting have been invented, created, produced within the logic of the modern colonial episteme. Hence the categorial genealogy of intersectional oppressions is imbricated coloniality. Velez (2019) offers a deep insight into Lugones' critique, particularly she dismantles Lugones' critique of intersectionality vs fusion as linguistic, endangering political coalitions which Lugones would never have intended. However Velez (2019) also proposes that Lugones' sustained questioning and shared thinking with intersectional theorisation sets out lines of thought and research that highlight the imbricated processes in colonisation in intersectionality that are enmeshed and cannot be disentangled. The coloniality of gender brings to the fore the questioning of the categorial logic of oppressions, not by naming the layers of categories, but by dismantling their meanings and origins.

What is relevant to this research is, beyond the semantic and analytic critique of intersectionality theorisation, the urgency to pursue research and praxis where the categories of oppression, race, gender, class are disrupted and not seen as separable categories in people's lived experiences. Hernandez Morales argues that 'decolonial, antiracist feminism represents an expansion of the present because it puts oppression in a broader framework of understanding due to its permanent efforts at dialogue with the social movement' (2021, pg 100).

Centering intersectionality as an analytical tool, is useful to view discrimination laws and policies in Colombia and within the global aid system as categorising Venezuelan forced migrant population homogeneously even when they are positioned differently such as women, LGBTQ+ people, (dis)abled people and children, undocumented people, indigenous and people of colour. Highlighting or ignoring intersectional and fused categories, governmental and international aid policies can have a huge differential impact on discrimination and inequality (Cho et al, 2013).

Intersectional research on (dis)ability, motherhood, othering and forced migration from decolonial feminist perspectives is not found in the literature. I have been critically threading intersectionality in the vivencias from CDS and DF lenses and methodologies but I have not delved into migration studies, the burgeoning field of critical migration studies or indeed the

praxis of Refugee Led Organisations that is a growing movement (Global Compact on Refugees, 2023).

A constant subject of internal discussion at the RLO and in the RLO movement we are in coalition, is navigating the humanitarian systems we have to operate within whilst developing anticolonial ways of thinking and working opposed to those systems. This is a parallel tension to the one I have encountered when navigating the psyche apparatus paradigm of (dis)ability whilst imagining alternate stories about (dis)ability with activist motherhood love that honour the humanity of our children. These parallel tensions are what Lugones (2014) refers to as leaving the categorial colonial logic intact when contesting oppressions. This parallelism in various oppressions is also apparent in Audrey Lorde's essay entitled There is no Hierarchy of Oppressions where she says:

> I cannot afford the luxury of fighting one form of oppression only. I cannot afford to believe that freedom from intolerance is the right of only one particular group. And I cannot afford to choose between the fronts upon which I must battle these forces of discrimination, wherever they appear to destroy me. And when they appear to destroy me, it will not be long before they appear to destroy you. (Lorde, 1984, pg 1)

These parallel tensions with their roots in the perpetuation of the categorial logic of the rationalistic western paradigm are particularly significant when working in communities such as the RLO. However many international rights agendas have inscribed women's rights, disabled people's rights, children's rights, indigenous peoples rights, protection for refugees and migrants rights into international conventions there is a failure in policy framing at international and national levels in addressing intersectional lived experience. As Oliver (2009) and Finklestein argued in Theorising Disability Politics and the Disabled People's Movement, having rights inscribed in conventions and laws does not translate to changes in people's lives as laws are not guaranteed to be enforced nor are rights in themselves the goal if they do not represent and include the people they are supposed to serve and remain accountable to them. I would add to this lack of representation and participation that by continuing to address human rights in siloed forms, ignoring intersectionality and silencing the geo-political causes we ignore their systemic common ground causes. These silences I will argue produce gaps in research, gaps in policies

and knowledge production from localised contexts. It is these gaps that local NGOs and RLOs, like the one I work in, attempt to fill by supporting people's access to rights.

2. Gaps in the research and knowledge production for praxis

This research has been localised in Bogota with workers in RLOs and with members of the forced-migration Venezuelan community that the RLO serves. As I focused on (dis)ability through the vivencias of conversing with mothers I found an entangled web of complex intersectionalities that cannot be served by being treated as identity strands. Following my conversations with fellow RLO workers, the notion of intersectionalities is visible in the themes and concerns that arise in shared dialogue and everyday practices. My fellow RLO workers, who are there in the field daily designing and implementing programs, have shared the complexity of the interlaced lived experiences of xenophobia, poverty, migratory status, (dis)ability, illness, gender violence, educational barriers, LGBTQI+ discrimination and they highlight the constant issue of differential representation. Angela says: "Let the decision-maker see what is really happening because if you don't know the reality and the decision-maker makes decisions from above then…well then nothing happens…."

In the context of this methodological research I have encountered many gaps within the fields of study that pertain to the concepts I set out to explore: (dis)ability, descolonial methodologies, forced migrations, othering and motherhood. There are particularly significant gaps in the overlapping intersectionalities of these fields where people's lives happen, where Venezuelan mothers, particularly those with children with a diagnosis, are juggling life with little specific support from government and aid agencies to cover the needs and remove barriers to educational, health and basic human rights. These multiple gaps in understanding could be categorised as data and knowledge gaps, policy and implementations gaps, and methodological and theoretical gaps in the representation of refugees with disabilities particularly children and their families.

I will address these gaps in three sections, first by highlighting the uniqueness of the Venezuelan Migration process within the context of LatAm as I have touched on throughout the thesis.

Secondly, highlighting decolonial thinking in critical migration studies relevant to intersectionality. Thirdly, within the context of Colombia I address the gaps at the intersectionalities of forced migration and disability from a feminist descolonising stance.

Uniqueness of the Venezuelan Migration

I have already in previous chapters characterised some aspects of the Venezuelan forced migration of the last decade. In this section I summarise some aspects and I highlight others characteristics that define the diaspora in unique ways and layer the difficulties Venezuelans face as my colleagues at the RLO talked about in Vivencias Intersectionalities. In less than a decade 8 million Venezuelans and counting have left the country which has put the open welcoming borders in LatAm to the test with a diversity of responses and difficulties for a coherent coordinated regional response (Gandini et al, 2020; RV4, 2023; MC, 2024). Colombia, despite its catch up policy roll out, has been celebrated for its unprecedented amnesty programs that include the Statute of Temporal Protection for Venezuelan s (Estatuto Temporal de Protección -ETPV) that gave a 10 year permit of residence to around 1.7 million Venezuelans of the 3 million that the government states are residing in the country (Migración Colombia, 2024).

LatAm countries have benefited from an initial migration of highly educated Venezuelan professionals. In later years this was followed by a migration group that has a strong work ethic but that has suffered a severe pauperisation first within Venezuela, and again when they migrate plus an increasing marginalisation during the COVID pandemic (Muños-Pogossian and Winkler, 2023; UNHCR, 2021; Reliefweb, 2020). The borders of LatAm have been openly generous to Venezuelans. However the lack of preparedness of LatAm countries with limited experiences of immigration and the sheer volume of Venezuelan migrants has created less welcoming and more restrictive migration practices (Gandini et al, 2020). As pointed out by my colleagues, the xenophobia towards Venezuelans in Colombia is now evident in daily life and the gaps between policy, legislation and implementation are impacting people's access to their rights to education, healthcare and inclusion in society. Social and economic inequality have been historically wide in LatAm and the Economic Commission for Latin America and the Caribbean (ECLAC, 2016) clearly outlines how intersectional inequalities exacerbate each other. They are developing a

social inequality matrix to stimulate inclusive social policies in the region. As Rosas and Zapatas say:

> "it is imperative to not only recognise that migration status introduces an extra layer of inequality and thus, of social differentiation, but that this occurs in already highly segmented contexts with multiple layers of inequality that feed on each other." (2024, pg 264)

The 8 million plus Venezuelan migration is a very recent exodus and arguably one of the most under-researched, underfunded and underserved mass migration in modern times. It is the largest migration ever known in Latin America, comparable globally only to the Syrian migration. They are both qualified as the migration crises of the 21st century and yet the Venezuelan migration is to date the most underfunded of "refugee crises" (Muñoz-Pogossian and Winkler, 2023; Bahar and Dooley, 2021).

> Based on the figures for 2020, total funding per refugee amounts to $3,150 per Syrian, $1,390 per South Sudanese, and just $265 per Venezuelan. In other words, funding for the Syrian refugees has been over 10 times larger than for Venezuelans, in per capita terms. (Bahar and Dooley, 2021, np, paragraph below Fig 2)

The lack of funding arguably originates from the low interest at a global level on the Venezuelan diaspora due perhaps to other global diasporas such as the Syrian and Ukrainian that are war caused and take up more media air space particularly in Europe (The Washington Post, 2023; Muñoz-Pogossian and Winkler, 2023). The UNHCR-led Regional Refugee and Migrant from Venezuela Response Plan for 2024 (R4V, 2024) reports that of the funding amounts required for the plan only 6% has been secured. Similar complaints to ours are made by Haitian and Sudanese refugee organisations (The New Humanitarian, 2024). This funding gap goes hand in hand with the gaps in data and knowledge production, gaps in policies and implementations as well as gaps in how knowledge can be planned for in representational methodologies and regionally relevant theoretical paradigms.

The image below, a screenshot from UNHCR's (nd) website about ongoing emergencies, highlights the differential category Venezuelan migrants have been placed in due to the international definition of refugee they don't fit within, although by sheer volume it is a

migration that cannot be ignored. All other countries on the list are catalogued as emergencies, Venezuela is catalogued as a 'situation'. I paraphrase Rivera Cusicanqui's previously quoted statement on why words matter and that in colonialism there is a very peculiar function where words do not designate, but cover up, and in this case where rights definitions become the barriers. The international definition of who is a refugee (UNHCR, 1951) for Venezuelans is a barrier that 'veils reality instead of designating it' (Rivera Cusicanqui, 2010, pg19).
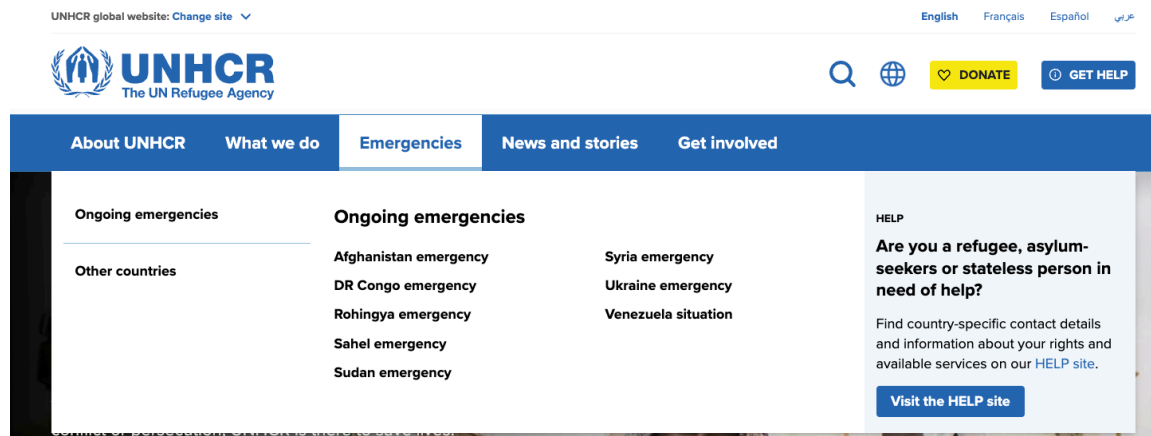

Illustration 3 UNHCR Ongoing Emergencies Webpage

As one of my colleagues at the RLO says the Colombian government was not prepared for the migration flow from Venezuela and without governmental support structures in place it has responded ad hoc reactively within already stretched Colombian social services and hence national and international humanitarian aid groups step in to fill gaps. They in turn knock on the door of Community based civil organisations and refugee led organisations to do the work in the cities or other territories. As I will refer to below there is no doubt that Latin American countries overall and Colombia in particular have had a compassionate outlook at the Venezuelan migration when compared to the USA and Europe's policies and governmental attitudes to any migration from the Global South. In particular in LatAm we do not have or use refugee encampments, reception centres nor imprisonment as a systemic policy. In other parts of the world refugees average 17 years living in some form of containment (Eastmond, 2007). In LatAm due to a variety of laws and agreements, history and solidarity, borders are more porous

so the issues of Venezuelan migration pertain more to being integrated into society where many live precarious homeless lives. Still the narratives of the Venezuelan forced migrants are ignored in the international community. No doubt the very nature and characteristics of the Venezuelan migration within present international law definitions have also resulted in a lack of funding for the Venezuelan diaspora. I examine this in regards to migration studies briefly in the following section.

Critical Migration Studies

Dear reader, I continue to remind myself that I entered this research focused on the field of (dis)abilities and its conceptualisation from descolonial paradigms. Forced Migration studies is not my field of academic expertise and I have not addressed migration as a colonial category in this thesis, fundamentally because the ethical concerns of representation, voice, coloniality and the need to descolonise myself as researcher and the research methodology took precedence. To explore, learn-unlearn and enact descolonial methodology had to come before I could address the intersectional contextual categories I placed in my original research question next to (dis)ability.

Hence this section is not a literature review nor a descolonial genealogy of the coloniality of migration within International Law and the humanitarian system nor is it a review of how the categories of migrants, forced migrants, refugees, and so on are defined. In the context of this research I wish to briefly mention critical perspectives in migration studies that are pertinent to intersectionality.

In the field of migration studies descolonising approaches are taking hold in academic studies examining the xenophobic roots of national border lines (Bashi, 2023) and particularly in the refugee-led movement focused on representation and participation (Jacobsen and Landau, 2003, Landau, 2019; UNHCR, 2024). Descolonial thinking points out the genealogy of western migration logic that places a problematic causation of migration focused on individual choices, criminalised during regularisation processes, rather than on the economic, political or social causations of migration. Migration studies are filled with binaries such as Internal vs. International migration; Temporary vs. Permanent permits; Regular vs. Irregular migration;

Forced vs. Voluntary migrants (Hong, 2020). Much of the terminology follows legal definitions enshrined in the Refugee Convention of 1951 (UNHCR, 1951) that was constructed post second world war with the legacy of post-war refugee migration in Europe. Migration concepts include specific legal terminology such as refugees (UNHCR, 2021) and other widely used terms such as migrant, forced migrant, displaced people. I have used these terms interchangeably in this research to signify people who have been forced to leave their country of origin not only due to the criterias of persecution set out by the Refugee Convention of 1951 (UNHCR, 1951), used in international law, but I have also adhered to the wider definition from the Cartagena agreement of 1984 signed by most Latin American countries. This expanded definition of who is to be considered a refugee and included in the right of no devolution states that refugees are:

… personas que han huido de sus países porque su vida, seguridad o libertad han sido amenazadas por la violencia generalizada, la agresión extranjera, los conflictos internos, la violación masiva de los derechos humanos u otras circunstancias que hayan perturbado gravemente el orden público. (Coloquio de Cartagena, 1984, pg 75 Conclusión 3)	…persons who have fled their country because their lives, safety or freedom have been threatened by generalized violence, foreign aggression, internal conflicts, massive violation of human rights or other circumstances which have seriously disturbed public order (UNHCR, under C in glossary of terms, 2021)

The Cartagena agreement at 40 years since its introduction has not led to significant implementation in the region perhaps partially due to it not being legally binding.The Chilean government is leading a review called 'Cartagena 40+' this year, a regional reflection on the Cartagena Declaration on Refugees in the continent in the current context of migration. In particular, the lack of implementation of the expanded refugee definition is under scrutiny. The RLO I work with was one of three RLOs amongst over 20 civil society base organisations invited by Comision Interamericana de Derechos Humanos (CIDH) in collaboration with UNHCR to take part in consultations. Just as I complete the writing of this thesis, an online audience was convened by the Chilean government on the 9th July 2024, to reinvoke the Cartagena agreement to honour the Latin American tradition of solidarity. Representation is

under review, at present only at a consultation level with no plans for representation at the design and implementation levels.

According to Landau (2019), most research that takes place today on the global infrastructure of migration is not concerned with south to south refugee flows nor on refugee representation nor on the settlement processes in particular locations in the Global South. Hong (2020) reinforces this by stating:

> Today's refugee regime – the global infrastructure of international and domestic laws, institutions, and legal processes that contour refugee flows – serves mostly a gatekeeping function for wealthy nations, mitigating the costs of refugee crises while fulfilling the humanitarian needs of a tiny percentage of the 70.4 million people who live in indefinite, forced displacement worldwide. Nevertheless, the dominant cultural narratives about the refugee regime that circulate in the Global North are narratives of salvation that center the self-proclaimed rescuers of refugees, or narratives of threat by an encroaching tide of refugee Others. (Hong, 2020, pg 34)

Intersectionalities of (dis)ability, forced migration status and lived experience of migration are the imbricated threads that run through all the stories and relationships related in Vivencias. From the internalised colonised migration our Abya Yala ancestors were subjugated to, having to migrate to other cultures within our own territories and bodies under the colonial gaze, to the present day reality of the Venezuelan diaspora that is beyond the 8 million mark, migration is a permanent story not a crisis. Migration and (dis)ability are modern/colonial stories. The legacy of coloniality is being researched and troubled within refugee movements (RRLI, Mustafa, 2023;) and in critical migration studies (Hong, 2020; Bashi, 2023; Jacobsen and Landau 2003; Landau, 2019). Similarly to (dis)ability studies, a lot of research is focusing on refugee voices, but in migration studies there is scarce literature focused on how refugee policies are constructed (Landau, 2019) and, I would add, who constructs them.

The RLO I work with also recently attended UNHCR events, The Global Refugee Forum in December 2024 (UNHCR, 2023) and The Global Consultation with NGOs in June (UNHCR, 2024). Speakers in side rooms from the main events focused conversations on Meaningful

Refugee Participation addressing the issues of the lack of representation of refugee voices in decision making spaces, including UNHCR, and in funding possibilities. In the events I have attended recently online and in person in Geneva, many intersectionalities are mentioned with specific calls for integration for women, racist readings of migration policies were called out and intersectionality as a priority for LGBTI+ people is often highlighted. Disabilities was named once in a list of specific groups. At every turn I find (dis)ability in this context remains invisible.

LatAm perspectives and regional methodology based research are imperative to move the sector away from the Global north narratives on migration that are focused on containment and criminalisation of migrants based on south to north migration policies that are beginning to infiltrate south from the Mexican-USA border policies (Muñoz-Pogossian and Winkler, 2023). It is also imperative to move away from siloed ways of conducting research that ignore the intersectionalities and representation of (dis)abled refugees and other focus groups of forced migrants in Colombia. In the Vivencia Rosemary says that the fundamental need the RLO fills is the regularisation process for residency status as this opens the doors for people to have access to their basic rights and Angela highlights storytelling and advocacy for refugees to sit at the decision making table. At our RLO we were able to start our own work thanks to the support of RLOs in other parts of the world, that is the power of coalitions, advocacy and self-representation working outside of the colonial hierarchical paradigm.

Descolonising research at the intersectionalities of Venezuelan forced migration and (dis)ability

By reviewing the gaps in research, funding and policies for the Venezuelan forced migration population, and within the International Refugee Regime, with its narrow definition of refugee status, I hope to have framed the enormous gaps that Venezuelan migrant families with a member with a (dis)ability have to confront. Research about (dis)ability in the Venezuelan diaspora across LatAm appears to all extent and purposes to be non-existent in the reviews I have undertaken of reports and research. Specifically as pertains to this research in Colombia, reviewing policies of international humanitarian organisations, governments and academic

research, this population remains invisible. Widening the research of this gap by investigating other intersectional categories and contexts that might account for (dis)ability in forced migration, such as poverty, gender, exploitation, school placement, discrimination, or child social services did not raise any data or storytelling accounts. As I said in the previous chapter, there is also a gap in research regarding experiences of mothering a child with a labelled (dis)ability in the context of forced migration and how motherhood is constructed in coloniality (Angelino, 2014). Researching the gaps of knowledge at the intersectionalities of Venezuelan childhood (dis)ability, motherhood and forced migration to Colombia is an urgent need.

In chapter 2, I highlighted the absence of data and specific knowledge on disabled Venezuelan forced migrant children in Colombia and their access to education and health services. This gap is partially referred to by the Platform of Interagency Coordination for Venezuelan Migrants and Refugees in their report 'Invisible within the Invisible' (RV4, 2022), but as I described previously, it does not describe children's lives. I also highlighted how the lack of research, data and information is reflected in an absence of specific, targeted policies and implementation plans for the inclusion and support of (dis)abled migrant children from Venezuela in Colombian governmental institutions. As my colleagues report, the families where children with (dis)abilities are excluded from education require lengthy legal support and there are no formal complaints processes for them to access, hence the only possibility is legal pro bono support from civil society organisations like ours. According to UNICEF 25% of Venezuelan refugees are estimated to be children (UNICEF, 2023), and as I estimated previously there may be around 120,000 Venezuelan children with (dis)abilities in Colombia. It is not documented or known how many are in school and whether or not they are receiving the accommodations or services they may need. These children and their families have to navigate a system within which they are not accounted for in multiple ways, as forced migrants and as (dis)abled.

Through multiple cross-referencing research I found one report on disability and migration online co-published by UNHCR and the Latin American Network of People with Disabilities and their Families (RIADIS). However, unusually for UNHCR-being such a large agency that tends to produce large statistical impact research-this report is of limited scale and scope, and not fully available. The report is called Disability and Human Mobility (UNHCR, 2021a) and was based

on research compiled in 6 countries plus a non specified number of countries in Central America in April 2021. The report is based on only 774 people across these 7 plus countries with a variety of research methodologies without a description of participants profiles regarding migratory status, country of origin or types of disability or ages. It highlights on the summary page online that 77.2% of persons with disabilities consulted stated that they received no help to emigrate. The only specific disaggregated data on children is that within the group interviewed 8 of 10 children had access to education. The full report, executive summary, data, results by country, and annexes are not available on the pages of UNHCR or RIADIS. What is available are a series of corporately-edited videos focused on what people with disabilities can say in case of their rights being violated and how humanitarian aid workers should talk to people with disabilities using accessible means in the context of humanitarian action. On the RIADIS (nd) website a search on migration and disability throws up five research links to migratory studies that do not mention disability. The Disability and Human Mobility report's main conclusion is the urgency for more research calling for persons with disabilities participation. It is a step, however, with no apparent follow up plans or funding and statements advising governments and humanitarian organisations to address the challenges, it is not apparent that UNHCR is planning to take next steps soon. The positionality of the UNHCR-RIADIS report appears based on (dis)ability as defined by the WHO's colonial definitions of (dis)ability. The inclusion and participation of disabled refugees's voices is not considered, named or planned for in the report.

Research that starts from the voices of Venezuelan disabled refugees is not present or available in academic or humanitarian literature. There are multiple layers of oppression at the intersections where invisibility, lack of representation and colonial aid and research structures require further uncovering and troubling. Even when the large agencies attempt to bring together data from across the continent children are absent, data is not reliably transparent and researchers such as myself cannot find the details of any reports to continue building on the known data. Hearing people from these intersectionalities is vital to the work we do at the RLO.

The absence of refugee representation as knowledge producers in these powerful organisational outputs becomes more exacerbated when we observe intersectional forms of discrimination and oppression such as, and not exclusively, gender, race, sexuality, social class, migratory status,

level of education, and as interests me (dis)ability in children. I reiterate that forced migrants from Venezuela from impoverished backgrounds with a member of the family with a (dis)ability are invisible in research, in knowledge production spaces, in statistics and in policy guidance. When their images or stories are used they are not considered as producers of knowledge. Their intersectionality does occasionally surface in the news or social media where stories and images create a human connection to vivencias normally invisibilised by governments, international organisations of 'humanitarian' aid and advocacy. There are artistic endeavours such as Javier Téllez's 'Amerika' film installation created in collaboration with Venezuelan refugees, psychiatric patients and people with disabilities whom he positions as political actors (Téllez, 2024), where representation and participation are put in the centre. However his exhibition to date is only visible in a gallery in New York.

The absence of national policy as well as the seemingly lack of urgency in humanitarian and governmental groups around awareness of disabilities in the Venezuelan refugee population, particularly children, are not possible to quantify because of this total absence of research and data. I find it difficult to ethically understand this gap when all countries in LatAm have subscribed to conventions on the rights of people with (dis)abilities as well as conventions on the rights of refugees including the Cartagena agreement. Could it be that the very same categorial dehumanising logic of siloing knowledge is contributing to or indeed structurally constructing these gaps of knowledge at the intersections of (dis)ability, gender, forced migration, poverty, education? Tentatively, as a naive researcher, I wonder if this question has been formulated elsewhere. From a descolonial perspective, undoubtedly, the unveiling of the priorities of the main actors who produce knowledge in the fields of migration and (dis)ability could explain some of the gaps in the research. However, following Lugones'(2021) questioning of the usefulness of categories invented in colonial thinking, I would suggest that knowledge production at the intersections remains invisible as a result of staying within the categorial logic.

Epistemologically this is a start of an idea, a suggestion, a seed I believe worth exploring further. The sentipensar I have is that if research starts from the communities, from their articulation of problems and barriers faced, then the intersectional categories could lose relevance. When the description of the problems is centred on people's knowledge of their lives and not on preset

research proposal criteria from organisations from the Global North or those operating within Global North epistemologies, then perhaps representation and participation can start to fill the gaps, absences and silences by formulating relevant research proposal and questions. The notion of losing categories, as Lugones (2021) I understand proposes, is difficult to conceptualise, may indeed seem utopic, even highly impractical in modernity as well as threatening the representation of the very people who are invisible in research and policy. But I suggest, following many descolonial thinkers whom I have been referring to throughout this thesis, that to dare to think differently does not necessarily seek an end result but rather is a shift in attitude, a daring to look with different epistemological eyes. Rivera Cusicanqui said in an interview "Nada sería posible si la gente no deseara lo imposible", "Nothing would be possible if people would not desire the impossible" (Cacopardo, 2018, Title pg). And as Lorde (2018) says in her often repeated eloquent phrase and title of her book "The master's tools will never dismantle the master's house". So I dare to frame this epistemological friction about trialling out the abandonment of categories. When I descolonially imagine the stepping out of colonial categories it is not to aim for a complete process in a temporal definite way. It is an intentionality, a wish, a goal of daily practices, within an organisation or research project or daily relationships, to challenge epistemic aggressions that are visible in daily lives and bodies.

The Venezuelan migration is underreported, underestimated and is often referred to as an invisible diaspora. Disabled people involved in this diaspora are invisible within the invisible (R4V, 2022). Their intersectional experiences of Venezuelan migration with a (dis)ability is not studied, documented, reported on, and policies to protect their rights are non-existent as I have argued. Equally how people come to be disabled or diagnosed during harsh and dangerous migration experiences is not researched. (Dis)ability is invisible in migration theory and research. "Migration theory grows without the disabled person, disability studies without the migrant, and practice without the disabled migrant." (Crock et al, 2017; Pisani & Grech, 2015). In the last Global Forum for Refugees at UNHCR, in a small side room, a group of refugee leaders were asking for support to be included at the decision tables. The International Disability Alliance pledged their commitment to support refugee leadership participation. There is a strong history of calling for participation and leadership in the disabilities movement (Goodley et al

2019), and as I stated in chapter 4 the slogan "Nothing about us without us" has been taken up by the refugee-led movement.

I have been centering my activism and research on the experience of Venezuelans in Colombia inhabiting the intersectional borders of (dis)ability and forced migration, in the context of mothers surviving in poverty. There is an urgency for mediating practices of solidarity and coalition in these intersections. Northern (dis)ability studies and Global North migration studies remain largely detached from the global South, particularly in an epistemological sense with some notable exceptions such as the journal 'Disability and The Global South' that published a special issue on 'Disability and Forced Migration' in 2015 and the recently published book this year in May, 2024 'Intersectional Colonialities: Embodied Colonial Violence and Practices of Resistance at the Axis of Disability, Race, Indigeneity, Class, and Gender' by Afeworki Abay and Soldatic (2024), not yet available in university libraries. There is a dedicated chapter by Mexican Alex Padilla on the experiences of disabled immigrants in central america through narratives of LatDisCrit and transmodernism. My engagement, that is just beginning, with (dis)ability and forced migration from a descolonial feminist intersectional perspective is novel in three ways: the questioning of the categorial colonial logic of the terms (dis)abled and migration, the context in which I am carrying out activist - research, and finally the learning how to enact community descolonial methodologies that move away from the western episteme of knowledge production.

The context of our histories, territories and cultures, and the epistemologies of our specific socio-geo-political spaces are necessary to carry out critical research on (dis)ability, forced migration and other intersectional identities from epistemologically constructed research within Abya Yala. This research attitude and focus is urgent and highly relevant to the marginalisation of human experiences in the context of displaced Venezuelan families with children with possible (dis)ability and/or rights to education not being fulfilled. And so I move on to a final review of the research questions reformulated throughout this research.

Research Questions: a final review

Reflecting on and challenging the globalised universalist discourses at the intersectionality of (dis)ability and forced migration in LatAm from descolonial perspectives has been the aim in the reformulation of the research questions at every step of this methodological research.

So whereas my initial research questions were concerned with exploring conceptualisations of (dis)ability present in Latin American, working in the field I realised how the notions of (dis)ability are imbricated in multiple intersectional categorisations of identities that are oppressive categories born in colonialism, developed and perpetuated in the modern/colonial western episteme (Lugones, 2021; Espinosa & Maldonado Torres, 2021; Barnes, 2008; Danel, 2021). As Goodley (2013) stated, "although we may start with disability we never end with it". In this research (dis)ability became an approach (Schalk, 2017), an attitude (Maldonado-Torres 2016) and a search to connect with others (Fanon, 2008) and to turn towards epistemic disobedience (Curiel, 2021). From descolonial feminist stances I have pondered how to do ethical research with people who are marginalised and oppressed in multiple imbricated ways, in particular with forced migrant Venezuelan mothers with school aged children with or without (dis)ability living in Bogota. I have established that there are various gaps in the research and epistemological stances where the vivencias of these mothers and their children are not visible, researched or reported nor are policies being created that can respond to their specific experience.

Earlier I quoted Patel who says "How we frame a research problem and its context is pivotal to understanding how it has already been understood, perhaps misunderstood and what stances are fruitful for further understanding it" (Patel, 2016 Pg 59)

I know what it is to arrive somewhere where nobody knows your name, your family background, with no extended family or support group. I know what it is like to not be able to go back home. But I have done this in the safety of a new job and school placements for my children. To leave behind everything that you have ever known and loved, careers and professions taking backward turns, living without legal protection, work exploitation, no health provision, food insecurity is a

reality for many. Those of us in privileged lives can read or hear about and empathise with all the issues that came up in conversation with Angela and Rosemary, but can we represent these stories? Should we? Spivak warns us about portraying 'Other as the Self's shadow' (Spivak, 2010, pg 35). The descolonising path became very clear to me: self-reflexivity and political awareness, what Freire (1974) called: 'conscientização'. The vivencias in this thesis are my 'conscientização' of what I learned, what I could relate to, what I see as injustices. It also gave me a clarity of who should portray people's stories: not me. I initially asked

> How do Venezuelan children and their families, embodying the intersections of forced immigration and disability, experience migration and inclusion into communities and schools in Colombia and back in Venezuela? (Arenas, 2020)

I have reformulated the research questions in each chapter and found that the only ethical valid question in this research that I can formulate individually arises from my experience and conversations with women about my positionality, my motivation for entering into the research and pondering how to do ethical research. In the original research proposal I framed resistance to the western epistemic knowledge system on (dis)ability as the background to the research questions. I expected and hoped for a dialogic process where the questions could be changed in collaboration with the participants. The reality of my privileged positionality in initiating the research forced me to take a step back and uncover the layers of coloniality in my mestiza identities. In my continuing self-descolonising I reflect on my privilege and uncover how the Psyche knowledge I was taught at university in Caracas emanated from the Global North. Critical self-reflection led me to question representation and 'othering' in the research and also to question the individualisation of knowledge production from the Global North in the form of doctoral dissertations. Troubling how I was intending to produce knowledge about displaced Venezuelan mothers with children with (dis)abilities, I have asked an evolving and reformulated set of questions throughout, the last question I have asked is:

- What research questions does the RLO community want to address?

This is the question I take away with me to the RLO. I have argued about the possibility of losing the categories as Lugones (2021) has proposed. And whereas in academic research this may seem as dislocating research from a field of studies, by placing the power of the questions in the

community we can delink from the modern/colonial paradigm of (dis)ability imported from the Global North structures of knowledge production. As I said in the last chapter the ethical imperative of the descolonising the research questions have taken me to the realisation that I do not want to answer my questions.

In the preface, I said I have left this research writing with more questions than when I started. This is where this thesis culminates, moving on to what methodological learnings I can take back to the RLO for dialogue on our research practices.

Methodological Learnings: Limitations and Principles

The structural dynamics of oppression in displaced populations and in (dis)abled groups in particular are multilayered. I have set out to enact descolonising methodologies that move away from viewing the poverty-stricken disabled refugees as 'others' and move towards dialogue and shared thinking. Displaced people bring with them whole lives, belongings, memories, longings, desires, imaginations. Displaced Venezuelans bring with them to Colombia and all over LatAm a culture of generosity and music and happiness and nostalgia, we all carry such nostalgia. Displaced Venezuelan s in many intersectional identities have the abilities to be knowledge creators as experts of their own lives. They should not be a "moving story" to attract funding or an example of a good refugee, they should have active roles in decision and knowledge making spaces.

Planning for the original research in Chile I was very much inspired by the readings of the Dialogic-kishu kimkelay-ta-che educational research methodology written about by Ferrada y Del Pino (2017). It translates from the Mapuche language as "no person knows or learns by herself". At the end of this research I return to the idea of formulating open-ended research constructed collectively, as formulated and practised by Fals Borda, the father of Participatory Action Research. A form of knowledge production where the community of people working with and served by the RLO can ask the questions and issues of concern in the community (Fals-Borda, 1987).

Fals never published a manual documenting how PAR functioned in its
early years; instead, he insisted that PAR drew upon local experience to
cultivate a philosophy, methodology, and set of techniques for conducting
research premised on the establishment of horizontal relationships
between external researchers and communities in the service of the
organizational objectives of the latter. (Pereira and Rappaport, 2022, np)

As I have referred to throughout this thesis, descolonial feminists place praxis at the heart of
descolonial movements and knowledge production. I have made the point in this chapter that
descolonial feminists have also unveiled monothematic, single issue, siloed knowledge identity
politics as inventions of coloniality/modernity global world system. Intersectional, imbricated,
contextualised, mestiza, collaborative, participative and localised research methodologies are one
of the key contributions of descolonial, anticolonial, black feminisms (Rivera Cusicanqui, 2018;
Curiel 2021; Lugones, 2010; Lander and Lang, 2020). Descolonising methodology is not about a
specific tool that will guarantee decolonising methods, as Maldonado Torres (2016) says it is an
attitude and as Curiel (2021) says it is about praxis in coalitions.

The reformulation of research questions has been my enactment of descolonial feminists' call to
praxis within research, questioning categorial intersectionalities and knowledge production. I
have reflected at every turn in this research on the ethics of representation in the methodology. I
have wondered who this autoethnographic research authorship belongs to? I take full
responsibility for the writing and they are my own reflections but how do I honour the people
who conversed with me? How do I honour people's reflections that changed my own? How do I
honour, beyond the acknowledgments page, our relational thinking that has become the
backbone of this research? These questions are central to producing knowledge about
intersectionalities that are barely researched in our LatAm context, specifically from the
perspectives of the forced migrant mother's vivencias. Espinosa-Miñoso et al say:

Anyone who wishes to contribute to antiracist and decolonial feminist
work must constantly work with others, inside and particularly outside of
the university, to avoid reproducing the elitism, arrogance and entitlement
that has often been part of academic knowledge production in universities.
(2021, pg xiii).

The limitations of this research have been in essence what the whole research has been about. I hope it has become apparent to the reader that this autoethnographic research has been about learning how to carry out a descolonial methodology as much as it has been about activism, (dis)ability and forced migration. I have been confronted with my own collusion in constructing knowledge from a western episteme, a methodology of presumed participation that was defined by myself as an outsider researcher that required self-descolonising and methodological change of direction. In chapter three I set out the research design and reviewed the ethical issues as well as troubling my methodology and research questions even as they evolved. In chapter two and in this present one I have established the research gaps at the intersectionalities of forced migration and disabilities. In chapter four I explored the meaning of the categories in the research question formulations. I have throughout set forth my evolving positionality and intentions of taking research learnings to develop research methodologies within the community I serve in the collaborative context of the RLO in Bogota.

The RLO has now been established for three years, we have worked with thousands of people and we are growing within the community. I take back to the RLO a summary of the methodological principles drawn from each chapter as a draft to commence work on research as we have the goal to develop our own research processes and storytelling methodologies. It is a draft proposal as these ideas need to be decided, developed and enacted for, in and by the collective. This way I bridge my continued ethical concern about representation towards the participation I had envisaged in my original proposal but could not enact. Following university rules as an individual research piece, this research has set the path towards collaborative research activism. The dissertation is finalised in this chapter but I will continue to explore how to do research within the intersectionalities of forced migration and (dis)ability from critical Descolonial Feminist stances in the context of working in the RLO. As an activist researcher I am committed to descolonising myself and how I approach my role at the RLO, and the research we choose to engage in together in the gaps we find relevant.

This is the moment to initiate some people-led research where the community can control what questions we start from and they can cite themselves in the research as experts of their lives and

vivencias. The narratives of exile, forced migration, intersectional complexities and overcoming barriers now play a significant role in contemporary Venezuelan s imaginary where we wrestle with the shadows of possible lives. As the largest migration in Latin American modern history spreads, the notions of homeland and belonging are morphing and narratives of 'othering' appear in our collective diasporic vivencias. There are plenty of coalitions to be built, research to do, and methodologies to co-construct.

These are the principles I have taken from each chapter for the draft proposal for the RLO, including a fifth one I add now from this chapter.

1. Critical Self-Reflexivity- Self-descolonising
2. Research for transformative activism- the personal is political
3. Explore Altern Methodologies for representation
4. Whose knowledge and what references
5. Producing and Mobilising Knowledge within the community

Critical Self-Reflexivity- Self-descolonising

From Chapter one in the Coming Home vivencia about my research planning trip, the dialogues, the encounters, what I witnessed and felt made me realise that having a research stance of listening was not enough. From descolonial perspectives, from critical theories and now from my lived experience in conversation with Chilean researchers, with Venezuelan migrants and refugees in Chile and Colombia the questions ringing in my ears were about belonging, privilege, authorship, insider-outsider positions. Who was going to benefit from the research? Espinosa-Miñoso (Barroso, 2016) talks of the need to practise humility when standing at the borders of where knowledge is legitimised. Hence this research was more about my methodological awakening, my own self-descolonising and learning how to enact descolonising research. I also wondered how my self-descolonising could be relevant to others? Self-reflexivity is central to uncovering our positionalities. Maldonado-Torres (2016), critical of methodology as a guarantee of truth in modern science, says descolonisation is a praxis, a feeling and thinking, an attitude that defines the positionality of one cognisant being in relation to other cognisant beings (Barroso, 2016).

Research for transformative activism- the community is political

Tent Research during the COVID pandemic narrated in Chapter two forced a pause on the research and an ever more complex situation for Venezuelan displaced people including the community based groups I had been collaborating with in Colombia. I turned first to crowdfunding walks and then towards activism with a Venezuelan women collective. Immersing in descolonial stances, searching for altern methodologies, worrying about self-introspection as elitist and impostor syndrome, I shifted towards activism. I focused on the notion of 'the personal is political' as an activist researcher in the sense that I found that the researcher and the activist spaces collide and offer altern understanding of producing knowledge within collective praxis. Moving towards making spaces that embody ethical praxis of descolonisation I turned to activist scholarship in joining the founding of an RLO.

As a community working to advocate for the participation of displaced people, the process of recognising our personal involvement in the community is a reflection of our political interests as individuals and as a group. The questions changed to ask who is the research for, who designs it and who is it answerable to. The personal is political as a positionality outlines the social systemic structures we are assimilated into, at the same time as we resist them. Descolonial feminists remind me about the need to dissent from the hierarchy of knowledge production by uplifting the power of communities and non academics to conceptualise.

In a collective care approach 'the personal as political' can be reframed to 'the community as political' since all reflexive knowledge within a community generates a collective as well as personal consciousness. Equally important is how we reflect on our collective political goals and critically consider how we are activists by working together in a manner consistent with the groups agreed expectations and in support of the community changes we are pushing for.

Exploring Altern Methodologies for Representation

In Chapter three, I described the methodological choices I have made in writing Vivencias through autoethnographic storytelling. I questioned how to explore knowledge in a way that was respectful and took into account the lives of the people I have formed relationships with during the research. I found in autoethnography and the writing of my vivencias a rupture with the dominant forms of researching, writing and producing knowledge that I was trained in. I do not suggest autoethnography as the form of altern methodology to take back to the RLO, rather I open the dialogue to create altern methodologies that must be designed within the research community to represent their own voices.

Whose knowledge and what references

Chapter 4, set out to explore what meanings the term (dis)ability can have in a decolonising research question in the context of Venezuelan mother's vivencias of forced migration. I used a genealogical reading of the conceptualisation of disability exported from the Global North using LatAm feminist descolonial literature. To seek to delink from and critically review the dominant western knowledge paradigm and to formulate research from altern pluriversal forms of knowledge requires delinking from Global North sources of information as the main source of references. In this thesis I have as much as possible sourced references from Abya Yala academic peer-reviewed knowledge producers in the social sciences, preferably located in southern geographies. I also referenced other types of latin american sources such as videos of lectures by decolonial thinkers available in the public domain, interviews, podcasts, and such. In my literature reviews I purposefully move away from dominant western academic epistemology by seeking other funds of knowledge, other world views not exclusively anchored in western Global North academic social science paradigms including critical paradigms from the Global North such as Critical Disability Studies and in this chapter, very briefly, critical migration studies. Concerns over representation, voice and praxis run through this thesis with a commitment to solidarity. Mike Oliver (2009) wrote in 1996

As researchers then, we labour to produce ourselves and our worlds. We do not investigate something out there, we do not merely deconstruct and reconstruct discourses about our world. Research as production requires us to engage with the world, not distance ourselves from it, for, ultimately, we are responsible for the product of our labours and as such we must struggle to produce a world in which we can all live as truly human beings. Thus, the research act is not an attempt to change the world through the process of investigation but an attempt to change the world by producing ourselves and others in differing ways from those we have produced before, intentionally or not (Oliver, 2009, pg 116)

Looking forward to research in the community, looking towards sources and references, must include voices of the community researchers as knowledge creators placing the community voices on the par with already authoritative academic and/or professional experts.

Producing and Mobilising Knowledge within the community

In this final chapter I have explicitly described the gaps of knowledge regarding the Venezuelan migration overall and throughout this thesis I have built the picture of the gaps in knowledge, research and policies that impact the lives of Venezuelan refugee mothers with children with (dis)abilities.

I have argued throughout this thesis and aligned myself with descolonial thinkers (Asher, 2017; Spivak, 2010, Wynter, 1994; Curiel, 2021; Lugones, 2021; Maldonado Torres, 2016; Tuhiwai Smith, 2012; Rivera Cusicanqui, 2018) on the ethics of questioning who carries out the research and who decides the questions. I join descolonial thinkers in highlighting the importance for the receptors, collectors, reporters, researchers of stories to make explicit their positionality and intentionality and to question epistemic privilege (Curiel, 2021). Stories are never neutral, research is never neutral and yet the portrayal of people at complex intersectionalities of the zones of non-human, such as forced migrants (Landau, 2019) and/or disabled people (Grech and Soldatic, 2016; Solli and Silva, 2012) tend to be portrayed as objective knowledge when they are told, counted and analysed by governmental agencies, international aid organisations, international humanitarian organisations or academic institutions.

We may not have funding or institutional power for research but we have our stories. Our way of working with the community is ever evolving in a world that does not work for forced migrants, for disabled people and for many at the intersectionality of the colonial wound. It is a story worth telling. The new objective we are laying out for ourselves is to produce knowledge within the communities, delinking from categorial logics and find ways of mobilising this knowledge through advocacy, storytelling and continued praxis.

Last Words for the descolonial hope of being

Descolonial perspectives problematise the certainties of the naturalised Eurocentric world premises. Latin American decolonial thought aims to create new epistemologies that don't answer to the structures of western academia and sets out to dismantle the internalisation of imperialism and the dark side of colonial perpetuation which is modernity. Modernity and the coloniality of knowledge is the continued belief system in Eurocentric modernity with its industrialisation, and urbanisation as the presumed inevitable routes to prosperity and social development. In reality, modernity forces us to live in ever more restricted, narrow and categorial spaces of understanding. I align with descolonial feminists in that there is no dismantling of systemic oppression without praxis and actions.

The critical perspectives on knowledge production presented feel fundamental to the social justice agendas of those of us working in praxis within critical views on migration, feminism, (dis)ability and require us to stay open to questioning and unlearning ways of knowledge production traditionally taught in academia and that are spread everywhere, violent truths that oppress the very people the system purports to help.

In descolonial practices in Abya Yala, reformulating research methodologies (Ocaña, 2018) has felt important to generate a transformation of the practices of those of us seeking collective construction of knowledge. My continuation in praxis based research will continue to be inspired by the Latin American epistemological and justice convergences from which to reorient ways of knowledge production that builds from the "south" and to provide knowledge that represents us as communities, cultures and groups with our own mestiza intersectional complex identities. In

my research I have had the explicit learning and intention to move away from extractivist knowledge production of academic research towards actions based knowledge production within advocacy groups such as Refugee Led Organisations and (dis)ability advocacy groups (Silvia Cusicanqui, 2010). However, I am aware of the complexities of balancing and unlearning, listening to the community, growing in the awareness of my research biases, and learning to do decolonial research through action. I imagine Abya Yala feminists like Maria Lugones, Ochy Curiel, Yuderkys Miñoso- Epinosa and Rita Segato would say it is 500 years of unlearning we need to collectively advocate in taking the descolonial turn.

This research, late in my professional life, has been an attempt to understand the wounds opened during my professional career and education, and the maternal-personal experiences I have had around (dis)ability. The unlearnings I have gone through I hope can generate some visibility, impact, and a growing awareness on the urgency of research on (dis)ability in the context of forced migration in Latin America, particularly in Colombia where the largest number of Venezuelan refugees have moved.

My approach to understanding the experiences of Venezuelan mothers forced migration to Colombia with children with /without disabilities changed throughout the research and has been informed by descolonial feminism and (dis)ability as epistemological stances questioning knowledge production. I have built on possible nodes of narrative dialogues between descolonial feminism and critical disability studies that examine notions of who is human. This is a rich space for growth in collaborative learning.

So have I answered my initial research questions? They were not the questions that became relevant. What became relevant was to do slow thinking, slow research focused on learning within human relationships, connections and activism. The ethical imperative of responding to the community rather than my original research questions has been the learning. My goal became to write research stories that crossed borders between disciplines, between 'reality' and imaginary social life, between national borders, between academic writing and fictional writing. Crossing multiple borders I have reframed my research questions and embedded the research in the academic LatAm literature of descoloniality, feminism and (dis)ability and more importantly embedded in lived shared experiences of activism with Venezuelan and Colombian women. I

have been relearning new ways to see and be in the world. I know the impact of the praxis at the RLO is far greater than any words on a research page.

This research has felt as if I am a Venezuelan trying to go back home, I left a lifetime ago, I am now a mother and I am still a Venezuelan trying to go home and now through no planning of my own, but through coalitions forged with Venezuelan women whilst I engaged in this research, I am part of a movement. As Gabo (Gabriel Garcia Marquez) says in his quote at the start of this chapter, 'life obliges us to birth ourselves over and over again'. I feel I have given birth to myself over and over in this research process, intellectual shifts, a sisterhood and an RLO were birthed, we birthed it ourselves in coalition. I think in a Latin American text in Spanish these words would sound emotional and acceptable as the sentipensar conclusion of a dissertation. Dear reader, earlier I would have worried that perhaps in a doctoral thesis for a Global North university these words of emotional rebirthing might sound melodramatic in English. At the end of writing I have stopped worrying, I hope to have engaged you the reader in the route I have experimented describing my descolonial unlearning. I hope I have left you with many 'sentipensares'.

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Appendix One: First Ethics Application April 2019

Application 026456

Amendment - Complete (Submitted on 25/10/2023)	Delete

Description of changes

My ethics was initially approved in 2020 and my estimated time of completion of data collection was Feb 2021. Due to the pandemic and the impossibility to travel I took a year out. My data collection period was extended until July 2022 by Anna Weighall via email. I completed my data collection including feedback from some interviews in July 2022 when I was in Bogota last year. However I have since received further feedback from some participants and my tutor advised me to submit an ethics amendment to allow me to continue to review and incorporate feedback from participants and discuss interview content with them. I would request this up to Dec 2023. Beyond that date I would not use any further feedback.

Additional ethical considerations

Do the proposed changes pose any additional ethical considerations?
No

Additional risks

Do any of the proposed amendments to the research potentially change the risk for any of the researchers?
No

Supporting documentation revisions

Do the proposed amendments require revisions to any of the supporting documentation? Please note that when uploading new versions of documents which you have previously provided, you should give a description of the document which clearly indicates that this is a new version, e.g. by providing an appropriate version number. It is also helpful to the reviewers if you clearly mark the changes you have made in the document itself (e.g. by highlighting new text or using tracked changes in Word).
No

Other relevant information

This amendment is requested up to December 2023.

Decision

should be approved

Original application

Section A: Applicant details

Date application started:
Mon 15 April 2019 at 14:29

First name:
Elizabeth

Last name:
Arenas Thomas

Email:
earenas1@sheffield.ac.uk

Programme name:
DEd Psychology and Education

Clinical trial or a medical device study?
No

Involves social care services provided by a local authority?
No

Is social care research requiring review via the University Research Ethics Procedure
No

Involves adults who lack the capacity to consent?
No

Involves research on groups that are on the Home Office list of 'Proscribed terrorist groups or organisations?
No

Indicators of risk

Involves potentially vulnerable participants?
Yes
Involves potentially highly sensitive topics?
Yes

Section C: Summary of research

1. Aims & Objectives

The aim of this research, to be carried out in Colombia, is to explore the experiences of Venezuelan disabled children and their families who have been forced into migration to Colombia owing to economic crisis and hunger in Venezuela. The flow of Venezuelans into other Latin American countries has exploded in the past 12 months, is not diminishing and has been categorised by the UN as the largest ever migration in Latin America. The greatest numbers are migrating to neighboring Colombia.

The main research question is: How do Venezuelan children and their families, embodying the intersections of forced immigration and disability, experience migration and inclusion into communities and schools in Colombia?

What do the participants' narratives express about their understandings of differences, learning, migration and inclusion? Specifically, what are the experiences of disabled migrant venezuelan children and their families on "school inclusion" when they arrive in Colombia? How may their insights inform practices for inclusion in schools and communities and build a sense of belonging?

The three major theoretical threads of this research are critical disability studies arising within the Global North, Decolonial studies constructed by Latin American thinkers and decolonising methodologies in social studies in Latin America.

Firstly, the initial aim of the research is an exploration of decolonising methodologies as a way to understand disability and forced migration within a Latin American context. The methodological decolonial stance is such that my objective is for the research questions to be guided, changed and reformulated, by and with participants in the context of shared narratives (Ferrada & Del Pino, 2017). As a Latin American researcher working within a European university my positionality is central to the methodological process. Dialogic reflexivity between the participants and myself will be the tool to weave the connections between their narratives and theoretical threads. Forced migrants live in ambiguous and unresolved situations that make telling their stories difficult whilst at the same time they need their stories to be heard and believed (Eastman, 2007). In Latin America oral traditions often are politically dynamic, keeping core values alive (fals-borda, 1987). The epistemological potential of storytelling resides in the dialogue and how this focuses attention on the internal dynamics of the "subaltern". In this way Latin American knowledge is constructed through the community practice of oral tradition (Rivera Cusicanqui, 2016). To explore decolonial methodology, my intention is to try to find ways of entering into dialogic research with Venezuelan families, children and the charity workers that help them. "Attending to context, to place, to temporality, is perhaps one of the strongest ways that educational researchers can interrupt coloniality" (Patel, 2016)

The second aim stems from the contested conceptualisations of disability described within Critical Disability Studies. Disability has been contestedly described as a cultural conceptualisation from the Global North. It is a construct utilised in psychology, in medicine, in disability studies, in education, in psychiatry, in sociology and in many disciplines and academic study areas (Parker, 2007). Western science has described disability as differences residing in an individual as measured against a modernist conceptual idea of what it is to be a normal human being. Critical Disability Studies very broadly have critiqued the human sciences of development, on the one hand, for posturing conceptualisations as decontextualised objective truths and not as theoretical frameworks for understanding development; and on the other hand, for focusing the causations of deviations from the norm as centered solely in the individual and not the environment and/or the injustices in modern society. Thus, Critical Disability Studies contest and reexamine the conceptualisations of disability. "A reductionist approach to knowledge acquisition suppresses complexity and views difference and diversity as problematic, thereby turning 'the Other into the same' "(Moss, 2014). How do these various conceptualisations and contested notions sit within the Latin American context?

The third thread is looking at disability from a decolonial stance to understand from a contextualised local perspective the embodied disabilities that are the lived experiences of migrating children. Latinamerican decolonial thought questions the continued hegemony in the western polarisation of the scientific universalisms of western modernity and the skepticism and decentralisation of postmodernity (Lander, 2000). How do decolonial lenses help us understand how disability is conceptualised in the practices in Latin America? Are these

practices colonial in nature and how do they impact the inclusion of disabled children and their families in forced migration from Venezuela to Colombia? How are these children seen through Latin American/Colombian eyes ? More specifically how are their disabilities perceived by the children themselves and their families? How are they perceived by the support workers in charity and educational institutions? How are these perspectives similar or different to western disability models? How do these perceptions impact their inclusion in a new country and in educational contexts. How does forced migration impact and shape children's disability? Decolonising disability is an area of research that is burgeoning and looking at the intersectionality with forced migration offers a context rich in intercultural exploration, a relevant context for a decolonial contesting of the Western hegemony on what it is to be human.

Ultimately it is the knowledge and views of the research community (participants and researcher) that will lead the research, so the questions are a starting point of a dialogue and a collaborative form of inquiry. How is disability/diversity conceptualised? Is it conceptualised? Are the hegemonic conceptualisations of disability from the west being used/resisted in these communities? How does internalising/resisting hegemonic conceptualisations of disability from the west affect the nature of inclusion in this context? What are the systems put in place in this context to support inclusion of migrant disableed children? These questions for this research arise from weaving together the threads of critical disability and the decolonial project. The possibility of exploring methodologies for decolonising disability and migration is the hope that drives the research. The pervasive hegemonic Western lens persists in placing disability migration problems as centered in the individual and as a burden to society. This oppression is conceptual but equally it is a lived oppression that is material, reproduced in the bodies of children, and the lived experiences of their families. This oppression is produced within economic abuse and extortion of the colonised (Meekosha & Soldatic, 2011). It is also produced in the segmentation of research and theorisation of disabled migrant children. "Migration theory grows without the disabled person, disability studies without the migrant, and practice without the disabled migrant." (Pisani & Grech, 2015). The power dynamics of oppression are multilayered. In the creation of knowledge about who we are as humans we need to ask ourselves: Who defines what it is to be human? Who decides what are the categories to be used? How do these forms of knowledge affect the lives of people and their inclusion and status in 'human' society? Decolonising proposals move away from viewing the poverty-stricken disabled migrants as 'others'. Forced migration is a social process where human agency and social networks play a major role. Self-narratives can question the othering and individualisation of migrant experiences (Caroll, 2017). Questioning how migration tends to be studied as a South to North phenomenon, in western lenses of integration and closing of borders. Understanding a south to south migration, within the Latinamerican continent is essential in the context of the mass migration of Venezuelans to other Latinamerican countries. Resistance to an exclusive western epistemic knowledge system is the background to the research questions. These questions will necessarily change through the dialogic process around the needs and priorities of the communities I hope to engage with. They will cease to be my questions and change to other questions: our questions.

2. Methodology

The decolonising methodology that is being formulated in Latin America has as its starting point the socio-political views of the participants, they question and act within the research to achieve their own development goals. One important objective of this research is to create community research spaces to reflect on disability, diversity and forced immigration together with participants through their own spoken narratives (Ferrada & Del Pino, 2017). The research postulates the use of decolonial theoretical threads to explore disability and forced migration to construct knowledge with the research participants that is local and contextual (Attiaa & Edgeb, 2017). It is open ended research that can only be constructed collectively, it can be described as community based dialogic research, where the participants are invited to formulate the questions and issues of concern (Fals-Borda, 1987). In the last decades, the social model of disability and the frameworks it has engendered within critical disability studies has led to research approaches where people with disability are seen as researchers and experts of their lived experiences (Goodley, 2014; Shakespeare, 2008). The role the researcher-expert who controls every aspect of the research, from question formulation to analysis, has changed to the role of a facilitator who sits on equal pegging with the participants (Richards, Lawthom & Runswick-Cole, 2018; Runswick-Cole, 2014; Broderick & Ne'Eman, 2008; Sinclair, 1993). Both these approaches: decolonising and critical disability studies inform the methodology as dialogic and participatory. The design of this research is based on open forums to define collective research questions, ways to collect information and ways to disseminate the stories collected. This will be decided with the participants and all impacting issues around confidentiality and anonymity with be decided together in an ongoing continuous consensual dialogue.

Pilot Study:

A conversation with a migrant family in The Netherlands with a child with disabilities. This pilot will have a focus on four aspects:

1. Rehearsing collaborative conversations around research question making
2. Trying out ways to write a narrative together with the participants- tell their story with the participants
3. Try out the children's activities with the child/children
4. Gain experience in the use of the technology for video and audio recording

The research plan:

Invitation to collective conversations (focus groups) with Venezuelan families with disabled children living in Colombia, charity workers supporting migrating families and educators in Colombian schools receiving Venezuelan disabled children. University lecturers of a teacher training degree in Bogota will also be interviewed. Children who have parental consent and wish to join will be invited to take part in individual and/or collective activities of map drawing, taking photos and drawing to describe their schools and communities they are living in.

Week One: First encounters (Conversations will be documented via video recordings and photos.)

*Adults from charity organisations, Venezuelan families and educators to join two group sessions to share stories and co-formulate issues and questions. Participants will be invited to use single use cameras during the week to document images that they deem important to the issues they raise.

*Group sessions with children (families present as they wish): Getting to know the children activity. Children will be given cameras to take photos of their daily lives if they wish to share the following session.

*Individual interview with university lecturer No.1

Week Two: Dialogue on research questions (Conversations will be documented via video recordings and photos.)
*Focus group sessions with adults (charity and school staff, teachers, families) focusing on continuing to share own stories, dialogue around the migration/disability stories, and threads of interest to the group. Photos they have taken will be used during the session as conversation prompters.
*Group sessions with children (families present as they wish) choice of activities where children's words are documented:
1. Walkabout-guided tour of their school, home or community
2. Children's drawings and/or map making of their move from Venezuela to Colombia
3. Children share and tell about the photos of their daily lives in their school, home or community, that they took during the week.
*Individual interview with university lecturer no.2

Week Three and Four: Revisiting Colombia a few months later. Dialogue on shared narratives and if/how to share with their community
*Focus group sessions with adults (charity and school staff, families): reflection and follow up of their stories. Dialogue on if and how to share their stories.
*Group sessions with children (families present as they wish): Activity to make posters with their photos, maps and drawings from previous sessions and new drawings with children's words documented
*Individual interview follow up with both university lecturers

3. Personal Safety

Have you completed your departmental risk assessment procedures, if appropriate?

Yes

Raises personal safety issues?

Yes

The field work will be conducted in Colombia through two charity foundations working with Venezuelan migrants into Colombia working in Bogota- capital city and Cucuta - border town. Bogota is the capital city where most migrants are walking towards to settle, and Cucuta, the most used border for entering Colombia from Venezuela where the researcher has extensive contacts and will be accompanied by known local guides. All research is being planned to take place within the charity and or educational institutions during work hours and a field work contact system will be in place as well as having the local guide available for all transportation. Furthermore, I am Venezuelan with Colombian family and am familiar with the overall cultural norms of interactions around social/gender/political relations, the exodus of my fellow Venezuelans, and am in continual readings of codes of Practice for the Safety of Social Researchers, including reviewing codes from Colombian Universities. I attach a risk assessment form in the attachments section.

Section D: About the participants

1. Potential Participants

1. Potential Participants
Participants are members of the school, charity and university communities I am approaching. The research involves five groups of participants:
*the children identified to the charity groups as disabled,
*parents or guardians of the children,
*educational staff at schools,
*charity workers in daily contact with the migrating families and
*university lecturers at a teacher training course.
The main criteria to join the research is to have lived experience of supporting people and/or living through the process of migrating into Venezuela for families with disabled children. Children participants will be invited to join in sessions with activities where they can tell stories of their migration and daily school life through different media. University lecturers will be invited by direct email and invited to individual interviews. Adult participants that sign up will be invited to join in focus group conversations around the themes of disability/learner diversity, migration and their experiences of support and inclusion into Colombian society and school system. These can include family members, charity workers and/or educational staff.

2. Recruiting Potential Participants

Through the charity groups invitations will be sent out in advance describing the research and inviting potential participants to come forward. Also during some events of the charity groups invitations will be posted.
The information invitation letter (attached) will set out the purpose of the research, how to make contact with the researcher to indicate their interest. As potential participants make contact they will then receive the Consent and Confidentiality forms (attached) for their consideration via email or in person at the charity and the researcher will be available by email and/or by phone to answer further questions as well as being present at certain dates at the charity location.
Children whose parents have given previous consent for them to participate will then receive information in a session to give their consent. The invitation will describe three different activities for them to join in to tell me about their daily life: plan and give a school tour, take photos of their school and/or make a map/drawing of their school. The invitation information session will include consent procedures

and picture forms.

The university lecturers will be contacted individually and information and consent forms shared via email.

For all participants consent will be ongoing, they will receive participant information sheets, consent forms and a meeting arranged with the researcher in which they are encouraged to ask questions about the interviews and raise any ethical concerns. They will also be encouraged to contact the researcher confidentially to discuss anything prior to consenting to take part.

2.1. Advertising methods

Will the study be advertised using the volunteer lists for staff or students maintained by IT Services? No

- not entered -

3. Consent

Will informed consent be obtained from the participants? (i.e. the proposed process) Yes

Information will be sent out across the migration population that the charities' serve to garner interest from families, parents or guardians. This information will contain the contact details of the researcher. Adults who would like to join the focus group and/or parents who give consent for their children to participate will receive participant information sheets and a meeting arranged with the researcher in which they are encouraged to ask questions about the research, consent, confidentiality and raise any concerns. They will also be encouraged to contact the researcher individually and confidentially to discuss any questions or concerns prior to consenting to take part. Children will only be invited if their parents have agreed in their taking part. Children's consent will then be requested and it will be highlighted they can leave the research any time they wish. Participation information letters and consent forms are attached. It is important to take into consideration that some participants may not be able to read and write. In these cases consent will be taken orally and documented via audio or video to be seen only by the researcher and her supervisor. The forms for children and teenagers have images to communicate information. It will be made clear at all stages that participants can change their mind and withdraw up until the moment of data analysis, and that their information will be anonymised at all times.

Another area of consideration around consent responds directly to the participative nature of the research. The intention of inviting participants to be part of the research question process as well as how their stories will be told could imply a further use of their voice and image recorded during the interviews. If the decision of sharing their stories through the media of video, photos and/or voice should arise further considerations around consent and confidentiality are being taken into account. Participants will continuously be able to choose how much of the recorded material is used and what parts of their stories will be included. Equally ongoing consent will be offered at all times on whether they wish to share their stories outside of the research context in other academic contexts in ways where they could be identified . When the participants are children double consent will be sought first from parents and then from the children themselves. In these cases identifying data such as names and faces will be obscured and hidden always- children may change their mind later as they grow up and not want to be recognisable, this way their anonymity can be preserved.

4. Payment

Will financial/in kind payments be offered to participants? Yes

No financial payments will be offered, however participants will be offered opportunities within the sessions to ask about sources of information for issues they need. Also following the charities guidelines, participants will be offered meals before or after sessions. This will not be advertised but offered in the sessions. (Families in these precarious circumstances who are giving up their time to join will need to be fed. This custom of offering food is culturally expected and routinely offered).

5. Potential Harm to Participants

What is the potential for physical and/or psychological harm/distress to the participants?

There is a potential for psychological distress to the participants, given the sensitive nature of the experiences of migration, of being accepted in a new country/community, feeling included, having children who may not be accepted, have difficulties adapting due to their disabilities as well as the re-living their stories of forced migration. Families will be supported in the process by the researcher and the charity staff.

How will this be managed to ensure appropriate protection and well-being of the participants?

If a parent or guardian, child or teacher is uncomfortable or distressed during an interview or group conversation, the session will be stopped and a designated trusted member of the charity staff will be available to discuss the matter with the affected person. Participants are free to withdraw from the research at any time and without penalty. The lives of forced migrants are difficult and stressful. This will be taken into consideration when arranging the time and place to meet and duration of the focus groups, interviews and/or children's activities. Charity safeguarding protocols will apply throughout the research process and institutional and national practices will be adhered to, to ensure family and children safety and compliance with charity policy.

6. Potential harm to others who may be affected by the research activities

Which other people, if any, may be affected by the research activities, beyond the participants and the research team?

- not entered -

What is the potential for harm to these people?

- not entered -

How will this be managed to ensure appropriate safeguarding of these people?

- not entered -

7. Reporting of safeguarding concerns or incidents

What arrangements will be in place for participants, and any other people external to the University who are involved in, or affected by, the research, to enable reporting of incidents or concerns?

- not entered -

Who will be the Designated Safeguarding Contact(s)?

- not entered -

How will reported incidents or concerns be handled and escalated?

- not entered -

Section E: About the data

1. Data Processing

Will you be processing (i.e. collecting, recording, storing, or otherwise using) personal data as part of this project? (Personal data is any information relating to an identified or identifiable living person).
Yes

Which organisation(s) will act as Data Controller?

University of Sheffield only

2. Legal basis for processing of personal data

The University considers that for the vast majority of research, 'a task in the public interest' (6(1)(e)) will be the most appropriate legal basis. If, following discussion with the UREC, you wish to use an alternative legal basis, please provide details of the legal basis, and the reasons for applying it, below:

What is the legal basis for processing my personal data?
According to data protection legislation, the legal basis applied in order to process personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). Further information can be found in the University's Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general.
Data protection information applies to personal information as defined in the General Data Protection Regulation (GDPR). This is understood as any information that can directly or indirectly help to identify a natural person: Name, ID number, personal address, online identifier or any physical, genetic, mental, economic, cultural or social identity. ' (Article 4(1) GDPR).
This ethics application includes the project methodological considerations around consent, confidentiality, data collection, anonymisation and pseudonymisation. Ongoing informed and participatory consent will be central to the research that is centered on participants as partners in the research process.
According to GDPR law the obligation of due diligence with the data relies on the data controller and the data processor. The researcher is the 'data processor', who 'processes personal data on behalf of the controller'. The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after the information and using it properly.

Will you be processing (i.e. collecting, recording, storing, or otherwise using) 'Special Category' personal data?
Yes

The University considers the most appropriate condition to be that 'processing is necessary for archiving purposes in the public interest, scientific research purposes or statistical purposes' (9(2)(j)) . If, following discussion with the UREC, you wish to use an alternative condition, please provide details of the condition, and the reasons for applying it, below:

N/A

3. Data Confidentiality

What measures will be put in place to ensure confidentiality of personal data, where appropriate?

The names and the roles of the participants and the names and locations of institutions will be protected at all times, including in any publication and dissemination of research findings in papers, seminars or conferences. Pseudonyms will be used during and after

interview data transcription. Data will be uploaded onto google drive in a password protected computer and/or a locked cupboard to which only the researcher will have access. All data and documents will be on the University's google drive server.

Following the dialogic and participative nature of this research participants will be invited to be involved in how their stories are told; the possibility of using their voices and images in photographs or videos may arise. In this case, decisions will be made together with participants about the use of their voices and images on audio, still photos and film. They will be encouraged to keep their names and contact details confidential and a conversation about the difficulty of guaranteeing anonymity will be implemented and documented. This will include decisions about how their recorded data is used, formats, editing rights, in what contexts it may be shared and the focus will remain on participants having the control of how much identifying information they want revealed in the possible audio-visual documentation of their stories.

4. Data Storage and Security

In general terms, who will have access to the data generated at each stage of the research, and in what form

The researcher will act as custodian of the data. Data analysis will take place on a password protected computer in the researchers' home or work place. Anonymisation in the form of pseudonyms will take place from transcription phase onwards.The researcher only has access to the data, all data will be stored on the University's google drive. If the data will be considered for future use in a follow up research project this will only happen with the consent of participants. The full details of any future follow up project will be made known to participants and a consent form deployed.

What steps will be taken to ensure the security of data processed during the project, including any identifiable personal data, other than those already described earlier in this form?

Primary data will only be accessible to the researcher. The researcher will store and carry out data analysis on password protected private computers. All electronic media and data such as interview transcripts or analysis, will be stored with password protection and encryption on all files. Video and audio recordings will be deleted 3 years after transcription. Any physical documents will be stored in locked cabinets which only the researchers will have access to. Any physical documents, which are scanned electronically will be stored under password protected and encrypted files.

In the case where participants choose to have their stories told through photos, audio or video recordings, as mentioned previously, data will continue to be anonymized to every extent possible. However documentation and filming will necessarily contain identifying data and information to allow the researcher to contact the participants regarding the use of the recorded material. The recordings themselves will contain identifying data. The literature and my experience through the charity organisations tends to indicate that forced migrants are often very interested in telling their stories and having them shared. In a participative and dialogic methodology every effort will be made for participants to be empowered in telling their story in their own way and sharing it how they see fit. Arising from a dialogic and participatory methodology the design of this research is based on open forums to define collective research questions and ways to collect information and share stories. The benefits and wishes to share must be balanced with the risks of losing anonymity and will be openly discussed in dialogue with the participants. balancing the risks with wishes they may express around the social and/or practical impact of telling their stories on how families of disabled children are supported and received in Colombia. The use of their data will remain in their control as a way to maintain safety. The participants are the experts of their lives and will be in control of how much identifying information they want revealed in any video/audio documentation.

Will all identifiable personal data be destroyed once the project has ended?
Yes

Please outline when this will take place (this should take into account regulatory and funder requirements).

All data such as interview transcripts or analysis and video/audio recordings, will be stored with password protection and encryption on all files, all data will be stored on the University's google drive. All data will be deleted 3 years after transcription. In the case of audio-visual stories being created with and by participants, only the stories themselves will be kept, all supporting data will be deleted. The storage of stories will be decided upon with participants, the researcher using university based IT for long term storage.

Section F: Supporting documentation

Information & Consent

Participant information sheets relevant to project?
Yes

Document 1070648 (Version 1) Information letter for adult participants	All versions
Document 1071203 (Version 1) Information letter for Teenager Participants	All versions
Document 1071202 (Version 1) Information Letter for Child Participants	All versions

Consent forms relevant to project?
Yes

Document 1070651 (Version 1) Consent form for Adults	All versions
Document 1071457 (Version 1) Consent form for Teenagers and their guardians	All versions
Document 1071456 (Version 1) Consent form for children and their guardians	All versions

Additional Documentation

Document 1073604 (Version 1) Fieldwork Risk Assessment form	All versions

External Documentation

- not entered -

Section G: Declaration

Signed by:
Elizabeth Arenas Thomas
Date signed:
Thu 12 December 2019 at 06:21

Offical notes

- not entered -

Appendix Two: Second Ethics Application (COVID Changes)

The University Of Sheffield.

Application 035970

Section A: Applicant details

Date application started:
Thu 9 July 2020 at 12:28

First name:
Elizabeth

Last name:
Arenas Thomas

Email:
earenas1@sheffield.ac.uk

Programme name:
DEd Psychology and Education- research not carried out due to COVID

Module name:
Dissertation- Not carried out due to COVID

Last updated:
06/08/2020

Department:
School of Education

Applying as:
Postgraduate research

Research project title:
The Open Borders of Latin America: Disabled at the Colombian/Venezuelan borders

Has your research project undergone academic review, in accordance with the appropriate process?
Yes

Similar applications:
The Open Borders of Latin America: Disabled Venezuelan Child Migration into Colombia

Section B: Basic information

Supervisor	
Name	**Email**
Katherine Runswick-Cole	k.runswick-cole@sheffield.ac.uk

Proposed project duration

Start date (of data collection):
Wed 15 July 2020

Anticipated end date (of project)
Sat 20 February 2021

3: Project code (where applicable)

Project externally funded?
N/A

Lander, 2000) and decolonising methodologies in social studies in Latin America (Ferrada y del Pino, 2017; Cusicanqui, 2012). Firstly, the initial aim of the research is an exploration of decolonising methodologies as a way to understand disability and forced migration within a Latin American context. The methodological decolonial stance is such that my objective is for the research questions to be guided, changed and reformulated, by and with participants in the context of shared narratives (Ferrada & Del Pino, 2017). As a Latin American researcher working within a European university my positionality is central to the methodological process. Dialogic reflexivity between the participants and myself will be the tool to weave the connections between their narratives and theoretical threads. Forced migrants live in ambiguous and unresolved situations that make telling their stories difficult whilst at the same time they need their stories to be heard and believed (Eastman, 2007). In Latin America oral traditions often are politically dynamic, keeping core values alive (fals-borda, 1987). The epistemological potential of storytelling is in its dialogue and how this focuses attention on the internal dynamics of the "subaltern". In this way Latin American knowledge is constructed through the community practice of oral tradition (Rivera Cusicanqui, 2016). To explore decolonial methodology, my intention is to seek digital means of entering into dialogic research with Venezuelan families, children and the charity workers that help them. "Attending to context, to place, to temporality, is perhaps one of the strongest ways that educational researchers can interrupt coloniality" (Patel, 2016) The participants well-being and autonomy of voice should be at the center of a project as the storytellers of their own stories. One of the many ethical issues to grapple with during this digital research is the ownership of the stories, the release of these stories needs to be iterative, negotiated and ongoing. Important ethical issues of digital research must include considerations of those excluded due to lack of access to digital tools, internet provision; the potential harm from reiterating stereotypes, and posiible revealing of engagement in illegal or dangerous activities (Gubrium, Aline C ; Hill, Amy L ; Flicke), 201. An important clarification is that the consent to participate cannot be equated to consent to share or disseminate stories, hence the decisions to share, the formats, the dissemination must all be ongoing and the ownership of the stories must be with the participants themselves.

The second aim stems from the contested conceptualisations of disability described within Critical Disability Studies (Goodley, Liddiard, Lawthom & Runswick Cole; 2017 & 2019). Disability has been contestedly described as a cultural conceptualisation from the Global North. It is a construct utilised in psychology, in medicine, in disability studies, in education, in psychiatry, in sociology and in many disciplines and academic study areas (Parker, 2007). Western science has described disability as differences residing in an individual as measured against a modernist conceptual idea of what it is to be a normal human being. Critical Disability Studies very broadly have critiqued the human sciences of development, on the one hand, for posturing conceptualisations as decontextualised objective truths and not as theoretical frameworks for understanding development; and on the other hand, for focusing the causations of deviations from the norm as centered solely in the individual and not the environment and/or the injustices in modern society (Shakespeare, 2014; Mallet & Runswick-Cole, 2014; Oliver, 2013). Thus, Critical Disability Studies contest and reexamine the conceptualisations of disability. "A reductionist approach to knowledge acquisition suppresses complexity and views difference and diversity as problematic, thereby turning 'the Other into the same' "(Moss, 2014). How do these various conceptualisations and contested notions sit within the Latin American context?

The third thread is looking at migration and disability from a decolonial stance to understand from a contextualised local perspective the embodied disabilities that are the lived experiences of migrating children. Latinamerican decolonial thought questions the continued hegemony in the western polarisation of the scientific universalisms of western modernity and the skepticism and decentralisation of postmodernity (Lander, 2000). How do decolonial lenses help us understand how disability is conceptualised in the practices in Latin America? Are these practices colonial in nature and how do they impact the inclusion of disabled children and their families in forced migration from Venezuela to Colombia? How are these children seen through Latin American/Colombian eyes? How are their disabilities perceived by the children themselves and their families? How are they perceived by the support workers in charity and educational institutions? How are these perspectives similar or different to western disability models? How do these perceptions impact their inclusion in a new country and in educational contexts. How does forced migration impact and shape children's disability? Decolonising disability is an area of research that is burgeoning and looking at the intersectionality with forced migration offers a context rich in intercultural exploration, a relevant context for a decolonial contesting of the Western hegemony on what it is to be human (Soudien, 2019; Beaudry, 2016).

Ultimately it is the knowledge and lived experiences of the research community (participants and researcher) that will lead the research, so the questions are a starting point of a dialogue and a collaborative form of inquiry. How is disability/diversity conceptualised? Is it conceptualised? Are the hegemonic conceptualisations of disability from the west being used/resisted in these communities? How does internalising/resisting hegemonic conceptualisations of disability from the west affect the nature of inclusion in this context? What are the systems put in place in this context to support inclusion of migrant disableed children? These questions for this research arise from weaving together the threads of critical disability and the decolonial project. The possibility of exploring methodologies for decolonising disability and migration is the hope that drives the research. The pervasive hegemonic Western lens persists in placing disability and migration problems as centered in the individual and as a burden to society. This oppression is conceptual but equally it is a lived oppression that is material, reproduced in the bodies of children, and the lived experiences of their families. This oppression is produced within economic abuse and extortion of the colonised (Meekosha & Soldatic, 2011). It is also produced in the segmentation of research and theorisation of disabled migrant children. "Migration theory grows without the disabled person, disability studies without the migrant, and practice without the disabled migrant." (Pisani & Grech, 2015). The power dynamics of oppression are multilayered. In the creation of knowledge about who we are and who we need to ask ourselves: Who defines what it is to be human? Who decides what are the categories to be used? How do these forms of knowledge affect the lives of people and their inclusion and status in 'human' society? Decolonising proposals move away from viewing the poverty-stricken disabled migrants as 'others'. Forced migration is a social process where human agency and social networks play a major role. Self-narratives can question the othering and individualisation of migrant experiences (Caroll, 2017). Questioning how migration tends to be studied as a South to North phenomenon, in western lenses of integration and closing of borders. Understanding a south to south migration, within the Latinamerican continent is essential in the context of the mass migration of Venezuelans to other Latinamerican countries. Resistance to one western epistemic knowledge system is the background to the research questions. These questions will necessarily change through the dialogic process around the needs and priorities of the communities I hope to engage with. They will cease to be my questions and change to other questions: our questions.

The language of communication of the research community will be Spanish, hence addressing the bilingual researcher's meaning making in the process of translation and interpretation from Spanish into English is an important ethical consideration (Shklarov, 2007). Ethical reflexivity on translation must be ongoing from the procedural ethics all the way to microethics during interviews and the written translation of participants' words. Reflexivity to remain sensitive to the ethics of cross language research with the implications and richness of subjective conceptual cultural understandings.

2. Methodology

The decolonising methodology that is being formulated in Latin America has as its starting point the socio-political views of the participants, they question and act within the research to achieve their own development goals. One important objective of this research is to create digital community research spaces to reflect on disability, diversity and forced immigration together with participants through their own spoken narratives (Ferrada & Del Pino, 2017). The research postulates the use of decolonial theoretical threads to explore disability and forced migration to construct knowledge with the research participants that is local and contextual (Attiaa & Edgeb, 2017). It is open ended research that can only be constructed collectively, it can be described as community based dialogic research, where the participants are invited to formulate the questions and issues of concern (Fals-Borda, 1987). In the last decades, the social model of disability and the frameworks it has engendered within critical disability studies has led to research approaches where people with disability are seen as researchers and experts of their lived experiences (Goodley, 2014; Shakespeare, 2008). The role the researcher-expert who controls every aspect of the research, from question formulation to analysis, has changed to the role of a facilitator who sits on equal pegging with the participants (Richards, Lawthom & Runswick-Cole, 2018; Runswick-Cole, 2014; Broderick & Ne'Eman, 2008; Sinclair, 1993). Both these approaches: decolonising and critical disability studies inform the methodology as dialogic and participatory. The design of this research is based on open forums to define collective research questions and ways to collect information. The design of the research is focused on uncovering the experiences of migrating families with children with disabilities in a respectful space to uphold their wishes, their stories, their choices; with continuing shared ethical reflexivity (Akesson &co, 2018).

The research plan: this research plan has been modified due to COVID-19 pandemic from face to face dialogues in Colombia to online conversations with adult members of venezuelan migrant families with young children or children with disabilities, members of the charity foundation, professionals working with families (doctors, teachers, psychologists) and academic researchers in universities. No children will now be involved in the research. Only adults. Due to the changing nature of the situation at present due to COVID the investigation could include families in Colombia, returnee families in Vzla, families separated with members living in different countries, families on the move. The changing nature of the present pandemic results in placing vulnerable people in an even more vulnerable unstable environment; walkers walking back thousands of kilometers, retracing themselves or families with no option but to live on the streets. It is a moment to deliberate not on the ethics of doing research during a pandemic but rather on the ethics of not doing research, not raising awareness, of contemplating what is the human objective of doing research.
Invitation to collective conversations (focus groups) with migrating Venezuelan families with disabled children living, charity workers supporting migrating families and professionals working with families. Academic researchers will also be interviewed.
Week One: First encounters (Call out for participants via a charity organisation social media sites)
Venezuelan migrant families will be invited to join a live information meeting where the Information of the research and consent guidelines will be shared. Questions will be addressed to ensure understanding on confidentiality and anonymity
Academic researchers and charity workers will be invited to join a live information meeting where the Information of the research and consent guidelines will be shared. Questions will be addressed to ensure understanding on confidentiality and anonymity
Invitations will be sent through the researcher's university email to Venezuelan families who show an interest to join two group sessions to share stories and co-formulate issues and research questions.
Invitations will be sent through the researcher's university email to academic researchers and professionals who show an interest to join two group sessions to co-formulate issues and research questions.
Invitations will be sent through the researcher's university gmail account (on the google icloud platform provided by the University of Sheffield) to charity workers who show an interest to join two group sessions to co-formulate issues and research questions
Previous to the sessions in week two each volunteer adult member will have a digitally recorded conversation and share their consent or not to participate. This will be documented via virtual online video recordings of the meetings through the researcher's university google meet application. These recordings will be deleted one year after publication of the dissertation.

Week Two: Dialogue on migration with disability stories and formulating research questions (Conversations will be documented via video recordings and photos.) Adult members of the families will be invited to digitally join with a charity member that is familiar to them if they wish, these sessions will be in groups.
Focus group sessions with adults (charity staff and families) focusing on sharing their own stories of migration, dialogue around the migration/disability stories, and threads of interest to the group. They will be invited to bring photos to the next session of issues that they have raised. These will be used during the second session as conversation prompters.
Individual interview sessions with academic researchers on formulating research questions around migration and disability.

Week Three and Four: Revisiting stories, sharing photos and dialogue on shared narratives and if/how to share with their community
Focus group sessions with adults (charity and families): reflection and follow up of their stories.
Use photos they bring as anchors to the conversation
Dialogue on how to share their stories in the research: format and structure. Possibilities could include: first hand narratives, fictionalised stories written by the researcher integrating their spoken experiences, verbatim oral play based on recorded group interview conversations,etc. To be decided together.
Group interview follow up with academic researchers (3-4 university lecturers depending on interest generated in week one)

3. Personal Safety

Have you completed your departmental risk assessment procedures, if appropriate?

No

Raises personal safety issues?

No

The field work will be conducted exclusively online through two charity foundations working with Venezuelan migrants in Colombia in Bogota- capital city, in Cucuta - border town, in San Antonio Vzla. Bogota is the capital city where most migrants are walking towards to settle, and Cucuta and San Antonio are the border towns on the most used border for entering Colombia from Venezuela where the researcher has extensive contacts. The foundations have other locations that could be involved but initially these are the focus centres. All research is being planned to take place online. If any safety issues could arise for myself as main researcher they would be in the area of mental well being, but not doing the research would result in more emotional issues than tackling them in ways that I hope will bring some benefit in raising awareness. I have plenty of support around me.

Section D: About the participants

1. Potential Participants

The research involves three groups of participants:, parents or guardians of the children identified to the charity groups as disabled, charity workers in daily contact with the migrating families and; professionals and university lecturers who work in the fields of interest around disabilities, decoloniality, and /or migration. Participants are members of the charity and university communities I am approaching. The main criteria to join the research is to have lived experience of supporting people and/or living through the process of migrating from and into Venezuela for families with disabled children.
Adult participants that sign up will be invited to join in focus group conversations around the themes of disability/learner diversity, migration and their experiences of migration and support. They will be invited to three sessions. These can include family members and/or charity workers.
University lecturers and professionals will be invited by direct email and invited to one individual interview and one group conversation.

2. Recruiting Potential Participants

Through the charity groups there will be invitations sent out in advance describing the research and inviting potential participants to come forward. Also during some digital events that the charity groups carry out invitations will be posted. Those interested will be invited to join a digital virtual meeting where research and consent information will be shared. Each person who decides to join will be invited to a short digital meet of consent that will be recorded with the university google app. Forms sent by email will also be sent so participants can choose a written or oral consent documentation.
The university lecturers and professionals will be contacted individually and information and consent forms shared via email.
The invitation (attached) will set out the purpose of the research, how to make contact with the researcher to indicate their interest. As potential participants make contact they will then receive the Consent and Confidentiality forms (attached) for their consideration via email or preferred media. The researcher will be available on google meets at certain times and dates of week one to answer further questions. The invitation information session will include consent procedures and picture forms.
For all participants consent will be ongoing, they will receive participant information sheets, consent forms and a meeting arranged with the researchers in which they are encouraged to ask questions about the interviews and raise any ethical concerns. They will also be encouraged to contact the researchers confidentially to discuss anything prior to consenting to take part.

2.1. Advertising methods

Will the study be advertised using the volunteer lists for staff or students maintained by IT Services? No

- not entered -

3. Consent

Will informed consent be obtained from the participants? (i.e. the proposed process) Yes

With the charities' collaboration, information will be sent out across the migration population they serve to garner interest from families, parents or guardians. This information will contain the contact details of the researcher. Adults who would like to join the focus group will receive an invite to a live participant information session and an online meeting arranged with the researcher in which they are encouraged to ask questions about the research, consent, confidentiality and raise any concerns. They will also be encouraged to contact the researcher individually and confidentially to discuss any questions or concerns prior to consenting to take part.
Participation information letters and consent forms will be shared digitally and are attached here. It is important to take into consideration that some participants may not be able to read and write, or might not have access to easily view documents online. In these cases consent will be taken orally and recorded via digital video to be seen only by the researcher and her supervisor. This will be done on the university's google meet application. It will be made clear at all stages that participants can change their mind and withdraw up until the

moment of data analysis, and that their information will be anonymised at all times.

No financial payments will be offered, however participants will be offered within the sessions opportunity to ask about sources of information for issues they need. Also following the charities guidelines, participants will be offered information about where to access humanitarian aid. This will not be advertised but offered in the sessions.

4. Payment

Will financial/in kind payments be offered to participants? No

5. Potential Harm to Participants

What is the potential for physical and/or psychological harm/distress to the participants?

There is a potential for psychological distress to the participants, given the sensitive nature of the experiences of migration, of being accepted in a new country/community, feeling included, having children who may not be accepted, have difficulties adapting due to their disabilities as well as the re-living their stories of forced migration. The pandemic has put these families under even more duress due to lack of income, health access, sanitary access and a general lack of basic necessities. The bridge of the researcher to the participants through the foundation enables information, support and resources to be offered at this crisis moment. Families will be supported in the process by the researcher and the charity staff.

How will this be managed to ensure appropriate protection and well-being of the participants?

If a parent or guardian,or charity worker is uncomfortable or distressed during an interview or group conversation, the session will be stopped and a designated trusted member of the charity staff will be available to discuss the matter with the affected person. Participants are free to withdraw from the research at any time and without penalty. The lives of forced migrants are difficult and stressful. This will be taken into consideration when arranging the time and place to meet and duration of the group sessions. Charity safeguarding protocols will apply throughout the research process and institutional and national practices will be adhered to, to ensure family and children safety and compliance with charity policy. As a researcher associated with the foundation Fundacolven I will be going through the same training given online to volunteer workers for the foundations provided by FUPAD: FUNDACIÓN PANAMERICANA PARA EL DESARROLLO.

Section E: About the data

1. Data Processing

Will you be processing (i.e. collecting, recording, storing, or otherwise using) personal data as part of this project? (Personal data is any information relating to an identified or identifiable living person).
Yes

Which organisation(s) will act as Data Controller?

University of Sheffield only

2. Legal basis for processing of personal data

The University considers that for the vast majority of research, 'a task in the public interest' (6(1)(e)) will be the most appropriate legal basis. If, following discussion with the UREC, you wish to use an alternative legal basis, please provide details of the legal basis, and the reasons for applying it, below:

A task in the public interest.

Will you be processing (i.e. collecting, recording, storing, or otherwise using) 'Special Category' personal data?
Yes

The University considers the most appropriate condition to be that 'processing is necessary for archiving purposes in the public interest, scientific research purposes or statistical purposes' (9(2)(j)) . If, following discussion with the UREC, you wish to use an alternative condition, please provide details of the condition, and the reasons for applying it, below:

Processing is necessary for archiving purposes in the public interest, scientific research purposes or statistical purposes'

3. Data Confidentiality

What measures will be put in place to ensure confidentiality of personal data, where appropriate?

The names and the roles of the participants and the names and locations of institutions will be protected at all times, including in any publication and dissemination of research findings in papers, seminars or conferences. Pseudonyms will be used during and after interview data transcription.

4. Data Storage and Security

In general terms, who will have access to the data generated at each stage of the research, and in what form

Data will be stored in a password protected computer and/or a locked cupboard to which only the researcher will have access. Data will be stored on the researchers University of Sheffield's google account, this account is password and username protected on a computer that is password protected with two factor Authentication.

What steps will be taken to ensure the security of data processed during the project, including any identifiable personal data, other than those already described earlier in this form?

Conversations with the participants will be video recorded as well as documented through video on the universities platforms through google meet. These will be used by the researcher for data analysis in ways agreed upon with the participants during the research process. Primary data will only be accessible by the researcher saved on the universities google services.

Will all identifiable personal data be destroyed once the project has ended?
Yes

Please outline when this will take place (this should take into account regulatory and funder requirements).

Once transcribed and anonimised primary data will be deleted.

Section F: Supporting documentation

Information & Consent

Participant information sheets relevant to project?
Yes

Document 1081560 (Version 1)	All versions
Adult participant information letter	

Consent forms relevant to project?
Yes

Document 1081561 (Version 1)	All versions
Online Consent form for Adults	

Additional Documentation

External Documentation

- not entered -

Section G: Declaration

Signed by:
Elizabeth Arenas Thomas
Date signed:
Thu 9 July 2020 at 13:17

Offical notes

- not entered -

Las fronteras abiertas de América Latina: La migración de familias venezolanas hacia Colombia

Información para participantes: Padres o tutores, personal y/o voluntarios que trabajan

Se le invita a participar en una investigación sobre la migración infantil venezolana hacia Colombia. Es importante que usted entienda por qué se está haciendo la investigación y lo que se le solicita, para que pueda elegir si participar o no. Por favor, tómese el tiempo necesario para leer la siguiente información detenidamente y discútala con otras personas si lo desea. No dude en preguntarme si hay algo que no entiende o si desea más información. Gracias por tomarse el tiempo de leer esta hoja de información para el participante.

¿Cuál es el objetivo de la investigación? Esta investigación busca registrar las diversas experiencias de las familias migrantes venezolanas con niñes incluyendo aquellos con diversidad de aprendizaje y/o discapacidades. La intención es aprender de las familias, escuchar sus historias y proponer formas de divulgar para poder ayudar a los migrantes a ser mejor comprendidos. Quiero aprender de sus experiencias de migración e integración en la sociedad colombiana. **¿Cuál ha sido su experiencia sobre el acceso a la integración en la comunidad? ¿Cual ha sido la experiencia de integración escolar o acceso a servicios básicos como salud, u otros apoyos que han necesitado como familia? ¿Cómo son recibidos, aceptados, apoyados e incluidos en la sociedad colombiana?** Esta investigación es colaborativa y quiero escuchar de Ud las preguntas que considere importantes en base a sus experiencias.

¿Quién llevará a cabo la investigación? Mi nombre es Elizabeth Arenas Thomas, soy profesora y psicóloga de Venezuela, vivo y trabajo en Europa. Mi investigación forma parte del programa para obtener un doctorado en Educación y Psicología en la Universidad de Sheffield en el Reino Unido. Invitaré a voluntarios o trabajadores de fundaciones y a familias a participar en conversaciones de grupo e individuales.

¿Por qué he sido seleccionada/o/e? Se han invitado adultos migrantes de familias venezolanas y aquellos que trabajan con familiares y niñes en toda su diversidad incluyendo aquellos con discapacidad y/o diferencias de aprendizaje para participar en conversaciones.

¿Estoy obligado a participar? No, usted decide si participa o no. Su participación es totalmente voluntaria. **¿Qué tengo que hacer?** Se le invita a participar en conversaciones de grupo y/o individuales, le haré preguntas y le invitaré a compartir sus opiniones, preocupaciones e historias.

¿Me grabarán y cómo se utilizarán las grabaciones? Las grabaciones de vídeo o audio de nuestras conversaciones realizadas durante esta investigación se utilizarán únicamente para su análisis. No se hará ningún otro uso de ellas sin su permiso por escrito, y nadie ajeno al proyecto podrá acceder a las grabaciones originales. Las grabaciones serán anónimas para que no se pueda localizar a los participantes. Sólo se utilizarán las transcripciones

escritas en presentaciones de conferencias o charlas. Algunas de nuestras conversaciones serán en persona y otras podrán ser por vía digital.

¿Cuáles son las posibles desventajas y riesgos de participar? No puedo prever ninguna desventaja o riesgo por participar en esta investigación. Sin embargo, a veces reflexionar sobre nuestras vidas puede resultar angustioso, o podría estar expuesto a pensamientos y sentimientos de otras personas, por ejemplo, en torno a la exclusión y la discriminación, historias que podrían ser dificil de escuchar.
No tiene que responder a todas las preguntas de las conversaciones; tiene derecho a no responder a las preguntas si así lo desea.

¿Qué obtendré con mi participación? Participar en estas conversaciones es una oportunidad para contar su historia y contribuir a este proyecto de investigación que pretende comprender la vida de las familias desplazadas venezolanas y darles voz sobre su situación, en particular la integración de los niñes en la comunidad de acogida..

¿Qué sucede si el proyecto de investigación se detiene antes de lo previsto? Aunque es poco probable, si por alguna razón el proyecto de investigación se detiene antes de lo previsto, se le ofrecerá una explicación completa y clara del motivo.

¿Qué ocurre si algo no me gusta? Si cree que algo ha ido mal o quiere plantear una queja, póngase en contacto conmigo: earenas1@sheffield.ac.uk. Si cree que su queja no ha sido tratada adecuadamente, puede ponerse en contacto con mi tutora, la profesora K. Runswick Cole.
Si sigue pensando que su queja no ha sido atendida, puede ponerse en contacto con la Directora del Departamento de la Escuela de Educación de la Universidad de Sheffield, la profesora Elizabeth Wood, que elevará la queja a los canales adecuados. Datos de contacto:
- Profesor Runswick Cole Cátedra de Educación Correo: k.runswick-cole@sheffield.ac.uk
- Profesora Elizabeth Wood Directora de la Escuela Correo: e.a.wood@sheffield.ac.uk
   La Escuela de Educación, Edgar Allen House, Universidad de Sheffield, 241 Glossop Road, Sheffield, S10 2GW Tel: +44 (0) 114 222 8172

Si su queja está relacionada con el tratamiento de sus datos personales, puede encontrar información sobre cómo presentar una queja en el Aviso de Privacidad de la Universidad:
https://www.sheffield.ac.uk/govern/data-protection/privacy/general

¿Se mantendrá la confidencialidad de mi participación en este proyecto? Como participante en la investigación, su participación en el proyecto será estrictamente confidencial. No se le identificará en ningún informe o publicación cuando redactemos los resultados de la investigación. Le daremos un seudónimo (por ejemplo, un nombre falso). Sin embargo, si me cuenta algo que me preocupa, por lo que Ud. está en peligro o en grave riesgo, es posible que tenga que compartirlo con otra persona, como un profesional o alguien de su confianza. Le haré saber si tengo previsto hacerlo. Sus datos (el relato de su entrevista) sólo los veré yo y los compartiré de forma anónima con mi tutor de la Universidad de Sheffield: Profesor Runswick-Cole.

¿Qué pasará con la publicación del proyecto de investigación? Tengo previsto compartir los relatos de diferentes maneras para garantizar que se compartan las historias que usted desea que se cuenten. Será un proceso de colaboración continuo. En primer lugar, tengo previsto publicar la investigación en mi disertación, la presentaré en revistas académicas y quizás comparta algunas secciones en conferencias internacionales. También se puede compartir con personas a quién Ud escoja si así lo desea (responsables políticos, directores de escuelas, fundaciones en Colombia, profesores, padres, niñes de su comunidad escolar o miembros de otras comunidades escolares que trabajan con y para niñes con diversas necesidades de aprendizaje).

¿Quién ha revisado éticamente el proyecto? Este proyecto ha sido aprobado éticamente a través del procedimiento de revisión ética de la Facultad de Educación de la Universidad de Sheffield. El Comité de Ética de la Investigación de la Universidad supervisa la aplicación y el cumplimiento del Procedimiento de Revisión Ética de la Universidad.

¿Cuál es la base legal para el tratamiento de mis datos personales? De acuerdo con la legislación sobre protección de datos, estamos obligados a informarle de que la base jurídica que aplicamos para tratar sus datos personales es que "el tratamiento es necesario para el cumplimiento de una misión de interés público" (artículo 6, apartado 1, letra e)). Puede encontrar más información en el Aviso de Privacidad de la Universidad https://www.sheffield.ac.uk/govern/data-protection/privacy/general

La Universidad de Sheffield actuará como responsable del tratamiento de los datos de este estudio. Esto significa que la Universidad es responsable de cuidar su información y utilizarla adecuadamente.

Si tiene alguna pregunta sobre el estudio, póngase en contacto conmigo:
Elizabeth Arenas Thomas earenas1@sheffield.ac.uk

Si ha leído la carta de invitación y está dispuesto a participar, por favor ponga sus iniciales para las actividades y firme su consentimiento.

Actividades	Iniciales
Confirmo que he leído la carta de invitación adjunta (Fecha: ___/_____/2022) para el estudio arriba mencionado y que he tenido la oportunidad de considerar la información y hacer preguntas y que éstas han sido respondidas satisfactoriamente.	
Entiendo que mi participación en el estudio es voluntaria y que soy libre de retirarme en cualquier momento sin dar una razón y sin perjuicio para mí. Entiendo que no será posible eliminar mis datos del proyecto una vez que hayan sido anonimizados y formen parte del conjunto de datos. Acepto participar sobre esta base	
Acepto que las entrevistas y las conversaciones de los grupos de discusión sean grabadas en audio/vídeo. Entiendo que esto es sólo para la recopilación de datos.	
Acepto que los datos recogidos puedan publicarse de forma anónima en libros, informes o revistas académicas	
Estoy de acuerdo en que el investigador conserve mis datos de contacto para proporcionarme un resumen de los resultados de este estudio.	
Entiendo que puede haber casos en los que durante el transcurso de las entrevistas/grupos de discusión se revele información que obligue a los investigadores a romper la confidencialidad, lo cual se ha explicado con más detalle en la hoja informativa.	
Acepto participar en este estudio	

_____ _____
Nombre del Participante Firma Fecha

_____ _____
Nombre de la persona Firma Fecha
toma de consentimiento

El investigador guardará una copia firmada del formulario de consentimiento de forma segura y usted, el participante, se quedará con una copia.

The Open Borders of Latin America: Venezuelan Child Migration into Colombia
Participant Information for Adults
(Parents or guardians, Charity staff and School staff)

You are being invited to participate in a research called **The Open Borders of Latin America: Venezuelan Child Migration into Colombia.** It is important for you to understand why the research is being done and what it will involve, so you can choose whether or not to take part.

Please take time to read the following information carefully and discuss it with others if you wish. Feel free to ask me if there is anything that you do not understand, or if you would like more information. Thank you for taking the time to read this Participant Information Sheet. This information is for yourself and your child should they participate in the study as well.

Elizabeth Arenas Thomas
earenas1@sheffield.ac.uk Doctoral
Researcher DEd Psychology and
Education University of Sheffield

What is the research's purpose? In this research I am looking to understand the experiences of Venezuelan migrant families with children who have learning diversity and/or disabilities. I would like to learn from families and other adults in support roles. I would like to listen to your stories so we can help migrants be better understood. I want to learn from your experiences of migrating and integrating into Colombian society. How are disabilities and learning differences accepted in your new community and what is your experience of the access to inclusive schooling? This research is collaborative and I want to hear from you what questions you think are important to be asked based on your experiences.

Who will conduct the research? My name is Elizabeth Arenas Thomas, I am a teacher and a psychologist from Venezuela, living and working in Europe. My research is part of the program to obtain a doctoral degree in Education and Psychology at the University of Sheffield in the UK. I will be visiting Colombia in December and March 2019 and inviting participants to take part in individual and/or focus group interviews. I am interested in learning what is the experience of Venezuelan

children with disabilities or differences and of their families. How are you received, accepted and included in Colombian society and schools?

Why have I been chosen? I want to invite Venezuelan migrant adults who are family members or who work with children with disabilities to participate in individual and group conversations. I am asking you to participate because of your professional and /or migrant family experience of living with and/or supporting a child with a disability and/or learning differences.

Do I have to take part? No, it is completely up to you whether you take part or not. Your participation is entirely voluntary.

What do I have to do? You will be invited to participate in group and/or individual conversations, I will ask questions and invite you to share your opinions, concerns and stories.

Will I be recorded, and how will the recorded media be used? The video or audio recordings of our conversations made during this research will be used only for analysis. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings. They will be anonymised so you are not traceable. Only written transcripts will be used in conference presentations or lectures. Some of our conversations will be in person and some might be over google meet.

What are the possible disadvantages and risks of taking part? I cannot foresee any serious disadvantages or risks in participating in this research. However, sometimes reflecting on our lives can be upsetting or distressing, or you might be exposed to other people's thoughts and feelings, for example, around exclusion and discrimination, which might be upsetting to hear.

You do not have to answer every question in the conversations; you have the right to say no to questions if you do not wish to answer them.

What will I gain from taking part? Participating in these conversations is a chance to tell your story and contribute to this research project that aims to understand the lives of children with learning diversity and their families in Colombia.

What happens if the research project stops earlier than expected? Although unlikely, if for any reason the research project stops earlier than expected, you will be offered a full and clear explanation as to why.

What if something goes wrong? If you feel something has gone wrong or would like to raise an issue/complaint, please contact me. If you feel that your complaint has not been dealt with appropriately, you can contact my tutor Prof Runswick Cole.

If you still feel your complaint has not been followed up on you may contact the Head of Department at the School of Education at the University of Sheffield, Professor Elizabeth Wood, who will escalate the complaint through the appropriate channels. Contact details:

● Professor Runswick Cole Chair in Education

Email:k.runswick-cole@sheffield.ac.uk

● Professor Elizabeth Wood Head of School

Email: e.a.wood@sheffield.ac.uk

The School of Education, Edgar Allen House, University of Sheffield, 241 Glossop Road, Sheffield, S10 2GW

Tel: +44 (0) 114 222 8172

If your complaint relates to how your personal data has been handled, information about how to raise a complaint can be found in the University's Privacy Notice: https://www.sheffield.ac.uk/govern/data-protection/privacy/general

Will my taking part in this project be kept confidential? As a participant of the research, your participation in the project will be kept strictly confidential. You will not be identified in any reports or publications when we write up the findings of the research. We will give you a pseudonym (e.g. a fake name). However, if you tell me something that worries me, whereby you are in danger or at serious risk, then I might have to share it with someone else; such as a professional or someone you trust. I will let you know if I plan to do this. Your data (your interview story) will only be seen by me and shared with my tutor from the University of Sheffield: Prof. Runswick-Cole.

What will happen to the results/findings of the research project? I am planning to share the narratives in a few different ways to ensure that the stories you want told are shared. This will be an ongoing collaborative process. Firstly, I plan to publish the research in my dissertation, I will submit it to academic journals and maybe share some parts in conferences in the UK and other parts of the world. I also want to know from you who you would like to know what we have talked about (policy makers, heads of schools, teachers, parents, children in your school community or members of other school communities who work with and for children with diverse learning needs).

In the future I might like to come back at another date and create some written narratives or theatre pieces with you where we can share the stories, this would be a collaborative project to find ways to process the stories and to share them to a wider audience. I will ask for your explicit consent for your story to be shared in this way and if you agree, we will ensure that the stories you have shared are untraceable back to you.

Who has ethically reviewed the project? This project has been ethically approved via the University of Sheffield School of Education's ethics review procedure. The University's Research Ethics Committee monitors the application and delivery of the University's Ethics Review Procedure across the University.

What is the legal basis for processing my personal data? According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). Further information can be found in the University's Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

Contact for further information If you have any questions about the study, please contact me: ?

Elizabeth Arenas Thomas earenas1@sheffield.ac.uk

The Open Borders of Latin America: Venezuelan Child Migration into Colombia
Consent Form for Parents/Guardians

If you have read the invitation letter and are happy to participate please circle yes or no and sign the consent form below

	Activities	Initials
1	I confirm that I have read the attached invitation letter (**Date: ___/_____/2019**) for the above study and have had the opportunity to consider the information and ask questions and had these answered satisfactorily.	
2	I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason and without detriment to myself. I understand that it will not be possible to remove my data from the project once it has been anonymised and forms part of the data set. I agree to take part on this basis	

3	I agree to the **interviews and focus group conversations** being **audio / video recorded**. I understand this is for data collection.	
4	I agree that any data collected may be published in anonymous form in **academic books, reports or journals**	
7	I agree that the researcher may retain my contact details in order to provide me with a summary of the findings for this study.	
8	I understand that there may be instances during the course of the **interviews/focus groups when** information is revealed which means that the researchers will be obliged to break confidentiality and this has been explained in more detail in the information sheet.	
9	I agree to take part in this study	

Data Protection

The personal information we collect and use to conduct this research will be processed in accordance with European data protection law as explained in the Participant Information Sheet.

_____   _____   _____

Name of Participant   Signature   Date

_____   _____   _____

Name of the person   Signature   Date
taking consent

The researcher will keep a signed copy of consent form in a secure manner and you, the participant, will keep one copy.

Appendix Four: Guide Questions for Conversations

Preguntas Guías para Conversaciones Español (English below)

Preguntas para participantes venezolanas (madres y colegas)
Esto no es una lista exhaustiva ni una lista de preguntas para preguntar directamente, son notas que tenía a mano para guiar mi conversación y áreas de interés.

Vida en Venezuela
¿Cual era tu trabajo en Venezuela?
¿En Colombia en qué trabajas?
Cual ha sido tu desafío más grande en esta migración?
¿Cómo te ha impactado la cuarentena por la pandemia?

¿Por qué decidiste contarnos tu historia?

Vida en Venezuela,
¿De donde eres en Venezuela?
¿Qué hacías en Venezuela? (estudios, trabajo)
¿Con quién vivías? ¿Quienes en tu familia vinieron contigo?
¿Que te hace mas falta Venezuela?

Migracion
¿Qué te hizo decidir salir de vzla?
¿Cuándo llegaste de Venezuela?
¿Cómo te fuiste de Vzla?
¿Por qué te fuiste? ¿Cómo tomaste la decisión?
¿Cómo fue la travesía? Por donde cruzaste la frontera?
¿Con quién te fuiste? ¿Quien dejaste en vzla? ¿Qué dejaste en Vzla?
¿Hacia dónde tenías pensado irte? ¿Cuál era tu destino?
¿Cómo fue tu viaje hasta aquí? ¿Llegaste con documentación?

Retos, barreras y necesidades
¿Cuáles han sido los retos de llegar a Colombia?
¿Cuáles han sido los retos de vivir en colombia?¿Cómo ha sido la experiencia migratoria?
¿Cuáles han sido las barreras personales más significativas para ti en tu integración en colombia? ¿En qué áreas has recibido ayuda?
¿Cuáles son tus necesidades en estos momentos?
Preguntas sobre Laborales, vivienda, comida, salud, escolaridad
Atención a necesidades que se puedan apoyar en la OLR para remitir

Preguntas Familiares- Integración de les niñes

¿Cuántos niñes hay en la familia? Edades, experiencia previa escolaridad

¿Están atendiendo la escuela en este momento? Escolaridad? ¿Cómo ha sido el proceso de cupo y de inclusión?

¿Está en un grado con niñes de la misma edad?

¿Se siente integrada? ¿Le gusta ir al colegio?

¿Ha tenido dificultades? ¿Qué es lo que más le gusta de ir al cole?

¿Que le gusta jugar a tu hije? ¿Qué hace a diario para disfrutar?

¿Cuáles son las habilidades de tu hijo?

¿Cual ha sido tu experiencia como madre de esta migración?

¿Qué ha sido lo más difícil de la incorporación a Colombia para tus hijos?

Explorar temas: Escolaridad- Discapacidad

Salud, Alimentación y ropa, Casa

Emocional (Duelo Migratorio)

Diagnostico

Tiene diagnóstico? Donde fue diagnosticada? Colombia or Venezuela? ¿Trajeron documentation? ¿A qué edad y servicios emitieron el diagnóstico? ¿Quién refirió al servicio y por qué? Como fue el proceso de diagnostico para ti como madre? En que te ayudo tenerlo?

¿Consideras que es útil tener el diagnóstico?

¿Cuáles son sus habilidades y los retos en la escuela?

Que servicios adicionales le proporcionan a tu hije por tener el diagnostico?

¿Qué necesidades tienen sus hijos en este momento?

¿Qué objetivos tienen en este momento para su hijos?

?Hay alguna otra pregunta qué piensas que te he debido preguntar?

¿Qué otra cosa quisieras compartir?

Preguntas adicionales Colegas de la OLR

Las áreas temáticas de esta conversación son acerca de las barreras a las que se enfrentan la población migrante venezolana para acceder a la salud y a la educación para menores de 18 años y para personas con alguna discapacidad. El objetivo es fomentar una conversación alrededor de sus experiencias profesionales con desplazados y la comunidad de acogida, no enfocado en los procesos de la fundación misma sino de la realidad profesional cultural en Colombia. Y quiero generar esta conversación en grupo

MIgración Venezolana

¿Cuáles son las barreras para los venezolanos para regularizarse e integrarse a la vida en Colombia?

¿Cuáles son las necesidades más importantes? ¿Cuáles son los servicios más solicitados?

¿Cuáles son los servicios de major dificultad de acceso?

Tocar temas específicos: Salud, medios de vida, Seguridad alimentaria y Educación: La escolaridad es una garantía que se cumple?

Discapacidad

¿Cómo ven la situación de venezolanos que tienen que navegar el ser migrantes y refugiados cuando alguien en la familia tiene una discapacidad?

¿Cuáles son las barreras más comunes para nines en general y para niños con discapacidad?

En su experiencia como es el proceso de conseguir cupo escolar para las familias que tienen niños con discapacidad? ¿Qué apoyos obtienen una vez dentro del sistema?

¿Qué historias resalatarian?

¿Qué historias han tenido impacto para uds con discapacidad?

De tantas historias que hemos tenido con las personas cuál historia les ha impactado más ya sea por la historia, el apoyo logrado de la fundación o por las barreras superadas que ha tenido que enfrentar?

Legal area

¿Cuáles son las restricciones en el sistema jurídico colombiano e internacional para la regularización de los migrantes Vzlanos?

¿Cómo creen que se entiende en Colombia la diferencia entre refugio y migración a nivel de servicios públicos?

¿Cómo creen que se entiende la migración venezolana a nivel internacional?

Perspectiva Profesional

Cuentenme dentro de su área profesional que las atrajo a trabajar con población desplazada?

Cuéntame más sobre su enfoque personal/profesional

¿Tienes una visión específica que traes a tu trabajo?

¿Cuáles son los principios/valores/marco de pensamiento/teoría en los que te basas cuando trabajas con la gente?

¿Qué aspectos de tu formación académica te han parecido más y menos útiles para trabajar con las personas? ¿Ejemplos concretos? ¿Qué has aprendido en el trabajo mismo acerca de la migración? Acerca de discapacidad?

¿Cómo lo definiría en sus propias palabras?

¿Qué es lo más impactante de su trabajo? ¿Cuál experiencia se lleva como empleado/ y como venezolana/colombiana que trabaja con la gente?

¿Qué otra formación o educación ha recibido en relación con la prestación de servicios para la población migrante? Para nines con discapacidad? de salud mental en situaciones de migración?

¿Qué herramientas o capacitaciones faltan en su educación, que si se obtuvieran podrían ser utiles en su trabajo?

Hay alguna otra pregunta qué piensas que te he debido preguntar?
¿Qué otra cosa quisieras compartir?
¿Qué historias piensas que sería importante resaltar acerca de la migración y discapacidad?

Guide Questions for Conversations

Questions for Venezuelan participants (mothers and colleagues)
This is not an exhaustive list or a list of questions to ask directly, these are notes I had on hand to guide my conversation and areas of interest.

Life in Venezuela
What was your job in Venezuela?
What do you do in Colombia?
What has been your biggest challenge in this migration?
How has the pandemic quarantine impacted you?

Why did you decide to share your story?

Life in Venezuela
Where are you from in Venezuela?
What did you do in Venezuela (studies, work)?
Who did you live with? Who in your family came with you?
What do you miss most about Venezuela?

Migration
What made you decide to leave Venezuela?
When did you arrive from Venezuela?
How did you leave Venezuela?
Why did you leave? How did you make the decision?
How was the crossing? Where did you cross the border?
Who did you leave with? Who did you leave in Vzla? What did you leave in Vzla?
Where did you plan to go? What was your destination?
How was your journey here? Did you arrive with documentation?

Challenges, barriers and needs
What have been the challenges of coming to Colombia?
What have been the challenges of living in Colombia? What has the migration experience been like?
What have been the most significant personal barriers for you in your integration in Colombia? In what areas have you received help?
What are your needs at the moment?
Questions about labour, housing, food, health, schooling, etc.
Attention to needs that can be supported by the OLR for referrals

Family Questions - Integration of children
How many children in the family? Ages, previous schooling experience
Are they attending school at the moment? How has the process of placement and inclusion been?

Are you in a grade with children of the same age?
Do you feel integrated, do you like going to school?
What do you like most about going to school?
What does your child like to play? What does he/she do every day for fun?
What are your child's abilities?
What has been your experience as a mother of this migration?

What has been the most difficult part of joining Colombia for your children?
Explore issues: Schooling- Disability
Health, Food and clothing, Home
Emotional (Migrant Bereavement)

Diagnosis
Does your child have a diagnosis? Where was she/he diagnosed? Colombia or Venezuela, did they bring documentation, at what age and services was the diagnosis made, who referred you to the service and why? What was the diagnostic process like for you as a mother? How did it help you to have it?
Do you think it is useful to have the diagnosis?
What are your child's skills and challenges at school?
What additional services do you provide to your child for having the diagnosis?

What needs do your children have at this time?
What goals do you have for your child at this time?
Are there any other questions you think I should have asked you?
What else would you like to share?

Additional Questions OLR Colleagues
The thematic areas of this conversation are about the barriers faced by the Venezuelan migrant population in accessing health and education for children under 18 and people with disabilities. The aim is to encourage a conversation around their professional experiences with displaced people and the host community, not focused on the processes of the foundation itself but on the professional cultural reality in Colombia. And I want to generate this group conversation

Venezuelan Integration
What are the barriers for Venezuelans to regularise their status and integrate into life in Colombia?
What are the most important needs? What are the services most in demand?
What are the most difficult services to access?
Addressing specific issues: health, livelihoods, food security and education: Is schooling a guarantee that it is fulfilled?

Disability
How do you see the situation of Venezuelans who have to navigate being migrants and refugees when someone in the family has a disability?
What are the most common barriers for children in general and for children with disabilities?

In your experience, what is the process of getting school places for families with children with disabilities? What support do they get once they are in the system?

What stories would you highlight?

What stories have had an impact for you with disabilities?

Of the many stories we have had with people, which story has had the greatest impact on you, either because of the story, the support you have received from the foundation or because of the barriers you have had to overcome?

Legal area

What are the restrictions in the Colombian and international legal system for the regularisation of Venezuelan migrants?

How do you think the difference between refugee and migration is understood in Colombia at the level of public services?

How do you think Venezuelan migration is understood at the international level?

Professional Perspective

Tell me about your professional area that attracted you to work with displaced populations?

Tell me more about your personal/professional approach?

Do you have a specific vision that you bring to your work?

What are the principles/values/framework of thought/theory that you draw on when working with people? when working with people?

What aspects of your academic background have you found most and least useful in working with people?

What are some concrete examples? What have you learned on the job about migration? About disability? How would you define it in your own words?

What is the most striking thing about your work? What experience do you take away as an employee and as a Venezuelan/Colombian working with people?

with people?

What other training or education have you received in relation to the provision of services for migrant populations? For children with disabilities? mental health in migration situations?

What tools or training are missing from your education, which if obtained could be useful in your work?

Anything else?

Are there any other questions you think I should have asked you?

What else would you like to share?

What stories do you think would be important to highlight about migration and disability?